





# USAID/IMPROVING THE QUALITY OF LEARNING IN ZANZIBAR (MKEZA) Summary of Activities Conducted by the Joseph P. Kennedy, Jr. Foundation



# IN SERVICE TRAINING FOR TEACHERS ON INCLUSIVE EDUCATION

# MODULE 4 ADVOCATING FOR CHILDREN WITH SPECIAL NEEDS



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# MODULE 4

# ADVOCATING FOR CHILDREN WITH SPECIAL NEEDS

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## **INTRODUCTION**

Good special education services are intensive and expensive. Resources are limited. If one has a child with special needs, he or she may wind up battling the school head teacher and teachers for the services your child needs. To prevail; he or she needs information, skills, and tools.

The intention of this module is to provide an overview of the main areas of advocacy. Advocating for special needs as an introductory module is supposed to explain many interrelated components of educational special needs of person with disabilities. Due to the broadness of the subject only a small portion of it will be covered. However after completion of this course you will have developed interest in studying advocacy and have a foundation of reading and understanding other related topics not included here.

Each presentation is focused on one important issue of disability and is related to some courses on special education / inclusive education offered by MKEZA MKEZA as carried out by the EQUIP1 consortium; managed by the American Institutes for Research (AIR) and primarily implemented by Aga Khan Foundation in Zanzibar and its partners.

Lesson One defines advocacy, gives it goals and types. Lesson Two is about advocates for special needs. The lesson includes the types and characteristics of disability advocates. Lesson three is on parental advocacy, and Practical parent advocacy is discussed in lesson four

Lesson five explains the don'ts for the parents, followed by lesson six discussions on how to deal with hostile environment-a case study implementation model. This is the also called a parents advocacy perspective.

Making relevant statements in disability advocacy is introduced in lesson seven, lesson eight deals with issues of self advocacy. The two last lessons; Policies that support advocacy activities in Tanzania are presented in lesson nine and lesson ten explains some developmental partners in the field of awareness and disability advocacy.

The module includes some possible questions presented in an interview and case study formats. These are questions which you are likely to be asked in your new career in advocacy. Take carriage!

# Lesson one

# ADVOCATE DEFINED

Read the following interview between Charles and Adriana

#### ADVOCATING FOR SPECIAL NEEDS - AN INTERVIEW APPROACH BY TOP SECRET FRIENDS-ADRIANA (MEXICO) AND CHARLES (TANZANIA)

On their way for a professional visit to Galilee; participant of the international seminar on Special Education-Integration Frames and Methodologies 5.9.2005 – 29.9.2005 using basket/voting everyone chose his or her so called SECRET FRIEND. This exiting exercise brought about but together different people from different continents to become what the author of this article calls "a pen-friend in dark gallery". It isn't just for co incidence Charles-Teacher of teachers/Consultant from Tanzania was very very very..... luck to be chosen by Adriana-the psychologist, a lady from Mexico.

The two friends had never ever known each other but until on their way back to Ramat Rachel from Galilee. After the disclosure of "who is who" my secret friend", and immediately after a lecture on Self Advocacy by Dina Sela, held at CET (Center for Education Technologies) in Tel Aviv, the two "no longer secret friends" conducted an on-line interview on the whole issue of Advocating for Special Needs. The author of this article was just lying somewhere and was able to edit this interview schedule as follows:

**Adriana (Mexico):** Charles, tell me what do you understand by the agenda of advocating for special needs?

**Charles (Tanzania):** Listen, my ex-top secret friend; Good special education services are intensive and expensive. Resources are limited. If one has a child with special needs, he or she may wind up battling the school principal (head teacher) and teachers for the services his or her child needs. To prevail, he or she needs information, skills, and tools. One among many ways of getting the required information is through ADVOCACY (*Advocacy is by its nature, a cerebral activity and involves great thought and creativity*). This implies use of advocate(s) **Adriana (Mexico):** What is advocacy in special needs?

**Charles (Tanzania):** Advocacy means to speak or take action either with, or on behalf, of, the children with special needs, to change the situations that cause learning barriers and bring about justice. This may involve speaking and working with groups, individuals, companies or governments whose actions or policies affect the learner who has special needs. Here is how the dictionary defines the term "advocate": *Ad-vo-cate* – Verb, transitive. To speak, plead or **argue** in favor of. Synonym is support.

What do you understand by the term advocacy?
 Write a letter to explain advocacy to your DEO

# Lesson two

# ADVOCATES FOR SPECIAL NEEDS

Read the following interview between Charles and Pakacha

Pakacha (Michakaini-Pemba): *Who should advocate?* Charles (MKEZA): Anyone can advocate for another person. Ok?

**Pakacha (Michakaini-Pemba):** If any can advocate, then what is special about advocating for special needs?

**Charles (MKEZA):** Such a good question! Believe me or not, there are so many unique aspects in advocating special for special needs. First and foremost the advocate must be one that argues for a disability rights; second he or she must be a supporter or defender of disability rights; thirdly he or she must be an advocate of disability rights and human rights. Advocacy for special needs must be one that pleads in another's behalf; an intercessor; these are advocates for learners with disabilities who are abused.

- Advocates argue for a cause; a supporter or defender; an advocate of civil rights.
- They pleads in another's behalf; an intercessor; advocates for abused children and spouses. They are lawyers.

Here are some advocates for children with special needs who work to improve the lives of children with disabilities and their families:

#### Lay Advocates

Lay advocates use specialized knowledge and expertise to help parents resolve problems with schools. When lay advocates attend meetings, write letters, and negotiate for services, they are acting on the child's behalf. Most lay advocates are knowledgeable about legal rights and responsibilities. In some states, lay advocates represent parents in special education due process hearings.

#### Educational Advocates

Educational advocates evaluate children with disabilities and make recommendations about services, supports and special education programs. When educational advocates go to eligibility and Individualized Educational Programs meetings, they are acting on the child's behalf. Some educational advocates negotiate for services. Others are less knowledgeable about special education law and how to use tactics and strategies. Educational advocates include:

#### • School Personnel

Teachers and special education providers often see themselves as advocates. Teachers, administrators, and school staff often provide support to children and their families. But because they are employed by school districts, school personnel are limited in their ability to advocate for children with disabilities without endangering their jobs.

#### • Parents

Parents are natural advocates for their children. Who is your child's first teacher? You are. Who is your child's most important role model? You are. Who is responsible for your child's welfare? You are. Who has your child's best interests at heart? You do.

You know your child better than anyone else. The school is involved with your child for a few years. You are involved with your child for life. You should play an active role in planning your child's education.

The education policy (law) gives parents the power to make educational decisions for their child. If you are a parent do not be afraid to use your power. Use it wisely. A good education is the most important gift you can give to your child.

**Pakacha (Michakaini-Pemba)**: thank you Charles, but how about persons with disabilities are they not advocates by themselves?

**Charles (MKEZA):** Yes indeed, I remember a lecture by Dina Sela in Dr. Dina is the educational counselor and works with Centre for Educational Technology-Tel Aviv, Israel. Dr. Dina's presentation was all about *Self Advocacy and self advocates*.

She said Self-advocacy means:

Knowing Yourself,

- Knowing What You Need,
- Knowing How to GET It

Self-advocacy is the ability to understand and effectively communicate one's needs to other individuals. Learning to become an effective selfadvocate, especially for individuals with a hidden handicap such as dyslexia, is all about educating the people around you. Therefore knowledge is the key to self-advocacy. Like anything else, the more you know, the better you understand, and the easier it is to explain. This journey of self-education is an ongoing process, as individual needs change over time.

## Pakacha (Michakaini-Pemba): Why should one advocate or argue?

**Charles (MKEZA):** there are many reasons for advocating in special needs, however I would like for the purpose of this discussion to underpin only two educational reasons. These are:

- 1. to ensure that the school provides the child with special needs with a "free appropriate public/regular education" that includes "specially designed instruction to meet the [child's] unique needs . . ."
- 2. To build a healthy working relationship with the school.

# **Pakacha (Michakaini-Pemba)**: *What is the role(s) of these advocates?*

**Charles (MKEZA):** Advocates for special needs performs several functions. I will mention just a few among the many roles.

- a) Supports, helps, assists, and aids learners with impairments at home and school
- b) Speaks and pleads on behalf of children with disabilities
- c) Defends and argues for disability rights.
- Advocates for special needs are negotiators. As negotiators, they discuss issues and make offers or proposals. They seek "win-win" solutions
- a) Gather information about disability
- b) Learn the Rules of disability advocacy
- c) Plan and prepare an intervention and instructional program
- d) Keep Written Records of a learner with special needs

- e) Ask Questions, Listen to Answers. (Advocates know how to use "Who, What, Why, Where, When, How, and Explain Questions" (5 Ws + H + E) to discover the true reasons for positions).
- f) I dentify problems areas of learners with disabilities
- g) Propose possible solutions regarding intervention problems
- h) Plan for the future; way forward of intervention plan
- i) Answer Questions about the progress of learners with disability.

According to The American Heritage Dictionary of the English Language, Third Edition an advocate performs several functions:

- 1 Supports, helps, assists, and aids
- 2 Speaks and pleads on behalf of others
- 3 Defends and argues for people or causes

# CHARACTERISTICS OF A GOOD ADVOCATE OF CHILDREN WITH DISABILITIES

- To date there is no regulatory framework to assess the competency for a lay, non-attorney advocate in special education. There is no uniform test or certification for these advocates, and they differ widely in their capabilities and experience. Thus, a smart parent consumer will verify that these advocates have taken formal training in the rules and regulations of special education, via workshops, university programs, or other training.
- 2. Experienced in Special Education matters Parents should ask lay advocates for a summary of their practical experience in special education matters. How ma Properly trained in special education law
- 3. How many Individualized Educational Program meetings have they attended? What sort of cases have they handled in the past, and with what results? Which school districts have they encountered? When do they call in an attorney?
- 4. It is essential that every advocate be able to answer this last question clearly. Every IEP dispute can become legally complex quickly. Good lay advocates have attorneys whom they can recommend (and hopefully with whom they have worked before) to a client if necessary.

- 5. All lay advocates should be clear in their own mind when their job has transformed from one of accompanying a parent through the predictable maze of special education to actually giving legal advice about what to do next. The latter is, by law, the province of the attorney. A good lay advocate will be very careful about making an actual legal judgment or recommendation to his or her consumer without first checking with an attorney.
- 6. Professional in Demeanor: Lay advocates who represent parents often come to the job, as do special education attorneys, because they have children with special needs. Attorneys and lay advocates who are themselves parents of special needs children need to separate their own experiences from those of their clients. By that, I mean they must keep foremost in their minds the child at hand, not their own child. This is especially true if the experience the advocate had with his or her own child was negative. In the role as a mediator one may see lay advocates who are as professional as attorneys. I have also seen many who are not. An unprofessional advocate will do more harm than good.

- 7. Well Supported at the Office: Like attorneys, lay advocates should have reliable communication with their clients by phone and email. They should also give regular status reports to their clients and be able to manage the research and meeting demands of the cases. Clients should feel that the lay advocate gave them sufficient time and attention, and explained the proceedings clearly. Although lay advocates do not have a recognized legal privilege, they should keep all confidences and should not discuss the case in any place where they could be overheard.
- 8. Sensitive to the Needs of the Child at Hand: The lay advocate must be able to reconcile the remedy to the needs of the child at hand. That is, the advocate must have a firm grasp of the distinguishing facts of the case as opposed to the facts of other, similar cases the advocate may have handled. Parents should believe that the advocate has tailored the remedy to the unique needs of their child, and not just attempted a remedy that is typical for children with a similar disability, or even another client with a similar disability.
- 9. Sensitive to the need of the client to make the final decision: Like an attorney, the advocate must offer options to the client with which the client can live. Similarly, the advocate must accept the client's decision with regard to the many options available, and not interject too much the advocate's own preference for one remedy or course of action over another.

 After having read these few roles and types of advocates who are YOU my dear reader?
 Are you an advocate kind of? Which kind?
 Can you advocate for special needs?
 Would you like to advocate for special needs?
 If not you who should advocate and argue for disability rights?
 Write a poem describing the role of teachers as agents of advocacy in schools
 Write an article on the types of disability advocates for publication in any local news letter in Tanzania.

# Lesson three

# PARENT ADVOCACY

Parent advocacy in usually done by parents of children with special needs. There are two major goals of Parent Advocacy. These are:

- 1. To ensure that the school provides your child with a "free appropriate public/regular education" that includes "specially designed instruction in order to meet the [child's] unique needs."
- 2. To build a healthy working relationship with the school.

## Categorizing Parents of Children with Special Education Needs

Parents of children with disabilities differ in behavior and in their cultural and moral values, believe, philosophy, and come from differentiated environment and background. As an advocate you may need to understand the categories of parents as this will help you to work with them in advocacy groups. The parents of children with special education needs come in several categories. These include:

- 1. Pacifists or those who gets things done;
- 2. Clinging vines or parent advocates;
- 3. Silent victims or fighters;
- 4. Dreamers or crusaders;
- 5. Waiters or initiators;
- 6. Bombshells or assertive parents;
- 7. Appeasing compromisers or action heroes.

**Not Assertive:** Parents are not assertive if they:

- 4 Beat around the bush;
- 5 Fail to describe problems;
- 6 Feel guilty or are afraid to be vocal;
- 7 Agree with professionals to keep peace;
- 8 I gnore the right to services;
- 9 Leave everything to others;

10 Accept excuses for inappropriate

Which are the parents you know and which are you? Assertive or are not assertive parent?

# Lesson four

## PRACTICAL PARENT ADVOCACY

What required of you as a parent?

Practical advocacy requires competency, and skills in the following areas:

#### **Gather Information**

Nicely, ask the case manager if your son took a make-up test. If he did not, then nicely ask the case manager "Why not?" Don't focus on who is at fault. After you talk to the case manager, say "thank you" and move on.

#### Prepare for Meetings

Parents should treat the Individualized Educational Plan meeting as if it is the first step towards a due process hearing by preparing for the meeting and building a record. If parents do this, you make it less likely that they will end up at a due process hearing. If a parent does end up at a hearing, he or she will be in a stronger position.

#### Ability to Prioritize Child's Needs

Everything parents want for their child is not equally important. Make a list of what the child really needs, what the parent want for their child (but may be willing to compromise on), and what would be nice to have but that the parent would definitely be willing to give up. Think about the evidence they have to support each requested item (i.e., reports, assessments, experts, other documents). If they prioritize their issues and have facts and evidence that support what they want, it is more likely that they will be taken seriously.

#### **Build Good Relationships**

Develop positive relationships with school personnel, to the greatest extent possible. Ask questions. Ask the child's team to explain things which were not understood (Unclear issues). Take the high road. As hard as this may be to do, being polite and courteous is always better than being rude and nasty. If a meeting is deteriorating with nasty comments or behavior from any team member, ask for a break or ask that the meeting be continued to a later date and time.

Good relationships with school personnel and central office staff to the

extent possible will generally ensure that issues you bring up will be taken seriously.

#### **Document Issues & Concerns**

Ask that items and issues strongly about be documented in the meeting summary or notes. Review the summary before leaving the meeting. Know rights about amending child's records.

#### **Use Advocacy Strategies**

Use advocacy strategies. Meetings do not have to be drawn out to the point of battle. For example, if the team cannot reach an agreement about the type or amount of service, suggest that the issue be tabled in order to obtain additional information from consultation or conversation(s) between your child's private therapist (if there is one) and the school therapist (if there is one). Rather than immediately asking for an independent assessment, disputes can sometimes be resolved by asking that an assessment be conducted by a school district evaluator who does not know your child.

UWZ (Umoja wa Watu wenye Ulemavu Zanzibar) wants to employ new advocates mission on awareness and disability advocacy. One among the prerequisites UWZ underpinned is a "realized practical disability advocacy" for applicants. Plan and prepare an advertisement for UWZ. The advertisement should also cater for use in the TV, radio, road sign posts and newsletters.

# Lesson five

# WHAT AS PARENTS YOU SHOULD NOT DO?

Parents as ascribed advocates should not do the following

#### 1. Complain Loudly & Often

Parent should not complain about every issue that comes up over the course of their child's school life. This is the equivalent of crying wolf, and ensures that when a serious issue does arise, they (parents) will not be taken seriously. This is because they are expending the same amount of complaint energy on the serious issue as you expended on trivial issues.

#### 2. Assume the Worst

Parents should not assume that the school district is out to get their child and deny services. While the reality is that the school district is a bureaucracy with its own interests to protect, most individuals in the district enter the field because they care about children. While they need to enter the special education and or inclusive education process with knowledge to protect child's rights, parents should treat the professionals with whom they deal as if those professionals have the child's best interests at heart.

#### 3. Have a Closed Mind

Parents need to be having an open mind at Individualized Educational Plan meetings. If the child's team proposes a placement with which you disagree, do not dismiss it, or refuse to observe it, or refuse to consider it. This is especially true if a parent may challenge the appropriateness of the proposed placement. Again, the Individualized Educational Plan meeting is important for record-building purposes. If the case goes to a due process hearing, it is important that you present as a cooperative person who thoughtfully considered the team's program, personally observed the program, and can explain why you believe the program does not meet your child's needs.

#### 4. Stint on Experts

As a parent, do not try to save money by stinting on experts. A parent needs to find experts who can provide sound professional opinions and

evidence. Experts are critical to successful cases, especially if parents are unrepresented.

If a parent truly cannot find experts, either through his or her children's medical service providers or otherwise, they (parents) need to think about how to use supportive (or even hostile) school personnel to his or her advantage.

1. Write a brief speech to address the parents meeting on what they should do and what they should not regarding the rights of a disabled child in inclusive schools

2. Write a paper to mobilize and help parents to conduct a charity walk or Harambee for a child with special needs who is hidden and overprotected in a nearby village.

#### Lesson six

## DEALING WITH A HOSTILE ENVIRONMENT AT SCHOOL (Parent Advocacy Perspective)

What is perceived positive aspect or condition of parent advocacy in order within a hostile school environment?

As a PARENT you should; "View your relationship with the school as a marriage without the possibility of divorce." Read the following case study of Sadiki. Read the following case study

#### CASE STUDY OF SADIKI

Parents of Sadiki are having great difficulty with a 'hostile environment' at the school. During his regular advocacy activities Mr. Mlaponi sported the Sadiki's mother Mrs. Zainab saying; "Our child is three years old and has an aid. The teacher and teacher's assistant are angry at the aid because she informed us that our son, who has feeding problems, was force fed during his first week in the school."

After she had told Mlaponi what happened, Mlaponi questioned the school and the teacher. From that point on, the environment has become unbearable for the aid and is having a negative impact on our son.

The head teacher informed the class teacher (Bi Fatuma) that she is not to tell the parents of Sadiki about anything that goes on in the classroom. They say the class teacher is not following the direction of the head teacher and is too overprotective of Sadiki. Sadiki's parents have had several meetings and have written several letters to the school head teacher regarding this situation.

"Does the head teacher have a right to tell Sadiki's parents what is going on in the classroom? My guess is yes. Is there any case-law or sections of the law that we can refer to?"

#### BAKARI & ELIZABETH ANSWER

**Elizabeth:** As a parent, your mission is to make the school want to help your child and your family. You will not succeed at this mission by blaming, writing complaint letters, or waving case- law at school personnel.

The school will react to perceived threats by pulling their wagons in a circle, preparing to defend for themselves if you sue them. Do not be surprised if the aide who took your side against the school is transferred or fired. These behaviors are not unique to schools. They happen in most organizations when there is a perceived threat from the outside.

**Bakari:** How do you react when another person - someone you do not know well - makes demands of you? If you are like most people, you dig in and hunker down for a fight. When a person makes demands on you, I doubt that you rethink your position. You prepare to defend yourself.

**Elizabeth:** Your child is three years old. You will be dealing with the school for many years. What can you do? You need to restructure your relationship with school personnel.

**Bakari:** In our training programs country wide, we tell parents, "Unless you are prepared to remove your child from public school forever, you need to view your relationship with the school as a marriage without the possibility of divorce. You need to focus on solving problems while protecting the relationship."

**Elizabeth**: I do not recommend that you stop advocating for your child. I do recommend that you learn effective *advocacy skills and techniques*. Start with:

- 1 Understanding the Playing Field, this includes
  - (i) Trust,
  - (ii) Expectations,
  - (iii) Power struggles between parents and schools and how to avoid them,
  - (iv) The parental role, and
  - (v) The need to understand different perspectives.
- 2. *How to DISAGREE with the Individualized Education Plan (IEP) Team* without starting School War.

Carefully handled, questions about Individualized Education Programs (IEP), and disagree with the IEP team without starting School War. From that point of view therefore parents require to develop skills on:

- 1 The Rules of adverse Assumptions,
- 2 How to use tape recording and thank you letters to clarify issues,

- 3 How to deal with an IEP team bully.
- 4 Parents need to learn to use tactics and strategies of
  - Persuasion and Negotiation.
  - o Letter-writing.
  - Focusing.

## NEGOTIATION AND PERSUASION

Learning to Negotiate is Part of the Advocacy Process

Negotiating solutions to disputes and/or claims saves time and money. Most of our experience is in the civil area, but the techniques and skills in special education cases are the same. By using these techniques, one rarely is forced to take a special education case all the way to a hearing. Here are a few techniques that have worked for some people. Perhaps they will be helpful for you.

## Four Rules to Guide You

- 1. Organize your records and files.
- 2. Distill your grievances (issues) into 1,2,3,4 outline format.

State your grievances in short declarative sentences. Eliminate or reduce modifiers, adjectives, four letter utterances, etc.

3. Correlate your evidence (documented supporting facts) to the issues. 1(a) (b) (c), etc;

4. Know what it is that you want. Be specific.

# LETTER-WRITING

In *Art of Writing Letters,* as parents you must put emphasis on the use tactics and strategies when you write letters to the school. You learn about the Blame Approach and the Storytelling Approach; the sympathy factor; first impressions; pitfalls; and the powerful decision-making Stranger. If you have a problem with the school or concerns about your child's program, you must document your concerns in writing.

# FOCUS

The things you need to focus on as a parent advocate are:

- 1. What information do you have about your child's progress or lack of progress?
- 2. How can you collect this information?
- 3. Once you have accurate information about his progress, how will you use it?

- 4. Take another look at your child's IEP and answer these questions:
  - a) Is the IEP based on complete, current testing?
  - b) Does the IEP include all legally required components?
  - c) Does the IEP follow the recommendations of the evaluators?
  - d) Are the goals and objectives measurable?
  - e) Are the objectives appropriate?
  - f) If your child is not making progress, did the IEP team increase the intensity of instruction?
  - g) Are the instructional methods research-based?
  - h) Are his teachers trained in the research-based instructional methods that your child needs to meet the goals in his I EP?
  - i) Remember, *special education is a service, not a place*. To reach his goals, your child may need to receive instruction from a teacher who has different certifications and training.
  - j) You need to do what is necessary to ensure that your child gets an appropriate education. You can't do this when you are focused on anger and blame. You must learn to manage your emotions and work with school staff as a team member. Although this can be difficult, your child is depending on you. Get a Comprehensive Evaluation
  - k) You need to get a *comprehensive evaluation o*f your child by an independent evaluator in the private sector. A comprehensive evaluation will give you a roadmap for the future.

Plan and draw a big poster/wall chart describing what expected of you as parents in regard to:

- 1. Things you should focus in your advocacy role
- 2. Dealing with hostile school environment

# Lesson seven

# MAKING RELEVANT STATEMENTS IN DISABILITY ADVOCACY

It is very important to make clear and relevant advocacy statements. For example when you make a statement like

- "I want my child/student to have a free appropriate education," this is like asking for a piece of string of unknown or undefined length.
- Your statement of "I want ...." must be followed by a "because."
- The "because" should come from your well-stated issues and your supporting factual evidence. Why? Because any issue that you identify as a grievance is a request that something be done differently than it is being done now.

#### Techniques & Tactics for making statements:

Here are some techniques that work for some people.

- a. Listen carefully to the other side.
- b. If you listen carefully enough, you'll find that the other side often gives you good clues about how to solve the problem.
- c. Don't formulate a response until you give the other side a chance to express their thoughts and ideas.
- There is a saying: "It is rude to continue talking when I am trying to interrupt." If you interrupt while the other party is talking, you will miss a lot of good stuff.
- 2. Think about watching a tennis player return the ball. Good players let the ball hit the ground before they take a whack. Players who predetermine their whack before the ball hits the ground get skinned.
- 3. Do not personalize statements made by the other side. If you personalize, you will get your thin skin handed back to you, wrapped up in a loss. **Remember:** you are engaged in a process to get the best deal you can for your student/child. You are not there to argue about whether you are overprotective or nasty. The school/family has to deal with nasty parents. The school's/family's primary responsibility is to the child despite any parental / school hostility.
- 4. Learn to outline conversations and recognize educational jargon.
  - Much of what is said during meetings is informal conversation

and is not germane to the issue(s) being discussed.

- Train yourself to recognize murky education jargon. For example, if the IEP team says, "The school/family feels \_\_\_\_\_\_," you can ask, "What exactly do you mean by "feel?" What you are after is information about the basis for the school's decision.
- 5. Try to figure out the best alternative to a negotiated resolution for you and the other side.
  - Some negotiation-instructors use a memory device called BATNA. (BATNA stands for Best Alternative to Negotiated Agreement).
  - Try to figure out what your best alternative course of action would be if your negotiation fails to yield the results you want or are willing to accept.
  - Do the same thing for the other side. (This means you need to know what the other side wants)
  - If your position is that the child needs X service and the school is providing Y service, you have several choices if the school is intractable. One option is to accept Y as offered. Another is to file for a due process hearing.
  - What service(s) are available between X and Y that are appropriate, reasonably calculated to provide the child with educational benefit, given this child's unique educational needs?
  - The method or procedure you determine during this process is likely to be your best alternative to a negotiated agreement.
  - If you decide that the school's best alternative is a due process hearing, it is unlikely that you will find an informal resolution between X and Y.
- 6. Learn how to deal with different kinds of negotiators, including hardball players. For parents who must negotiate without formal training and time to practice negotiating skills outside the trenches, here are a few techniques that will give them a better chance for success.

# a) Prepare.

Before you attend a meeting or negotiation at any level, review

your documents and notes. Outline your grievances and the facts that apply to these grievances. Do not try to negotiate or argue your position based on a general working knowledge of historic events. It won't work. Know the facts that are relevant to your grievance. There has been a lot of ink put on pages describing what relevance or materiality means; for your purposes, use the "so what?" test.

- b) Know what you want to accomplish with specificity.
  It does no good to argue a point and not be clear about how and in what manner you want your position to be implemented.
- c) Know what your "throw-a ways" are.
  When you review your "wish list," decide which items on your list are not important to your overall grievance or claim.

**Remember:** Negotiating is Part of the Advocacy Process

Opposing lawyers sometimes get together to lay out their respective cases. They banter back and forth about their opinions and whether a theory will fly or prevail or reach a jury or trump a position. Through this process, they get a notion of the other side's case and can squish it through the filter of conversation and reach a guess about the strengths and weaknesses of the other side's case.

1. Give an advice to a parent and person with disability, on how he/she can make relevant statements of advocacy.

2. Suppose you are a person with disability or a parent of a pupil with disability staying a bit far from school make statements to convince the school and the DEO that the distance from home to school do affect your learning/childs' learning process.

# Lesson eight

# SELF-ADVOCACY: AN IMPLEMENTATION MODEL

What is self-advocacy? As we mentioned earlier Self-advocacy is about:

- 1 Knowing oneself, self recognitions
- 2 Knowing What You Need,
- 3 Knowing How to GET It. The methods toward getting the needs/ desires

These are the three parts for becoming an effective self-advocate:

- 1. Knowing oneself,
- 2. Knowing your needs, and
- 3. Knowing how to get what you need.

#### Know oneself

Diagnostic testing is the first step towards better understanding your needs. A psycho-educational evaluation is a series of tests used to diagnose specific learning disabilities and to identify individual strengths and weaknesses.

Be aware of co-existing disorders (learning disabilities that are found together). For example, a person with dyslexia has roughly a sixtypercent chance of also having Attention Deficit Disorder (ADD) or Attention Deficit with Hyperactivity Disorder (ADHD). Therefore, it is important to find a psychologist or neuro-psychologist specializing in diagnosing language-based learning disabilities and related disorders.

In order to communicate with others you need to understand what tests are used and what and how they measure. A good evaluation should include the following:

- 1. aptitude test
- 2. achievement test
- 3. test of memory
- 4. test of phonological processing

The results and recommendations should be clearly stated in a written report and clearly explained in a one-on-one meeting. You should know your skills levels, strengths, and weaknesses.

#### Know What You Need

After you receive a formal diagnosis, it is important that you know your

skills, strengths, and weaknesses. Learn about your disability and how it affects your daily activities, communications, and social interactions. It's important to keep in mind that no learning disability effects two people the same way.

There are three areas worth investigating to determine what you need to improve your skills and/or compensate for your weaknesses:

- 1. interventions,
- 2. accommodations, and
- 3. Modifications.

**Interventions:** are evidence-based instructions to improve skills (reading, spelling, math, comprehension, speech, etc.). This instruction is multisensory, systematic, and direct with the opportunity for guided practice.

Intervention may also include psychological counseling and/or support groups to help you work through the emotional aspects of living with a hidden disability. The goal of intervention is to improve skills and work towards independence. Regardless of age, it is never too late for intervention.

Accommodations: are tools to help accomplish a goal that do not change the integrity of the task (books on tape, extra time for test, copies of handouts before a meeting, editor, use of a calculator, etc.). Accommodations compensate for disabilities, and vary from person to person based on the type of disability and the degree to which it interferes with daily activities.

The ability to use some accommodations is dependent upon intervention. For example, spelling, typically a major difficulty for people with dyslexia, must be mastered at class level for a person to use a spell checker independently. Many people with dyslexia benefit from using the spell checker on the computer along with a hand-held spell checker that reads words and provides definitions. When you use these two spell checkers together, you can accurately spell words that look alike and/or sound alike.

Individuals with a physical handicap who use wheelchairs are entitled to ramps and elevators to have "equal access" to buildings. The same is true for individuals with language-based learning disabilities.

For example, if a person with a learning disability has difficulty reading

or writing, voice recognition software on a computer would be an appropriate accommodation. This software allows the person to speak reports and e-mails into the computer, and to hear information off the screen. This accommodation does not change the quality of writing the individual is capable of creating, but assists the person to accomplish the goal. Accommodations are not meant to replace intervention, but to assist with day-to-day tasks.

**Modifications**: are alterations to assignments that do change the overall task; for example, writing a two-page report instead of a four-page report. It is important to keep in mind that nearly all employers and most educational institutions (colleges and universities) do not provide modifications.

It is important that you understand the differences between interventions, accommodations, and modifications and how they may or may not meet your specific needs. This knowledge will help you better communicate what you need and why.

Communication takes practice and can be emotionally draining. It's easy to get caught-up in feelings of guilt that you are asking for "special treatment" or that you don't need an accommodation because you excel in other areas. Having a supportive friend and/or support group to help "coach" you through this process is important to keeping you grounded.

#### Know How to Get What You Need

The Associations for persons with disability, NGORC and the government of Zanzibar guarantees equal access and equal opportunities to individuals with physical and/or hidden learning disabilities that significantly interfere with one or more major life activities (communicating, reading, physical movement, etc.).

Public and private institutions are required to provide "reasonable accommodations" to individuals with a documented disability, as long as these accommodations do not create an undue hardship for the company or university. Employers and universities are prohibited from discriminating against a person with a learning disability if they are "otherwise qualified."

Accommodations help to overcome the obstacles of the disability. If the

disability does interfere with a work or educational activity, it is the responsibility of the individual with the disability to share this information with their supervisor, human resources person, administrators, and/or professors.

Documenting communications and interactions in a journal and keeping copies of all letters, e-mails, policies, and procedures is a good way to provide information if you have difficulty getting your accommodations and you need to file a complaint.

Understanding your rights and knowing how to clearly communicate with others in a constructive way is just as important as clearly communicating your disability and individual needs.

- 1. Where are you likely to see self advocates?
- 2. Who are self advocates in your area?
- 3. What methods do they use in their advocacy activities?
- 4. Write a paper on any a topic "policies that support self advocacy in Zanzibar"

# Lesson nine

#### POLICY TO SUPPORT ADVOCACY ACTIVITIES IN TANZANIA

There is no doubt that there are good legal documents to support special education in Tanzania. These are:

#### Policy: Tanzania Mainland

In the early days of Independence in 1964, the Government emphasized that the provision of basic social services to the entire population was one of the Government's major priorities. The Arusha Declaration made services to disabled persons a national responsibility, and specified that support to them, as well as to children and the elderly, was the responsibility of all. In 1975, the Ruling Party, in a circular addressed to all regional Commissioners, directed that services to disabled persons should be provided in their communities, except where persons with disabilities had no supportive relative.

In 1981, however, the Government recognized the necessity of adopting special measures for persons with disabilities, particularly in towns, who had no family or community on which to rely. Cabinet Paper No. 19 of 1981 was the first national document outlining the basic principles that should guide services for disabled persons, and became the basis for the two disability acts concerning employment and care that were passed by parliament in 1982.

#### National Policy on People with Disabilities

In 1999, the Government stated its intention to elaborate a National Policy on People with Disabilities in the National Population Policy Draft. Responsibility for the promotion of employment opportunities, especially for youth and people with disabilities, lies with the Ministry of Labor and Youth Development, in liaison with other institutions. The Ministry of Community Development, Gender and Children is required to ensure that special attention is paid to programs that are directed at elimination of social-cultural and discriminatory practices against the girl child, elderly and people with disabilities. Persons with disabilities are identified as a target group for which the Ministry should adopt the following strategies:

- Encourage the private sector, NGOs and religious organizations to invest in provision of social services for people with disabilities;
- Develop talents and capabilities of disabled persons; and
- Establish social security measures that address problems of people with disabilities.

## The Tanzania Education and Training Policy

The community benefits of integration are stressed in policy of the Tanzanian Ministry of Education and Culture, which states that disabled children should be integrated in regular schools near their home, so that they share school resources and experiences with their non-disabled peer group. Thus, efforts are being made to ensure that more disabled individuals get access to education. The steps being taken to achieve this goal include: integration of special education into normal schools; establishment of centers to prepare special education teaching/learning materials; training of teachers; establishment of centers for early identification of disabilities.

The Integrated Community-Based Adult Education Program administered by the Ministry of Education and Culture aims to provide essential skills to illiterate and neo-literate people with special attention to women and people with disabilities. So far, it covers four regions. The aim was to reach all regions throughout the country by the year 2003. Traditional and modern vocational skills are offered with a view to promoting selfemployment. The adult education facilitators are professional and Paraprofessional. Local communities participate in the program by establishing Centers of adult education.

Patandi Teachers' College offers certificates and diplomas in special education and is the only Tanzanian Institute to do so.

## Mainstream Policies

In Tanzania Mainland, there is a series of policies and measures which are interesting from a disability viewpoint. While these do not expressly mention disabled persons, they could be extended to specifically target unemployed disabled persons:

# 1. The National Poverty Eradication Strategy (NPES) (1998)

The National Poverty Eradication Strategy (NPES) (1998 includes among its goals the reduction of unemployment. The strategy to be adopted includes job creating development programs, allocation of areas for informal sector activities and facilitating MSE operations and promoting investment in MSE development.

# 2. The Tanzania Assistance Strategy (2000)

The strategy puts emphasis on the following issues relating to employment: generation of labor market information; stimulation of employment creating investment; enhancement of women's employment; promotion of labor-based public works; coordination of employment generation efforts; raising labor productivity; enhancement of enterprise development; reorientation of vocational education and training.

## 3. The National Employment Promotion Services Act

This act (NEPSA) (1999) aims to identify strategies and to create an institutional framework for promoting employment. The functions of the employment promotion services include placement, vocational guidance and employment counseling, active labor market interventions, labor market and occupational information, advisory services for lawful income generating undertakings and promotion of self-employment and co-ordination of trainings needs.

## POLICY: ZANZIBAR

In Zanzibar, priority has been given to the development of policies regarding the promotion of people with disabilities. A disability policy has been recently formulated (2004), which views disability as a human rights issue. It focuses on culture and attitudes of the society towards persons with disabilities, poverty, employment, education, health services, environment and communication. It also addresses the following issues:

- 1. Adaptation and review of mainstream legislation in order to achieve equalization of opportunities for persons with disabilities;
- 2. Review of the social policy system in order that it benefits people with disabilities;
- Promotion of self-representation of people with disabilities in decision making bodies;
- 4. Promotion of community-based rehabilitation as a mean to further integration of people with disabilities;

5. Highlighting of the responsibilities of Government Ministries, Disabled Persons' Organizations, NGOs and other Institutions.

The policy also addresses specific target groups such as women, youth or elderly people with disabilities; disabled persons living in rural areas; people with learning difficulties and people with more than one disability. The next step envisaged is the development and enactment of disability-related legislation.

#### Policy on Special Education

Zanzibar adopted a policy on special education in 1990 and then enacted the Zanzibar Education Master Plan 1996-2006 which provides for inclusive education. This Plan focuses on disadvantaged groups, such as girls and children with disabilities and addresses issues of access, equity, quality and relevance of basic education. In addition, it aims at providing vocational training aimed at creating self-employment among youth after completion of basic education.

#### The 'Zanzibar Poverty Reduction Plan:

Basic Education and Skills Development', reports that although efforts have been made to promote equalization of opportunities in the field of education, disabled children are still a disadvantaged group in Zanzibar and still have limited access to education. Few schools cater for their specific needs and are mainly located in urban areas with only few qualified teachers to assist disabled children.

1. What policies, traditions beliefs, or moral values and norms seem to be the barriers toward disability advocacy?

2. Write a position paper against the barriers you mentioned in activity number 1, above.

# Lesson ten

#### DEVELOPMENTAL-STAKEHOLDERS FOR ADVOCACY MECHANISMS

International and local governmental organizations (GOs) and nongovernmental organizations (NGOs), for example MKEZA, NGORC, TLB, TSB, USAID, JPKF, UNESCO, CBM, SIGHT SAVERS, UNICEF, and MASHAV (Israel) are few among many core/key stakeholder-partner in the implementation process awareness and disability advocacy. It is also a realization that, even the sustainability of the practices remains to the good influences and support in resources (material and human) of the government, GOs and NGOs. All parties GOs, NGOs and the Government) has roles to play in the awareness and disability advocacy mechanisms. Following are some of the Non-Governmental Organizations and International Organizations and what they do.

#### People with Visual Disability

Training and employment-related services for persons with visual disabilities in the United Republic of Tanzania are provided by: Chama Cha Wasioona Tanzania, The Singida Blind Women's Training Centre, Zanzibar National Association of the Blind and Tanzania Society for the Blind.

Chama Cha Wasioona, the Tanzania League of the Blind was established in 1964. This association, with local branches in all regions of the country, promotes the education, training, employment and general welfare of and visually impaired people. Its main activities are the following: construction of Branch Development Resource Centers for blind and people with low vision; running of education programs; conducting of socio-economic and rehabilitation programs; staff and leadership training programs; sports, recreation and culture.

#### People with Hearing Disability

The associations providing training and employment-related services for hearing impaired persons in the United Republic of Tanzania include 'CHAVITA', the Tanzania Association of the Deaf and Katumba Rehabilitation Centre.

CHAVITA was founded in 1984. It promotes the education, training, employment and general welfare of the deaf. It has opened 13 grassroots

region branches in the 20 regions of Tanzania Mainland. Its main objectives are to unite deaf people and facilitate the empowerment of the deaf community, to work for full education opportunities for deaf Tanzanians, and to develop and promote Tanzanian Sign Language as the language of deaf people in Tanzania.

## People with Physical Disability

The following organizations provide training and employment-related services for persons with physical disabilities: Usa River Rehabilitation Centre for the Physically Handicapped and the Association of the Physically Disabled of Tanzania (CHAWATA).

Usa River Rehabilitation Centre trains young people with physical disability in various areas, such as carpentry, welding, and tailoring, shoemaking and secretarial work. In addition to training students, the Centre provides them with follow-up support once they return to their villages. And through the Village Outreach Team, it trains and educates people with physical handicap who are unable to leave their villages.

CHAWATA was founded in 1969 and has local branches in different regions of the country. It has a revolving loan fund scheme providing capital for disabled persons to become self-reliant in productive activities.

# People who are Mentally Challenged

Mentally Handicapped Youth Trust Fund (MEHAYO) is a youth project for persons with intellectual disability, which provides vocational training in gardening, poultry-keeping and fish farming.

The Tanzania Association for Mentally Handicapped (TAMH) is an NGO whose main aim is *lobbying and advocacy* for the rights and empowerment of persons with intellectual disabilities. Its main activities include promotion of awareness of the rights and needs of persons with disabilities; empowerment of persons with intellectual disabilities; mobilization of parents and other members of the society; and networking with Government Institutions and other local and international organizations.

# Other Organizations

The Organization of People with Disabilities of Zanzibar (UWZ) represents persons of all categories of disability. Its main objectives are to influence the Government to implement services for disabled persons, educating persons with disabilities about their rights, raising awareness in the community on disability and running training and income generating activities. Founded in 1985, it operates five programs: membership development; women and gender development; community-based rehabilitation; training and income generating activities; and advocacy.

What are GOs and NGOs operating in your area? What are the positive or negative outcome (if any) of their work in regard to the rights of children with special needs?

#### FURTHER READING

Disability Rights Commission - A *New Law about Disabled People*-Duty to promote disability equity USA

PAI Advocacy (2003) **PAI** *Advocacy Services Plan 2003 - 2008.* Protection & Advocacy, Inc. 100 Howe Avenue, Suite 185N Sacramento, CA 95825 (916) 488-9955 or (800) 776-5746 TTY: (800) 719-5798

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Zanzibar Education Culture and Sports Policy