A PROJECT FOR ENHANCING THE QUALITY OF MEDICAL AND PSYCHO-EDUCATIONAL SERVICES FOR CHILDREN WITH AUTISM IN THE GAZA STRIP

David Henley Ph.D., M.D. Child Neurologist, Uppsala University Sweden

Henrik Pelling M.D. Child Psychiatrist, Uppsala University Hospital

Josefin Mannberg Psychologist and CBT Psychotherapist, Habilitation Center for Children and Adults, Uppsala

Lena Nilsson Speech-Language Pathologist, Habilitation Center for Children and Adults, Uppsala

ABSTRACT

In creating a Community Mental Health Program a whole variety of problems, in complexity and prevalence, need to be addressed, arising from infringements of human rights as well as biological vulnerabilities, and their interactions. Autism is one such area where all studies show a high prevalence, independent of the prevailing environment. In the last years, psychopedagogical approaches have made an important contribution which combined with "task sharing" (training trainers) can give a unique opportunity for treatment that was previously reserved for high income countries with specialized professionals.

Methods

A team from Uppsala University Hospital, Sweden (child neurologist, child psychiatrist, child psychologist and speech-language pathologist) has been carrying out week long training workshops on medical and treatment aspects of Autism, twice yearly now for three years, within the Gaza Community Mental Health Programme (GCMHP). Between workshops the twelve course participants are given extensive homework assignments.

The participants are located throughout Gaza, working within GCMHP or in small, recently created Centers for children with special needs, including Autism.

These participants—the becoming "supervisors"—will train parents to deliver the appropriate interventions. What is crucial here is the establishment of a group of "supervisors" for training parents, and also eventually new supervisors. Parental participation is the cornerstone of "task sharing" as well as enabling increased treatment intensity!

The course uses a curriculum based on Applied Behavioral Analysis (ABA), a behavioral therapy approach for promoting joint engagement, communication and learning. Included also is necessary diagnostic and medical information.

Emphasis is on early detection and intervention so that we are initially dealing with children under four years of age.

Findings

Psycho-pharmacology has previously been the treatment mainstay of Autism in Gaza. In addition, the few working with children with Autism have paid little attention to training parents to deliver appropriate interventions. It was clear that there was limited diagnostic knowledge available and nearly no methods for delivering proper interventions.

Today, within the framework of GCMHP and the network of day-care centers, psychopedagogy (ABA) has taken over the role of psycho-pharmacology, and is delivered primarily through parental involvement, in itself also an empowering process. Of course it will take a while before we can judge the long term development of these children.

GCMHP and the network of day-care centers have published two extensive reports dealing with Autism, one concerning the "State of Autism in the Gaza Strip", the other concerning

Screening and Assessment. One of the participants has started an Autism Website in Arabic visited by many followers in the Middle East.

Interpretation

The coupling of evidence based interventions with "task sharing" (training parents) begins to bridge the gap between resources and needs, and has opened the door for vastly improving the quality of life for children with Autism and their families even under the conditions prevailing in Gaza

PROLOGUE

Gaza houses a child population of about one million, which essentially is under constant psychological and physical stress. It's not a post traumatic situation, but more accurately can be described as ongoing.

It is in this environment that we have now had a twenty-five year cooperation with the Gaza Community Mental Health Programme (GCMHP). The work was initially directed towards the acute needs of the high risk groups but, of course, has changed and developed with time and the ongoing situations. Developing strategies for care has also been important because of the dearth of resources and the overwhelming needs.

INTRODUCTION

GCMHP has become proficient in working with children living under traumatizing conditions. It was here, also, that they began to make use of the "training trainers"/"task sharing" model, whereby family and school staff, for instance, help children learn to cope with their situation.

Coupling mental health with human rights helps to break down the stigma associated with problems of mental health. But in creating a mental health program a whole variety of problems, in complexity and prevalence, need also to be addressed, arising from infringements of human rights as well as biological vulnerabilities, and their interactions. The growing field of pediatric Neuro-Psychiatry illustrates one such area, which includes, Autism, ADHD/ADD, Tourette Syndrome, for instance, and where all studies show a high prevalence of these disorders. In the last few years much has been learned as to how to treat such problems, which at present is only now making its way to Gaza. Thus, together with the senior staff of GCMHP we have decided to introduce these new evidence-based treatment approaches delivered together through the model of "task sharing" which is quite a unique undertaking since previously such work was reserved for specialized professionals.

BACKGROUND

It was during 2013 that concrete plans were forged concerning Neuro-Psychiatry at GCMHP. During one visit, together with the senior staff, we looked at a 'Time Line' of projects for children undertaken during its 20+ year history; why and what had been started, what was dropped or persisted and what were deficiencies and expected future needs. During a second visit, we followed up these discussions with a Workshop on the concept of Community Mental Health, in general not particularly well established, and certainly less so in a Gazan context, where it is nearly non-existent. In the end, emphasis was placed on Neuro-Psychiatric disorders because of the expected prevalence in Gaza, the lack of available knowledge there, available evidence based treatments, and the possibility of working with the model of "task sharing". We were all conscious that these were long term plans, and even if Autism was to be a starting point, related problems like ADHD/ADD would also eventually have to be included.

In early 2014 we located other team members in Uppsala to join us in this work. Doctors have their role in Autism, for instance, diagnosis, comorbid medical problems and raising awareness, but the primary treatment forms are psycho-educational, where the expertise is found with other professions. A psychologist and speech therapist, who have been working with, and developing, our Autism Program in Uppsala, Sweden now for many years, joined the team. A fifty day invasion of Gaza in the summer of 2014 had delayed the second visit as well as the team visit which now took place in February 2015.

Our Gaza visit in April 2015 was directed towards getting a more detailed and up to date idea as to the prevailing situation for children with Autism. Our visit also coincided with that of Professor Charles Cowan, a child neurologist from the United States, which added to the depth of our discussions. We met about 60 children from different parts of Gaza, suspected of having an Autism diagnosis. We felt that we were meeting many children of well-educated parents, who themselves had suspected the diagnosis through external contacts or were self-informed from books, TV or Internet. There were few professionals with knowledge in the field, and treatments were often psycho-pharmacological, Hyperbaric Oxygen Therapy (taking place outside of Gaza) or diets, none of which have been shown to be evidence-based, with little professional follow-up. We had also parent meetings where very appropriate discussions took place, namely what could/should be the role of parents in the treatment of the children with Autism.

In June 2015 GCMHP completed: **State of Autism in the Gaza Strip 2015: Resources, Attitudes and Opportunities.** It was funded by Islamic Relief – Worldwide and supervised by Islamic Relief – Palestine & Right To Live Society and published also in Arabic.

The survey revealed a consensus that there are no accurate or official statistics regarding children with Autism (ASD) in the Gaza Strip. There are only 7 institutions working clearly and directly in this field. They provide different services to 237 children and 285 children are put on a waiting list. The survey showed that 69.7% of families discovered that their children's behavior was abnormal before the age of three. The services reached limited places and the professionals were in more than 50% in need of training to help to deal with children

with ASD and behavior modification training. 60% succeeded to diagnose their children properly after the age of three. More than 60% of the children were diagnosed by a professional from one specialization only. The research team made a number of recommendations:

- The necessity to build an accurate database and statistics for children with ASD.
- The necessity to raise the community awareness about autism.
- The necessity to train specialist, in part by international experts and trainers.
- The necessity to train parents.
- The necessity to create a unified network with an accredited referral system and have an interdisciplinary team to diagnose complicated cases.
- In collaboration with the local and private institutions the Ministry of Health should develop a standard and protocols for diagnoses, care and rehabilitation.

DECIDING AND PREPARING FOR AN AUTISM PROJECT WITHIN GCMHP

Evidence based Guidelines

Today parental involvement is an integral part of all programs for children with autism, no matter on which theoretical foundation the program rests. Parental participation is both ideologically and empirically grounded. As it is important that parents can influence the direction of the child's Individual Program they need to be given the opportunity to participate in setting goals for the children's training and education. If parents are going to participate in training they need to receive knowledge, skills and information, preferably written in the child's training program; how you can interact with your child and expectations concerning progress. To participate actively in the training of the child, parents need the opportunity to learn general principles about how to teach the child. They also need regular supervision to learn how to apply these general principles on new problems and new situations. To feel good and reduce stress parents need social support. Research has shown that parent participation enables clear treatment gains. One of the hardest goals for a trainer is to achieve generalization of the child's newly acquired skills during training sessions in daily life. Parents' participation gives opportunity for intensive and continuous training which is essential for the child's development. To be involved as a parent makes the parenthood less stressful and contributes to their empowerment.

Needs in Gaza

- Professionals need to know more of the crucial areas in Autism: social
 communication, social interaction and repetitive behavior that limits activities and
 interests. It's also important to know how to deal with children with Autism and
 behavior modification (Applied Behavioral Analysis- ABA).
- Providing training for all professionals in the Gaza Strip working in this field needs a defined and comprehensive training plan with a time frame and special arrangements before inviting any experts to Gaza.

- Professionals need to concentrate on behavior therapy, speech therapy, occupational
 therapy and special education, and avoid medications, except for special
 circumstances. In other words, there should be a wise use of treatment with
 medicines.
- One must also become aware of the difficulties of entering the world of Autism for variety of reasons. Stigma and social isolation increase family burden and limit willingness to seek services. Economic demands as well as well as difficulties reaching disability service resources certainly plays a role. Children with Autism are usually denied access to normal schooling. Finally, the limited quality of services and extensive medication could frighten knowing parents. These issues must clearly be dealt with. In addition, despite the principles surrounding this particular project, there are many parents who don't want to take part in delivering the expected interventions. They would prefer a model whereby they leave their child at a Center during the day with the expectation (or hope) that this training would suffice. Some of these parents do not even participate in the Center's meetings or planning. This is often a disturbing behavior.

Role of Doctors

What we describe here will eventually be the role of chosen/interested/special doctors in Gaza. At present, this describes the activities/direction of the two medical doctors belonging to the team supporting this project.

An important task is concerned with increasing awareness of neuro-psychiatric disorders with emphasis on Autism and ADHD in Gaza, including symptoms, causes, frequency and treatments. And in particular here, as it isn't all together accepted, has to do with emphasizing the value of "task shifting" in the treatment of Autism, that is, the important parental role when it comes to interventions, that is, interventions-treatment are primarily delivered by parents. Further it is important that doctors give support to the now generally accepted view that the evidence-based interventions for Autism are nearly exclusively of a psychoeducational nature (ABA) and medications, or other medical treatments, play a very minor role, or even, in fact, can result in serious unwanted side effects.

Early detection (leading subsequently to early intervention) is crucial so that it is important to educate the staff of relevant organizations, for instance, primary health care, or kindergartens. Diagnosis and a medical work-up are important so that the parents feel confident as to the problems they are dealing with in their child. And it is not always necessary to use expensive medical tools, where often a good history and physical, in experienced hands, are most important in diagnosis. The doctor's work-up is also to exclude associated medical problems that can also occur with Autism, or comorbid problems, like hyperactivity or sleep difficulties that are very frequent. Diagnosis is a team approach, where different diagnostic instruments play a major role.

During this three year project, we have worked a lot with dissemination of relevant medical information about Autism in a broad sense, put a lot of emphasis on the important role of

educating parents who then can deliver the necessary evidence-based interventions and stressed the frequent misuse of medications, or other medical treatments, in the treatment of Autism. Of course, other underlying disorders should be treated, such as epilepsy, hearing, vision or motor impairments. The role of the doctor here is critical. There is today overwhelming evidence that psycho-education (ABA) is the treatment of choice and it is important that doctors support this.

How to become a Supervisor for Early Intervention ABA in Gaza?

For professionals there is much to learn to insure implementation of recommended practice into a coordinated and consistent family-centered approach. In this project we invited professionals; speech and language therapists, special teachers, psychologists, social workers and child psychiatrist to enter supervisor training, starting in February 2015. The professionals came initially from three organizations but expanded to six during the three year period (see below). Supervisors must recognize that intervention planning is directed both towards the adult learner as well as the recipient child. Research on methods of training parents or other caregivers support the use of adult learning strategies. That is, encompasses the adult's experiences and motivation, and makes use of demonstration and modeling, specific feedback, problem-solving strategies to increase independent decision making and generalized use of information, self-assessment of effectiveness and quality of supervising. We planned for a 3 year long education and training for Professionals to become Supervisors in ABA Early Intervention for children with Autism.

Education for Supervisors

The Education for Professionals to become Supervisors in Early Intervention ABA of children with Autism started with the first workshop, February 2015, the second four day workshop in September 2015, and the third four day workshop February, 2016. It then continued, half yearly during 2016 and 2017. So in this paper we will label this group of Professionals as Supervisors. We know that a lot of knowledge is required as a Supervisor. As a Professional you also need to shift your focus from being a trainer of the child to training parents. To be sure that the Professionals make this transition, they need ongoing opportunities to acquire these skills. Homework assignments during the six months between the workshops allows for such training. So according to these three areas, knowledge, behavior changes and attitude, we planned the course as follows:

- Supervisors must have knowledge about autism, learning principles and teaching principles (ABA).
- Supervisors need to have in depth knowledge in the core areas of autism like Social Communication, Social Interaction and Play in relation to normally developed children.
- Supervisors need to have in-depth knowledge about treating defiant behavior caused by a lack of communication skills.
- Supervisors of Early Intervention for children with Autism need knowledge, training and experience about supervising skills.
- Supervisors need training to make an Individual Plan with comprehensive and appropriate goals together with parents. It's necessary to make a protocol for Individual Plans in Arabic

- Supervisors need experience in making a Training Program with appropriate exercises related to the goals. It's necessary to make a protocol for a Training Program in Arabic.
- Supervisors need training to match individual parent's needs and background in order to best carry out the parent education
- Supervisors should together make a manual in Arabic for further teaching of Professionals in Gaza.

PROJECT IMPLEMENTATION

The Project was planned for a three year period, with weeklong Workshops every six months. The emphasis was on training the 'Professionals' to educate the parents, and to some degree, the network around the child with Autism, to deliver appropriate psycho-educational interventions. Many of the children also attend a Center for some hours daily. During this time period some new Centers and Professionals joined the workshops (finally to be 7 Centers and 12 professionals). The new arrivals were often compensated with extra training. Between workshops, extensive homework assignments were given to the group of Professionals. These Professionals, although belonging to different organizations (Centers), then began to meet together.

This influx in the system can give an impression of poor planning. Working together over organizational borders is no easy task. None-the-less, we feel we were helping to open doors so that different skills and experiences could mingle and help develop this collective network.

Project Report

The different activities, like lectures, meetings, discussions, that took place during the six Workshops are recorded according to the dates of the Workshop. In **APPENDIX 1** we have compiled the power point slides that were used for the different lectures given at Workshops by the Swedish team. The italicized sections for each Workshop mostly represent the work and discussions of the participants. discussions related to the homework assignments, and meetings, even between Workshops, related to Autism Project Further information concerning homework assignments is given in **APPENDIX 2.**

February 2015 (Workshop 1)

We began with a "First-Step" Parent Education for 22 parents to children 4 years old that recently received a diagnosis of autism. During the Parent Education 11 professionals from *Gaza Community Mental Health Programme*, *Right to Live and Palestine Association for Autism Rehabilitation* participated. The purpose was to present models of involving and educating parents in treating their children through evidence-based interventions. In the afternoons during the week we continued the workshop just with the professionals in order to emphasize the shift from Professionals training children to Professionals involving parents in the intervention. We talked about the importance and evidence for involving parents in the training. One afternoon we invited parents to come together with their children and we

supported the Professionals in supervising parents about how to arrange for joint engagement in play-activities with their children.

Data from Different Centers, Participants and Course Leaders Workshop 1

Date: 16-19 February 2015

Trainers: Dr. David Henley- Dr Henrik Pelling, Lena Nilsson, Josefin Mannberg Trainees were from:

- Right to Live Society
- Palestinian Society for Autism Rehabilitation
- Gaza Community Mental Health Programme
- A member from the Norwegian Refugee Council,

Main topics:

- 1. Autism: History, symptoms and causes
- 2. *Communication*
- *Teaching and learning, learning theory*
- 4. Applied behavior analysis(ABA)
- 5. Reinforcement
- 6. Play and interaction
- 7. Visual Aid Support
- 8. Factors for a successful treatment

The course included:

- 1. Daily discussions with parents about important issues
- 2. Bringing the kids to the course to teach parents how to communicate and play with them
- *Papers for the professionals to read*

Note / The 2nd and the 3rd day of the training were attended by the parents. There were practical exercises of children and their parents with the professionals

No homework this time

In April 2015, a meeting was held Rawya Hamam -project coordinator- and autism trainees to have feedback regarding the first training workshop, and the following is the summary:

- The training was great and very important
- The training material was supported by scientific evidence and practical experience
- The trainers were cooperative experts and filled with hope and interaction which had a great impact on the trainees, especially the professionals
- The trainees (specialists from GCMHP) have theoretical and basic information about autism but the training provided them with practical techniques and effective ways to deal with autistic children

- The trainees (specialists at Right to Live Society and the Palestinian Society for rehabilitation and Autism) also have basic theoretical information about autism and have some experience working with autistic children which helped them know if the methods they use are correct or to change them. In my perception, both associations have fairly appropriate diagnostic mechanisms and have the plan and the goals which are suitable for the children. However, they lack the right implementation of these mechanisms but the training played a vital role in providing them with these methods
- Unfortunately, parents had despair, frustration, lack of awareness and unclear expectation of their children. In addition to a lack of confidence in their abilities, some of these parents are still in denial and some mothers feel guilty towards their children
- When we asked the parents about their dreams for their children, the dreams reflected despair and frustration. For example, all of them wish that their child can speak but none of them wish that they could deal with this child or that this child can go to school
- The training changed this perception and raised awareness among the parents and succeeded in motivating some of them and encouraging them and also provided them with effective ways to communicate with their children and interact with them. As well it provided them with appropriate ways to enter the world of their children. In addition it provided appropriate intervention methods and solutions to some problems they face with their children
- The meeting of parents with each other provided an excellent means for exchange of information and experiences which had a great impact on them
- Most parents did homework and recorded their children as required and enjoyed bringing their children on this day
- Some rushed to the library to buy toys and tools that were used in the training and went home and started in the application despite the lack of time. However, others were meant to bring the child only to make sure of the diagnosis Group expectations for the next training
- 1. Increase awareness and change perceptions
- 2. Follow-up with parents and remind them to apply the exercises they have learned with their children
- 3. Mental health support, motivate and encourage mothers
- 4. More ways to communicate and interact with their children
- 5. Listen to more success stories in Sweden
- 6. Hold more meetings for parents

September 2015 (Workshop 2)

In September we carried out a 4-days workshop with the group of Professional, from the previously mentioned three organization as a next step in their education to become Supervisors of Early Intervention ABA for children with Autism. During these 4 days we worked with Individual Plans and the importance of Parent Education and supervising parents. Two homework assignments for the next workshop in February 2016 were:

• **Homework 1** – That you as the supervisor have formulated one Individual Plan together with parents.

• **Homework 2** – That you together as a group have planned and booked a "First-Step" Parent Education in Arabic to be carried out the during spring 2016.

As a continuation of the week, the Professionals from these three organizations decided to meet regularly as a group and plan for the Autism Interventions and Parent Education, sharing the experiences with each other. It is important that the group of Professionals have opportunities to meet regularly during their education to become Supervisors of ABA.

During the week we also invited parents from February to come and share their experiences of being involved with the training of their children. They agreed that it was successful and thought it obvious to involve parents in the training of their children, which also helps to reduce parental stress.

Data from Different Centers, Participants and Course Leaders Workshop 2

Date: 14-17 September 2015

Trainers: Dr. David Henley- Dr Henrik Pelling-Lena Nilsson-Josefin Mannberg

Trainees were from:

- Right to Live Society
- Palestinian Society for Autism Rehabilitation
- Gaza Community Mental Health Programme
- A member from the Norwegian Refugee Council,
- A doctor from UNRWA 1F

Main topics:

- 1. Discussion about the last Workshop (recommendations and evaluation
- 2. National Guidelines
- 3. Implement an autism intervention
- 4. Education and supervision
- 5. Individual Plan (IP), mapping and setting goals
- 6. Long term and short-term goals
- 7. Excessive and deficit behaviors
- 8. Homework 1 and 2

The Workshop included

1. Parents sessions to discuss their benefit from the last Workshop

Workshop Homework:

First Homework (HW1)

- For the Professionals (individual homework)
- You as a Supervisor need to make an individual plan (IP) for one child together with his parents and teachers.
- This HW is due Feb 2016

Participants for this work (GCMHP, PSAR and Right to Live)

- 1. How should the Individual Plan (IP) we use in Gaza be formulated?
- 2. Translation of individual plans
- 3. Coordination

Second homework (HW2)

- Group homework Professionals together
- That you as a group have planned and booked the first Parent Education in Arabic in Gaza to be presented for Lena and Josephine in Feb 2016 and the Workshop to be held in April 2016

Participants for this work (GCMHP, PSAR and Right to Live)

- 1. Which organization can be responsible for the Parent Education?
- 2. Who are going to be the educators?
- *3. When and Where?*
- 4. Which (parents) should we invite?

2nd workshop Evaluation -September 2015

First / Information gathered from Trainees:

The most beneficial subjects during participation in the lecture:

The implementation of what was gained during the training in the work field:

Suggestions:

2nd /Information gathered from Parents

The extent of benefit of the training and which subjects where most beneficial?

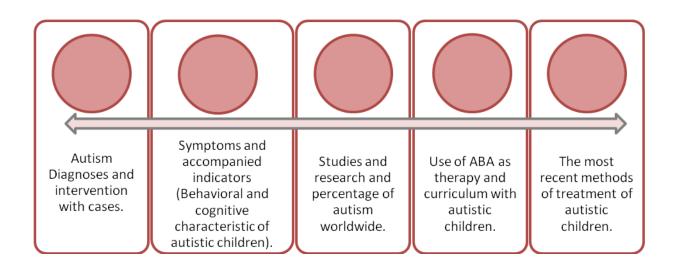
The implementation of the skills gained in dealing with their children / the most suitable means:

Trainees general Comments and suggestions

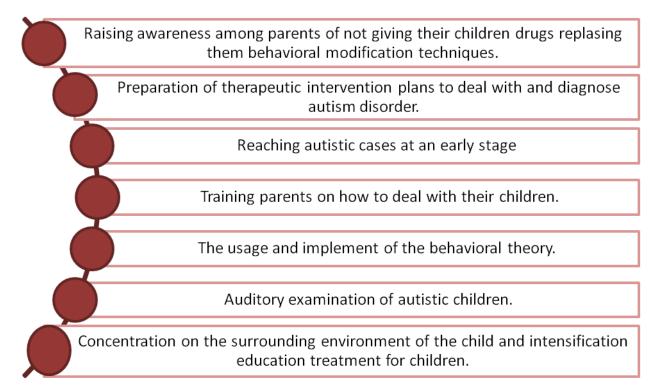
2nd workshop Evaluation -September 2015

First / Information gathered from Trainees:

The most beneficial subjects from the lecture:



The implementation of what was gained during the training in the work field:



Suggestions:

Training on the applied behavioral analysis program "ABA".

Training a number of specialists on diagnoses of autism

Connection with organizations working with autism through studies and publications.

Continuation of similar training programs.

Visual presentation of some cases and discussion with the professionals.

2nd /Information gathered from Parents

The extent of benefiting from the training and which subjects where most beneficial?

Discussion of cases presented by parents and provide suggestions to deal with their children.

The usage of means and tools that assist in achieving the goals and enhance the child concentration.

How to teach their children in the visual communication and the importance of interaction and social integration of the child

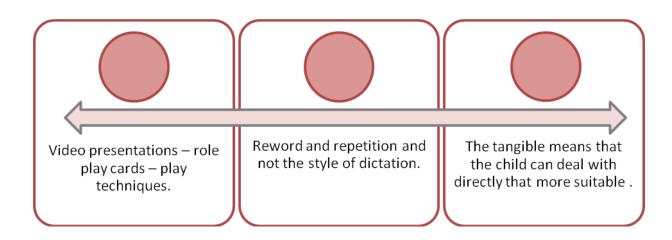
Ways of implementation of therapeutic plan presented by the professional.

Training the child on the proper usage of the toilet.

The importance of encouraging and integrating the child with other children.

How to deal and teach with their autistic child.

The implementation of the skills gained in dealing with their children / the most suitable means:



Trainees general Comments and Suggestions

To draw the attention of the community about autism and raising awareness through public meetings.

Intensification of such training courses and engaging the fathers in such training course to take responsibility with the spouse.

Provide more education for the parents

Field visits for organizations working with autistic children.

• In November 2015 a meeting was held including Rawya Hamam -project coordinatorand autism trainees to have feedback regarding the second training workshop, and the following is the summary: The attendance of the parents from the Palestinian Society was very good. The meeting was excellent but it could be better if the same parents continued to attend.

- The group of parents who attended was very interested and had the intention to commit and continue. They talked about a lot of positive changes and how they benefited from training and the impact of training on their lives.
- The need to communicate with the directors of the associations and explain the project again, the conditions and the need to follow up and support the trainees in the course.
- The need to communicate directly with all parents who attended the training, and explain the nature of the project and emphasize the importance of commitment and follow-up. Moreover, parents should be asked if they can continue with us in the project and make a list of the people who committed and had the intention to continue so that we can communicate with them directly next time and not through associations only.

February 2016 (Workshop 3)

The 4-days education for Professionals included a follow-up of the two **Homework Assignments, 1 and 2** (see above), from September 2015.

The work for the remainder of the days was to improve their knowledge about early signs of Autism. It is important that Supervisors of Early Intervention of ABA have in-depth knowledge in areas of autism like social communication, social interaction and play in order to make comprehensive Individual Plans together with parents.

A one day workshop focused on making Training Programs and educate/motivate parents about the importance and purpose of training in connection to prioritized goals in every person's Individual Plan. We also carried out an afternoon session on using games for training social interaction and social communication.

New homework assignments for September 2016:

Homework 3 – That you as the Supervisor have made a Training Program and supervised parents as to how they could train their children in functional communication, social interaction and play/activity so they can reach their short-term goal in the Individual Plan.

Homework 4 – That you carry out the Parent Education – "First-Step" during spring 2016 for parents to children with autism (see attached document)

- Who is going to be course leader?
- When are you going to hold your course?
- Which parent should be invited to the first Parent Education?
- Where are you going to hold the course?

Data from Different Centers, Participants and Course Leaders Workshop 3

Date: 22-25 February, 2016

Trainers: Dr. David Henley- Dr Henrik Pelling-Lena Nilsson-Josefin Mannberg

Trainees were From:

- Right to Live Society
- Palestinian Society for rehabilitation and Autism

- Gaza Community Mental Health Programme
- Emaar Society
- Baitona Society
- Fajer Society
- Basma Amal

The third workshop was similar to the previous workshop, but the main differences were the focus on the mother's role in the treatment process, how to make an Individual Plan for each autistic child (short-term and long-term goals) according to the priorities and the family's cooperation in the treatment process. They presented examples of trainings, songs, games and communication skills according to A-B-C (Antecedent-Behavior-Consequence)

Training topics:

- 1. Presenting Homework 1
- 2. Video: The diagnosis of Mio using ADOS (Mio is a child from Uppsala)
- 3. Individual plan for Mio
- 4. Evaluation

The course included:

- 1. Video for early signs of autism
- 2. *Visit to the PSAR*

Course Homework:

Third Homework (HW3)

Individual homework

You as a supervisor should supervise parents as to how they could train their child in Functional Communication Interaction in play activities so they can reach their short-term goals in the Individual Plan.

Fourth Homework (HW4)

Group homework

Carry out the first Parent Education course during April 2016

Write evaluation to be presented for Lena and Josephine in Sep 2016

Based on a brief and informal assessment by the participants, we present the following Recommendations:

- 1. To concentrate on the tools used with the autism diagnosis and to practice them more.
- 2. To know more about how to deal with older autistic teenagers.
- 3. To know how to deal with severe autistic children and children that weren't diagnosed early.
- 4. To have more workshop where there would be children to practice the games with their parents
- 5. To have means rather than pictures as not all children respond to that
- 6. To know other communication ways.
- 7. To learn to do the diagnosis as Professionals just like the trainers.

Meeting with some of the heads of autism centers:

After finishing the third training workshop, a meeting was held where Dr David, Dr Henrik, Lena ,Josefin ,head of Right to Live Society, the head of the Palestinian Association for Autism Rehabilitation, Dr. Taysir from GCMHP, Ms. Rawya and Mr.Ahmad, Abu Nada the head of Baitona society and others attended. Ms. Rawya welcomed the attendance and said

that the aim of this meeting is to hear from the trainers and the working associations something about the autism project here in Gaza (its goals, and where we're heading next). David started talking about how the idea of presenting autism here in Gaza came about. He said that he was delighted that many people were already working with autism, and the thing that attracted him the most was finding that people started using ABA (Applied Behavioral Analysis). David added that despite that, when he visited around 60 autistic children, 58 of them were on medications. David mentioned that there are at least two approaches to dealing with autism; one medical with many limitations, and psycho-educational means which is a primary reason for having these workshops in Gaza. ABA has developed as a modern approach and these developments should be continually followed up.

Then Lena said that she's surprised by the change we made in Gaza for the last three years because she knew about ABA from a conference she attended. ABA later developed because they faced the questions of "How can we help". That's why they suggested making regular classes to let people know more about autism. In this way, Lena said, we're helping ourselves as therapists because the more people know about autism, the easier it becomes to detect the symptoms and make the intervention faster, easier and earlier. Lena talked about that the first step should be a social worker meeting the parents and how important it is to establish a good relationship because this will be the basis from which the intervention process starts. Then, she said it's so important to have parents around when investigating their children.

Recommendations:

- 1. Engaging the mother in the investigation and intervention process
- 2. Having a plan in which we can guarantee that the 12 participants would be professionals.
- 3. Talking more about when to use medications and when not to.
- 4. Agreeing, locally, to cooperate to come up with one protocol.

In July 2016, a meeting attended by Rawya Hamam "local project coordinator and autism trainees was held, and the following is the summary:

- 1. Reinforce the cooperation among trainees in helping each other in doing required home works
- 2. *Networking among the centers which work with children*
- *3. Short presentation for the three achieved training courses.*
- 4. Discussing the subjects that the trainees wish to receive during the next training.
- 5. Recommendations and suggestions from the participants.
- 6. Mrs. Rawya suggested that the participants should make a face book page for autism trainees group and one of those trainees should be in charge for the page to ease the connection and to provide for the needs of the trainees.
- 7. She also mentioned that the homework has been translated and it will be sent for all the participants.
- 8. Mrs. Khetam then spoke about Al-Amal Assembly in Nosairat, that she has connected with them and she is going to make a meeting with the parents so they could attend the workshops. Mrs. Rawya then requested that such meetings should be documented and she requested that:
- 1. Mrs. Khetam should connect with Al-Amal Assembly and schedule a workshop for the parents about psychological stress.
- 2. Mrs. Zahiya Al-Qarra should meet with Fajer Assembly and make workshops about the initial symptoms of autism.
- 3. Mr. Mohammed Abu Shoqair with Mr. Alaa Al-Askari should make a workshop about behavioral modification.

- 4. Participants from Right to Live Society and from Palestinian Assembly for Autism Rehabilitation will make documented workshops for the parents.
- 5. Mrs. Rawya suggested that they should make a brochure for the trainees to inform them about the activities done with focusing on the presentation method.
- 6. Mrs. Rawya confirmed that every trainee must write reports about autism activities attached with photos and short videos.
- 7. Everyone asked for a clear plan for the coming training on September 2016 which might include:
- Verbal Communication in which a child could make a sign or pronounce a word to request something, and there has to be training about dealing with children with intensive autism.
- A way to deal with an autistic child after going to school.

In August 2016, a meeting attended by Rawya Hamam "local project coordinator and autism trainees was held to have feedback regarding the fourth training workshop and the participants asked for training on how to use Vinland habilitation program and more practical activities regarding communication with autistic children

September 2016 (Workshop 4)

Follow up the **two homework assignments**, **3 and 4** (see above) from February 2016

Present your Training Program connected to the Childs Individual Plan and reflect over your experience supervising parents about the training program.

After having carried out the Parent Education – "First-Step" it would be evaluated as follows:

- Give examples from the parent education that went well?
- How was the response from parents?
- What was difficult with the Parent Education?
- What do you want to change for the next time?
- What challenges can you see in the future for Parent Educations?

The content for the rest of these days will be:

- Education and training of Supervisors in Skills of supervising parents (Collaborative Consultation in Natural Environments, Woods, Wilcox, Friedman and Murch: 2011).
- Give 1-day Workshops on in-depth training of Social Communication, Language and Speech and basic knowledge about Alternative and Augmentative Communication (AAC). (It is possible to invite more professionals to this specific workshop.

<u>Data from Different Centers, Participants and Course Leaders</u> <u>Workshop 4</u>

_Date: 19-22 September 2016

Trainers: Dr. David Henley, Dr Henrik Pelling, Lena Nilsson, Josefin Mannberg

Trainees were From:

- Right to Live Society
- Palestinian Society for rehabilitation and Autism
- Gaza Community Mental Health Programme
- A member from the Norwegian Refugee Council,
- Emaar Society
- Baitona Society
- Norwegian Refugee Council
- Fajer Society

Main Topics:

The fourth workshop discussed home works and many individual plans for autistic children, Speech and language, reinforcing and shaping procedures and videos.

PBS:POSITIVE BEHAVIOR SUPORT

How to deal with challenges of severe autistic cases?

How to deal with over 6 years old autistic children?

How to teach autistic children to deal with external Environment?

A video for the most difficult child in Uppsala portrayed a boy with both Downs Syndrome and Autism

Supervising an autism intervention with homework for Feb 2017

At the end of the 4th training course, the trainee's recommendations were as the following:

- 1- Move to the practical part where we know more games.
- 2- Host some real children and implement the games with them.
- *3- Not to only focus on the theoretical part as attention needs to be paid to the practical part.*

New homework to February 2017:

Homework 5: Social communication (not specified yet)

Homework 6: Supervisor skills (not specified yet)

February 2017 (Workshop 5)

Follow up the two homework assignments, 5 and 6 from September 2016.

The content for the rest of these days is to give:

- 1-day Workshops about supervising defiant behavior caused by a lack of communication skills.
- 1-day Workshops in implementing Alternative and Augmentative Communication (AAC).

New homework assignments for September 2017:

Homework 7: That the group of Supervisors have written a manual for Supervisors in Arabic and presented it on the last education occasion.

Homework 8: That every one of the Supervisors have participated in planning, carrying out and evaluating the Parent Education – "First-Step".

<u>Data from Different Centers, Participants and Course Leaders</u> <u>Workshop 5</u>

Date: 20-23 February 2017

Trainers: Dr. David Henley- Dr Henrik Pelling-Lena Nilsson-Josefin Mannberg

Trainees were From:

- Right to Live Society
- Palestinian Society for rehabilitation and Autism
- Gaza Community Mental Health Programme
- Emaar Society
- Baitona Society
- Fajer Society
- Basma Amal

Main Topics:

- Follow up homework 5 and 6
- Participants' presentation "PPT-Videos,,"
- Summary of social communication and AAC
- Early Intervention Update with new evidence, TED-talk, and we will also look at Autism Navigator about parent-mediated interventions.
- Workshop with a case of a 3 year old boy.
- *ADOS video with the boy*
- Survey and functional analyze of behaviors

Continue Workshop with the case

- ADOS video with the boy
- Survey and functional analyze of behaviors
- Individual plan with goals
- Intervention strategies
- Training program
- Supervising

- Update about Autism Intervention -around the world
- A model for Supervision
- New homework 7 and 8
- Summary of this week

At the end of the 5^{th} training workshop, the participants recommended the following:

- 1- Provide them with records and videos of the way they deal with children with autism.
- 2- provide them with new activities that can be applied on beneficiaries

Provide alternative for the medications they use.

In April 2017, a meeting attended by Rawya Hamam "local project coordinator and autism trainees were held", and the following is the summary:

Trainees asked for using different tools and new variable techniques, to change the mechanism of tests implementation, to change diagnosis process, and to visit The Palestinian Society forAutism Rehabilitation in order to meet an autistic child which requires a long time to deal with the child properly; as Dr. Lena Nilsson suggested such visit

September 2017 (Workshop 6)

Follow up the two homework assignments, 7 and 8 (see above) from September 2016

<u>Data from the Different Centers, Participants and Course Leaders</u> Workshop 6

Date: 11-14 September 2017

Trainers:Dr.David Henley- Dr Henrik Pelling-Lena Nilsson-Josefin Mannberg

Trainees were from:

- Right to Live Society
- Palestinian Society for rehabilitation and Autism
- Gaza Community Mental Health Programme
- Emaar Society
- Baitona Society
- Fajer Society

Basma Amal

Main topics:

The sixth workshop included many activities of training,

Follow up homework 7 and 8 and present all the home works from the first to the final one

Make a schedule for presentation from each organization about 1,5 hour each

Participants' presentation of homework (pp, video, manuals)

Make a schedule for presentation from each organization about 1,5 hour each

After Intervention "Low Arousal Approach" – Tools for Parents

Participants' presentation "PPT-Videos,"

Workshop with a case of a 3 year old boy.

ADOS – video with the boy

Survey and functional analysis of behaviors

How to teach children with autism to deal with external Environment?

Self Control – Challenging Behaviour

Summary and discussion

Visions about Autism intervention in Gaza

Possibilities

Challenges

Closing

Certificate distribution

Brief descriptions for the trainees' presentations:

Day 1 of Autism Workshop, September, 11th 2017

Alaa Habib from Right to Live started his presentation. He talked in detail about what they do in their place and what model they use. He showed pictures and some videos of their model conducting. The trainers felt very impressed with the presentation. They had a small discussion about the presentations and proposed some questions to discuss on Thursday.

Farah Jabr from Palestinian Association for Autism Rehabilitation gave a very good presentation about homework assignment 7 and 8. The trainers asked questions and expressed their admiration of the work implemented in their association.

Day 2 of Autism workshop, Tuesday September, 12th 2017

Sobheia from Snabel School has started the day with a presentation of the intervention model used in their place. She showed pictures of the children she work with.

Then, Khetam from GCHMP presented the model they follow in GCHMP and clarified that they work with autism children in two stages only: diagnosis and supervision. She made it clear that the work of those places dealing with autism is merely complementary.

In Ahlam's presentation, she talked about some success stories from her work, one being about her son. The trainers were very impressed with her work and asked for videos.

The last presentation, by Alaa Askari, was quiet different, as his intervention model wasn't the same as used by the others. He had good tools of evaluation that helped the parents of autistic children.

Those presentations have raised number of questions and the trainers have written them down for further discussion.

Day 3 of Autism Workshop, Wednesday September 13th, 2017

Dr. David Henley and Dr. Henrik Pelling visited 3 Centers belonging to the project, which of course they had visited previously, but now wanted to follow up certain aspects of the project and also hopefully prepare for a more in-depth evaluation. Specifically they wanted to discuss the parent's role in the treatment process, in cooperation with the staff at the Centers. They visited Fajer Association for Autism, The Palestinian Society for Autism Rehabilitation and Right to Liv Society. They discussed the following:

- 1- The number of the autistic children and the number of the classes in each association
- 2- To what extent are the parents active in training.
- *3-The differences between the cooperative and non-cooperative parents.*
- 4- Problems they encounter in general.

The first visit was at Fajer Association for Autism, and met Ms. Amal Al-Khoudary. She said that they have 40-50 autistic children distributed in 10 classes with suitable conditions. Then she talked about the problems they encounter with many parents who don't participate in learning about Autism interventions nor are particularly active in helping the Center develop in the "Task Sharing" strategy. None-the-less it was very clear for her that the training course which has been implemented in cooperation with GCMHP was very beneficial and helpful to the trainees and the Center as well. Ms. Amal stressed the positive changes they have noted from the interventions now used by the staff who deal with the autistic children. Finally, Al-Khoudary talked much about the financial crisis they are going through because of the economic status in the Gaza Strip.

The second visit was with The Palestinian Society for Autism Rehabilitation. The delegation met Ms. Ghada Darwish who we in fact think has created an important success story in the Gaza Strip. Ms. Ghada said they have 50-70 Autistic children divided into groups. She mentioned that the training courses were extremely good and deserve their full appreciation.

She feels that the Center's work before the training was not well organized and depended on the staff's previous experiences, not particularly basic principles. Then, she talked about the differences between the parents who take part in the training and those who just expect the Center to do the work. They are working themselves to try to improve the cooperation for the children's benefit. Regarding the problems they face in the Center, Ms. Ghada said that they have a problem with The Ministry of Education because they refuse to open classes for the autistic children in the governmental schools. Dr. David Henley and Dr. Henrik Pelling understood why the Center keeps the children for long periods of time, as other possible schooling opportunities were simply too expensive.

The last visit was at the Right to Live Society and there they met Ms. Adala Abu Sitta. Dr. David interviewed and Dr. Henrik viewed the children and the classes. The Center also works with children with Down's Syndrome and new research shows that many of these children also have autistic characteristics. Ms. Adala said that they have 80 autistic children who they feel are developing well. She felt that the training course has been very beneficial to the staff and hope it could also continue. Most of the parents are cooperative and actively participate in learning and delivering interventions for Autism.

Focus Group with Autism Trainees

Time and Date: Wednesday 13-9-2017

The interviewer: Dr.Sally Saleh-research unit

The results of the focus group interviews were as follows:

1- General Opinions:

- The training added new knowledge to us.
- The focus on communication skills was excellent and new for us to deal with autistic patients.
- The international experts are well-skilled in training us.
- There are some repeated topics we already learned from them in the previous years.

2- Issues to improve:

- To consider implementation of the theoretical part.
- To provide us with the training material, full manual.
- *To include field work training under the supervision of the international experts.*
- To conduct training on psychometric tests.

Autism Training 2015-2017

Prepared by Farah Jabr and Maha Azzam From Palestinian Society for Autism Rehabilitation

- 1. Before joining the Autism Training Program, the Palestinian Association for Autism Rehabilitation was providing its services to children and their families, relying on independent and individual efforts. But after training, the association had greater confidence in working with autistic children since the training was a reference to the work of professionals and it arranged their ideas and efforts in an organized scientific manner.
- 2. The program stressed the need to work with parents and the need to educate them beside their participation in the therapeutic intervention plan for their children. This enabled the Palestinian Society's specialists to hold more meetings, training courses and workshops for the parents.
- 3. The program explained the importance of educating the network around children and raising awareness in the community; this encouraged the specialists in the Palestinian Association to increase awareness seminars that target all groups and segments of society and give them confidence to participate in the scientific days and autism conferences.
- 4. The specialists have learned new ways of communication, conversation, speech, behavior modification and strategies to help them deal with and supervise the parents.
- 5. The program has clearly influenced how individual plans, programs and educational goal support autistic children.
- 6. Before the program, the Palestinian Association began receiving cases of autistic children less than 3 years. The program for this category of children was limited to the mother's presence once a week to discuss some solutions and objectives with specialists in various fields (speech and communication, occupational therapy, psychotherapy and community rehabilitation). The first meeting on February 2015 emphasized the importance of early intervention, which proved to the Palestinian Society that the early intervention program initiated by the Association which is based on diligence is an important and necessary program and must be developed.

A success story

- On February 2015, a child (F-A), two years and 4 months came to the community. He was the only child in the family; his father worked the whole day and his mother was a university student. Therefore, his life was quite routine, lacking social communication.
- The parents complained about; the child's typical movements such as looking from the corner of the eye; shaking and fluttering hands; excessive attachment to objects; adherence to a particular routine; and his weakness in the ability to communicate verbally and visually.

- He was the first child to enroll in the early intervention program, which was developed after the training; it is based on the diagnosis of the child along with the rehabilitation sessions in the association; it provided psychological support and education for the mother; it enabled her to deal with and communicate with her child through the meetings and courses.
- An individual plan for the child included the mother's role in areas of rehabilitation (communication, psychological, occupational and community). Working with the child went hand in hand with the mother and the mother was persuaded to work with the child at home.
- A year later, the child was gradually integrated into a normal kindergarten three days a week in the beginning, in addition to the child's attending the three sessions of the association the other days. The specialists followed the child and observed the changes that occurred with him during this period.
- After 6 months, the child's was full time in the kindergarten and was able to interact and communicate with his teacher and his colleagues, non-verbally.
- Thus, we have achieved a 'success story' with the child by integrating him into his community (family and kindergarten) and by enabling the mother to communicate with the child, work with him and adjust his behavior.
- The success story was obtained by Farah Jabr and Maha Azzam on Tuesday 12.9.2017.

Thanks and appreciations from Fajer Community-Sobhia Medhat Sabra.

- The course was really informative for me; I learned better ways in dealing with parents and children besides our training for the parents on how to deal with their children with our special goals.
- My impression of the role, people, the place and everything was fantastic
- *I benefited from colleagues through discussion, questions posed to the team, the trainer, and the situations that were presented.*
- I thank GCMHP for allowing me to participate in this session.

Dr. Amal ALghoul -Basma amal center

Thanks for everybody that give to me knowledge about autism

Because of this course I feel that I know how to identify autism, how to support children with Autism; how to make use of tools of evaluation such as M-CHAT, gallium or Car; and how to set goals and try to achieve them.

We know how to use ABA and how to use it.

How to use ABC to maintain the level that the child has achieved.

How to think about goal setting, arrive at it easily and with little cost.

I feel I am good in this field because of your help, so thank you, thank you very much for everything.

Now doctors trust and believe in me and my ability to recognize autistic children; how to work with them and create a trust between us; and how to enter into their world and take their hands to come into our world and understand us.

Gaza Community Mental Health Programme -suggested protocol by :Zahiya-Khitam

Gaza Community Mental health Programme is a non- profit NGO association, which was founded in 1990, and works in the field of the mental health and human rights. The Programme strives to enable the Palestinian community to gain a high level of community mental health through the provision of clinical, social, training, research and advocacy services for children, women and victims of violence and human rights violations. In addition, the Programme adopts a community- based service philosophy to reach as many as possible of the target group through the public awareness campaigns. Those campaigns are launched to increase the public awareness about the mental health issues and to overcome the problems of ignorance and shyness associated with mental illness. All of which can be implemented through lectures, public gatherings, publications and articles.

Autism

In 2015, autism course in diagnosis and rehabilitation was initiated, so that a group of GCMHP's professionals received this training to date.

Intervention measures

Those measures begin by receiving the cases coming through the center. Then, the case is reviewed by a professional, such as a medical doctor or psychiatrist. Through the review, the patient's history is taken and the current complaint of the parents. The medical history of pregnancy, childbirth and the development of the child's normal growth, in terms of movement, language, physical growth, social communication and social interaction, are taken.

The history of the child's symptoms

In another session, the child is interviewed to assess his case in the treatment room through playing. The child is treated by observing his behavior, collecting information about his situation and trying to differentiate between his diagnosis and other disorders that would be similar, especially that autism is accompanied by several disorders like mental retardation, hyperactivity and ADHD.

The condition of the child/family is discussed with the medical team concerning the diagnosis and the arrangements for cooperation. Then, a session is arranged with parents to educate

them about the diagnosis, the child's condition, the nature of the illness, their role in the rehabilitation and the importance of the rehabilitation centers in improving the autistic child's abilities. All of which requires the assistance of parents in the referral of the child to a rehabilitation center near the family's place of residence. According to this, the case can be referred to one of the partner centers like Right to Live Society and Palestinian Society for Autism and Rehabilitation

The team plays an educational role about autism and early detection of children, especially for the cases under 3 years, through other programs and partner and non-partner organizations such as kindergartens, schools, organizations, public gatherings. Also, this role can be achieved by the media especially through writing articles, making radio and television interviews.

The free telephone counseling is considered to be one of the most important means of education and awareness of mothers about autism, whether by the mother's consultations or helping mothers to know the proper ways to raise the child and communicate with him. This can't be isolated from providing the child with the psychological support.

Autism Diagnosis:

1- The information collected by the family especially related to the child himself, and his medical history.

Hearing, sight, articulation and medical tests are required to ensure that the symptoms are not of a treatable organic problem. Epilepsy that should be treated medically. In addition, CT brain scans might be helpful if the diagnosis is unclear. One should avoid expensive medical technology if not necessary.

- 2- The professional's observations of the child in a diagnostic session. The observations are taken through the assessment of the child's communication, interaction and skills.
- 3- The major diagnostic tool which is the Autism Diagnostic Interview with the participation of the pediatric psychiatrist at the center (Sami Owieda).
- 4- The exclusion of autism's similar disorders like Asperger syndrome, Rett syndrome, Down's syndrome and mental retardation.
- 5- The assessment tests for intelligence and mental and linguistic abilities conducted by the psychiatrist. Different tests are used like Wechsler test for children or other tests that suit the level of the child.
- 6- The assessment of the child's ability to communicate and interact through playing with the child and establishing the extent of his interaction with the professional, play and games.

The team involved in the intervention process for the Autism.

Referral

After the confirming the diagnosis, making the necessary tests, educating the parents about their child's case and assuring their continuous role in improving the abilities of their child, they are referred to one of the autism rehabilitation partner centers, where the child is presented to a specialist in psycho-educational approaches.

Rights

The parents are made aware of the rights of the autistic child in the society through his integration with other children, treating him humanly and not violating his rights. He is also being referred to the social affairs to claim his rights of the provisions for disability and illness of children according to the applicable laws in force in Palestine.

LESSONS LEARNED

As we have mentioned previously, during our visits and direct involvement with Autism in Gaza, we found only few medical professionals experienced in diagnosing children with Autism and using evidence based psycho-educational treatments. On the other hand it is gratifying and impressive to see the recent development of different centers in Gaza clearly making use of psycho-educational treatments. Many have long waiting lists of applicants which go along with our impression that there are many children with an Autism diagnosis in Gaza. Studies throughout the world, including the Middle East, would also support this assumption.

The parents were impressed by the psycho-educational approach and could even begin to apply them. Their expectations were in general realistic and they hadn't expected that we would come with 'magical' medical marvels. Few of the parents felt that their child was helped by the medical treatments they had been previously receiving. In fact, quite a few parents talked about their child's improvement after gradually withdrawing medications.

That parent with whom we had contact had no difficulties shouldering the role of being the major trainers for their child, but of course realized the need for having exchanges with professionals versed in the field. They seemed intuitively to understand the need for a certain degree of training intensity, not just a couple of hours weekly in a center or with a private trainer.

Parents with a child attending one of the other organizations would often hear how well their child was doing 'there' but at home the parents were faced with the same problems. The training of parents was not always an essential ingredient with these organizations. This shortcoming became a little clearer to some of the professionals from these organizations.

CONCLUSIONS

This is a fairly unique undertaking since there is still the general belief that only professionals themselves can carry out the necessary training of children with Autism, and transferring these skills to non-professionals, like parents or other caretakers, just won't work. Today, science tells us that caregiver implemented psycho-educational interventions are clearly the treatments of choice. It was good to see that this approach is now well received in Gaza. The days when psycho-pharmacology is the knee jerk response to the treatment of Autism, seems to be limited.

Perhaps we are just at this moment caught up in the enthusiasm of the parents when they saw that they could help their children. On the other hand we do realize that this is a long term commitment if it will work and reach significant numbers of children. This is just the beginning and we think it will take a lot of work to cover all the needs.

This has been extremely pleasurable and rewarding work which we feel has landed among enthusiastic and dedicated parents and professionals. We were very impressed with the persons devoted to developing the work with this most vulnerable segment of the child population, despite all the short comings in Gaza due to frequent incursions and a long term, ongoing boycott

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Uppsala, 2017

David Henley, Ph.D., M.D. is a child neurologist who has been working at the Department of Pediatrics, Uppsala University, Uppsala, Sweden/Child and Adolescent Habilitation Center, with disabled children now for 35 years, particularly with children with neuro-psychiatric disorders. He has also extensive experience working in low income countries.

Henrik Pelling, M.D. is a child and adolescent psychiatrist who is working at the Child and Adolescent Psychiatry Clinic at the Uppsala University, Uppsala Sweden particularly with children with neuro-psychiatry disorders. He has extensive experience working in low income countries.

Josefin Mannberg is a psychologist and CBT psychotherapist who has worked with early intervention and challenging behavior of persons with autism now for 25 years at the Child and Adolescent Habilitation Center in Uppsala, Sweden

Lena Nilsson is a speech and language therapist who has worked for 30 years with children with autism, Down's Syndrome and Mental Retardation at the Child and Adolescent Habilitation Center in Uppsala, Sweden. She had further university education in psychology and ABA and is a member of a Swedish National group of speech and language therapists working with evidence based guidelines for Swedish Habilitation Centers about Communication, Language and Speech Interventions in small children.

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