

A Project for Enhancing the Quality of Medical and Psycho-Educational Services for Autistic Children in the Gaza Strip

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 changing 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" 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 only now makes 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 “training trainers” 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, 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 and actual evidence based treatments, and the possibility of working with the model of “training trainers”. 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 and comorbid medical problems, 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 now for many years, joined the Team. A 50 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.

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 instruction, advice and information, preferably written of the child's training program, how you can interact with the child and about the child's 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 regularly 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 not use medications, except for special cases as required. In other words, there should be wise use of treatment with medicines.

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 psycho-educational 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 is important so that it is important to educate the staff of relevant organizations which work with, or come in contact with, children, for instance,

primary health care organizations, or kindergartens. Diagnosis and a medical work-up is 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 the year and a half that this project has been going on, 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. There is today overwhelming evidence today 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 from three organizations; Gaza Community Mental Health Programme, Right to Live and Palestine Association for Rehabilitation and Autism. Supervisors must recognize that intervention planning is direct 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 years 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 will then continue, 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 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

February 2015

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, Right to Live and Palestine Association for Rehabilitation and Autism 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.

September 2015

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 now it obvious to involve parents in the training of their children, which also helps to reduce parental stress.

February 2016

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?

September 2016

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).

New homework to February 2017:

Homework 5: Social communication (not specified yet)

Homework 6: Supervisor skills (not specified yet)

February 2017

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”.

September 2017

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

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 center in Gaza clearly making use of psycho-educational treatments. Many have long waiting lists of applicants which goes along with our impression that there are many children with an Autism diagnosis in Gaza. Studies throughout the world would also suggest and 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.

They 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.

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 Autistic children, 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 treatment of choice. It was good to see that this approach is now well received in Gaza. The days when psychopharmacology 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 develop 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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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.

