Protocol:

Counseling with parents of children with disabilities

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1. Introduction

Families of children with disabilities are at increased risk of experiencing a number of difficulties compared to families with no children with disabilities. A number of studies have reported that parents of children with disabilities tend to experience more stress in relation to their parenting, especially when the child appears to be problematic. Study summaries with parents of children with disabilities report that it can be generalized that in comparison with other parents, parents with children with disabilities are less pleased with their parental role, report less self-efficacy, more feelings of helplessness, and recently have an increased risk of experiencing psychological disorders such as anxiety and depression.

The well-being of mothers of children with disabilities seems to be significantly more vulnerable as they absorb family stress and tend to protect other family members. Also, in line with traditional gender roles, the responsibility for looking after the children with disabilities may disproportionately fall to mothers in comparison with fathers, thus resulting in higher stress. Lastly, the parents of children with disabilities report more marital distress than other couples, even though the degree of divorce in these couples is not higher.

On the other hand, the high degree of distress to parents is negatively related to their ability to develop good relationships with a child with disabilities, providing less support, more punishments and in general more problematic behaviors of the child. Naturally, when parents manage to develop a positive family environment, the development of children with disabilities is optimal. For example, a study of families with Down syndrome children reported that adult children brought up in families with high cohesion, harmony, and child-supportive approaches

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have demonstrated more adaptive behavior, less behavioral problems, and less isolation from their peers compared to children with Down syndrome brought up in families with the lowest level of these characteristics. 8 These data point to the need to provide increased assistance to parents of children with disabilities. Unfortunately, the professional attention and professional services offered are often directed at the child and specifically to their disability.

On the other hand, due to legislative and social changes, the nature of the relationship between parents and professionals is changing by offering more involvement of parents in decision-making and in professional services to their children - in accordance with the partnership model between professionals and parents. 9 This model emphasizes that the needs and resources of each family member should be considered and has created space to develop models of therapeutic or counseling work with parents of children with disabilities. Furthermore, there is evidence that the emotional or educational support of the entire family or parents of children with disabilities leads to less experiencing of stress and more effective adaptation / confrontation with the problems encountered with the child with disabilities.10

Therefore, the purpose of the protocol is to describe the basic structure of counseling sessions with parents of children with disabilities using the following formats: individual therapy and self-supporting groups with parents of children with disabilities.

To better understand the counseling process with parents of children with disabilities, theoretical concepts relevant to families with children with disabilities will be briefly presented: systemic family theory and phases of facing the defeat in the context of the birth of the child with disabilities. It should be noted that the protocol addresses only specific issues identified by theoretical models and research evidence as important when working with the parents of children with disabilities. Since the protocol will not cover theories and counseling skills in general, this document can only be used as an additional tool in counseling with parents of children with disabilities.

Each family is unique. Guidelines on the assessment of family dynamics in families with children with disabilities

Initially, it is well known that parents, families and children with disabilities are unique and consequently our counseling work should reflect an approach adapted to the unique characteristics of those parents. Each parent brings a number of unique values, beliefs, attitudes, life experiences and current circumstances to the counseling process. Being aware of and understanding these factors can help you develop a positive relationship with them. When assessing the family, the concepts mentioned below are important to be addressed:

**Characteristics of family members**

- Initially, it is important to consider all the characteristics of family members (including age, gender, occupation, hobby etc.). The use of a genogram (see note on resources for the use of genograms) often helps clarify the characteristics of family members and relationships with one another.

**Cultural style**

- Assess cultural stereotypes about disability in the context in which the family is living. It is important to assess and address whether some of these cultural stereotypes implicate blaming the parents (and in particular the mothers) for their children's disability.

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12 http://familytherapybasics.com/blog/2016/11/26/family-of-origin-exploration-for-the-therapist-create-your-genogram
**Ideological style**

- Family beliefs are passed through generation after generation. Ask about the important family values. For example, some families may have beliefs that emphasize the intellectual achievements of family members as a value, and this can bring out adaption difficulties if a child with disabilities is born within the family. It should be noted that these beliefs also tend to be challenged and changed when coping with the child with disabilities.

**Coping styles**

- Assess the internal and external (functional or non-functional) strategies that parents are using to better manage the stress associated with parenting of a child with disabilities. Internal strategies include passive assessment (e.g., problems will be resolved over time) and reformulation (making adjustments to attitudes to live with the situation constructively), while external strategies include the use of social support (family and additional family resources), spiritual interpretations, (clerical advice), and formal support (use of community resources and professional services).

**Marital couple subsystem**

- It is important to assess the relationship between two parents as a couple. How did the child with disabilities affect their relationship? Conflict between the couple contributes to the stress and discomfort of children. When a couple has conflicts, the child may become the target of anger or enter into alliance with one parent against another. For example, couple disagreements can be predicted if one parent faces stress he got from the birth of the child with disabilities by avoiding him/her (e.g., more work) and fails to provide practical and emotional support to the other parent who may have taken the entire responsibility for looking after the child.

**Parental subsystem**

- This is different from the marital relationship and refers to how the couple functions as parental unit. Here it is important to address what the parenting styles are and how parent roles and responsibilities are assigned to each parent. It has been observed that sometimes
other children or grandparents can take these roles. Potential conflicts and tensions related to this need to be addressed.

- Assessing gender roles especially with regard to responsibilities related to the care for the child with disabilities is of paramount importance. If the mother carries more responsibilities than the father, the mother may be experiencing a higher level of stress.

- As brothers and sisters grow up, they take greater responsibility to look after their brothers / sisters with disabilities, but the distribution of responsibility is not always seen as fair by the siblings and can thus become the basis for negotiation or conflict.

**Boundaries**

- Invisible barriers that regulate the amount of contact with others between family members, and between family and the outside world
  - They protect the family's autonomy.

- Three categories of boundaries
  1. Clear – Strong but flexible links that allow a degree of autonomy to members
  2. Rigid - means disconnection within and between systems; family members are isolated from each other
  3. Close - characterized by highly bonded relationships; extreme dependence and providing support when not needed.

1.2. Important periods in the lives of the parents of children with disabilities

Families of children with disabilities go through a number of phases that, to a great extent, are unique for them. Whereas due to obstacles, stagnation or imbalances that may occur throughout the life of the child with disabilities, the typical stages of family development cycle may not be implemented. Likewise, some child development points (for example, ability to speak) can be reached more slowly or not reached at all. Fewell describes some periods that are particularly difficult for parents of children with disabilities.\(^\text{13}\)

1. Facing the disability. Obtaining an accurate diagnosis (more on this in the second section of the protocol); emotional adaptation (more on this in the second section of the protocol); informing other family members.
   - At this stage, parents should be helped to manage stress during the diagnostic process and be helped to develop effective (partnership-based) relationships with clinical experts. Particular attention should be paid to cases where the diagnostic process is lengthy and where the placement of an accurate diagnosis is not achieved.
   - Informing other family members, friends or colleagues at work may be difficult or postponed in some cases - by making the family more isolated and preventing potential social support. It is important to elaborate the factors that make it difficult to share this information (for example, cultural stereotypes or parents' beliefs about the disability that may induce feelings of shame or expectations that others will be reluctant to support). Subsequently, the counselor may challenge stereotypical beliefs, help develop an information sharing plan with others (for example, through role play), and provide information on services that provide social support (e.g., self-supporting groups of parents of children with disabilities).

2. Early Childhood. Anxiety associated with a child's typical development shortage; Development of parental skills for children with disabilities.

3. Beginning of formal education at school. Personal views between inclusive or separate education; Facing other children's reactions; extracurricular activities.
   - At this stage, parents can be instructed to join self-supporting groups to receive more social support. Parents can also be instructed to be more involved in the education process of their children, and to advocate for better school environment for their children.

5. Adulthood: Adaptation with continued responsibilities; Decisions to put the child with disabilities in institutions; Lack of opportunities for socialization; Planning for the future of a child with disabilities.

2. Individual counseling with parents of children with disabilities

2.1. Basic counseling skills in working with parents of children with disabilities

The skills listed below are considered to be particularly important in working with this target group:

1. Positive Considerations: Counselors should communicate the acceptance of family members as valuable persons, supporting them just as they are, without judging them.

2. Empathy: Counselors should be able to understand and communicate the feelings and mentality of the family, using their perspective.

3. Concreteness: Counselors should communicate in a concrete, clear and accurate manner, and specifically answer questions of family members.

4. Warmth: It is important for counselors to show warmth in verbally and nonverbally manner, and not be distant or cold.

5. Use of medical jargon: Counselors are recommended to avoid medical jargon (especially if the term used is not clearly explained). The counselor may ask whether it was sufficiently clear and whether it is necessary to clarify again.

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2.2 Educational counseling

Educational counseling is appropriate when families need information on their child's disability. This approach is based on the premise that families know little about the disability until they face it on their child. Therefore, it is important to provide as much information about the disability at this time. It should be noted that additional knowledge and instructions may be needed to communicate at different stages of child development while their condition can be stabilized, hampered or improved. The process of client education is often referred to as psycho-education, and instructions on the psycho-education of parents of children with disabilities are presented in the following box:

### Psycho-education

Some evidence-based recommendations on the form of education of parents about the diagnosis of their child (Halpern, 1984, p.171):

- Communicate in a clear, simple and straightforward language.
- Be willing to spend extra time with parents.
- Communicate the strengths, positive attributes of the child before communicating the diagnosis of disability.
- Be aware of your personal feelings and attitudes.
- Take seriously the parents’ assessment of their child.
- Provide specific advice for the next steps.
- Provide the prognosis information honestly, with a warning about the difficulty of the prediction.
- Show respect for the child and the family.

### Checklist:

- Parents were informed about the diagnosis of the child's disability and its effect on their daily lives
- Parents were informed of the options and course of child treatment
- Parents were counseled in practical form how to face and meet their child's daily needs
- Parents were prepared to take care of their child
- Parents were encouraged to ask questions (it may be suggested that parents make a list of questions)
2.3 Managing problematic behavior of children with disabilities

In addition to functional and intellectual delays resulting from a developmental disability, children with disabilities are also at increased risk of having problematic behavior or mental disorders (including anxiety or depression). Studies report that parents with proactive and positive practices are more likely to reduce negative behaviors in children, thus affecting the reduction of parental stress by further reinforcing positive parenting practices. A study has summarized some of the strategies that counselors can use in their work with parents of children with disabilities to address their child's behavioral problems:

- To instruct parents to receive services through similar programs such as the Applied Behavioral Analysis (ABA);
- Using role-playing with parents to improve their communication style with children or problem-solving skills;
- Using video recordings to analyze the interaction between parent and child, and then decide on the type of intervention;
- Using the positive discipline method.

2.4. Addressing the emotional responses of the parents of children with disabilities

2.4.1. Stages of confrontation with defeat

In general, families facing with a disability in their child initially go through a stage of disbalance, followed by efforts to adapt and normalize. It has been suggested that these stages sometimes resemble the stages of adaptation with defeat, but scientific evidence for this is

inconsistent. Moreover, it should be noted that due to the fact that all families are different, passing through these stages may not necessarily have this sequence, it can go through a stage, stagnate or regress. The stages that parents may pass through and addressing them in the counseling process is presented below:

1. Denial and shock. Typical emotional reactions include confusion, numbness and feeling of helplessness. If parents continue to deny that their child has a disability over a long period of time, and seeing explicit evidence of the disability, then they may push the child beyond his or her ability; they may not benefit from useful early intervention programs or make endless visits to professionals to provide an acceptable diagnosis. Other family members may be neglected at this stage.

   - It is recommended that the counselor gives a sincere assessment of the situation that parents are facing. This can be achieved by requesting an evaluation from other clinical experts, if appropriate. On the other hand, it is important not to have parents' hopes disappear and not to insist on drastic changes in the style of parents dealing with the disability. Small changes in the process of coping and normalization may be more adequate or functional for the family.

2. Anger. This emotional reaction often reflects the anxiety of parents towards a drastic change in their lives. Counselors should allow parents to express anger and pain - without being judged. Counselors should also normalize these reactions.

3. Negotiation. Parents sometimes think they can do something to get rid of their child's condition. At this stage it is advisable for the parents to focus attention on the positive characteristics of the child, to encourage involvement in the relationship with the child and to maintain optimism. Moreover, parents may be invited to think about the development of a more balanced life, by returning to their activities other than taking care of the child.

4. Depression. Counselors should distinguish whether the parent is experiencing dysphoria or clinical depression. Dysphoria may be common in some of the developmental disabilities of

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children with disabilities. Similarly, such reactions may be normalized and not judged. Counselors can invite the parent to see what he / she can do to increase feelings of satisfaction in everyday life.

5. Acceptance. Parents become more objective about the child's condition, are less emotionally reactive and use coping strategies oriented towards problem solving. During the counseling process, these improvements should be recognized and enforced.

2.4.2 Other common emotional reactions from the parents of children with disabilities

Feelings of guilt:\textsuperscript{20}

- Elaborate opinions that are related to this feeling. For example, parents may believe that they are being punished for a bad deed or "negative" opinions during pregnancy.
- Parents may try to "compensate" for the perceived bad acts by overprotecting the child, which can hinder the child's independence and disconnect the relationship with other family members.
- Listen and understand these opinions without judging (see cognitive techniques for changing dysfunctional opinions)

Feeling of shame:\textsuperscript{21}

- The negative beliefs and attitudes of the community and society towards children with disabilities may incite feelings of shame on the parent.
- Listen and understand these opinions without judging (see cognitive techniques for changing dysfunctional opinions)
- Parents may be instructed to join self-supporting groups or advocacy groups to raise community awareness of people with disabilities.

2.5. Possible techniques in counseling with the parents of children with disabilities


1. **Cognitive approach** aims to change thinking so that it becomes more realistic and more functional. For example, parents may believe that having a child with disabilities means that they will no longer be able to experience joy in their lives, or that others will refuse them because of this. For more information, refer to the source listed in the list of references.22 23

<table>
<thead>
<tr>
<th>Basic techniques on cognitive re-structuring of automatic dysfunctional thoughts</th>
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</thead>
<tbody>
<tr>
<td><strong>Goals:</strong></td>
</tr>
<tr>
<td>➢ Consider the validity of automatic thinking.</td>
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<tr>
<td>➢ Consider the possibility of other interpretations or other views.</td>
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<tr>
<td>➢ De-catastrophize the problematic situation.</td>
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<tr>
<td>➢ Know the impact if you believe in automatic thinking.</td>
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<tr>
<td>➢ Find the distance from thought.</td>
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<tr>
<td>➢ Take steps to solve the problem.</td>
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<tr>
<td><strong>Specific questions:</strong></td>
</tr>
<tr>
<td>o What evidence do you support this idea with? What is the proof against this idea?</td>
</tr>
<tr>
<td>o Is there an alternative explanation or perspective?</td>
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<tr>
<td>o What is the worst that can happen (if I'm not already thinking the worst)? If this happens, how can you face it? What's the best thing that can happen? What is the most realistic result?</td>
</tr>
<tr>
<td>o What is the effect of your automatic thinking? What could be the effect of changing your thinking?</td>
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<tr>
<td>o What would you say [to a special friend or family member] if he or she were in the same situation?</td>
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<tr>
<td>o What can I do?</td>
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</table>

2. **Emotional adjustment techniques** can be used to train parents to manage emotional states functionally (know, affect the intensity or accept different emotional states) and altering

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ineffective emotional management form (e.g., self-hurting behavior or abuse with substances). For more, refer to the source listed in the list of references.\textsuperscript{24}

3. Self-supporting groups

3.1. The format of self-supporting groups

Self-supporting groups vary in their format, while some recommendations are offered in order to increase the effectiveness of the group. It is recommended that the groups are: \textsuperscript{25}

- closed (new members are usually not included in the existing group);
- separated on the basis of the type of disability (for example, a group can be created only for the parents of children with Down syndrome);
- the meeting may last 1 and half hours;
- Meetings are held on a weekly basis;
- meetings are recommended to be held in the afternoon (or at other hours suitable for parents);
- 12 to 15 meetings in total;
- 8 to 12 group members;
- Meetings can be of educational nature and emotional support.

3.1.2. Selection of group members

It is important to use some general criteria to select those parents who may benefit from this experience: \textsuperscript{26}

- Parents feel relatively comfortable in a group context.
- They are mainly mature and emotionally stable, but their functioning is temporarily impaired;
- They are not too self-centered and monopolistic;


✓ They have expressed feelings of anger but have control skills;
✓ They are not too controlling, masochistic, or passive-aggressive, and have no psychotic tendencies;
✓ They are sensitive to others, and are open to listen to the opinions and instructions of others.

3.2. The basic skills of the group leader (psychologist)

Below are some of the basic skills for leadership of self-supporting groups, which are recommended in the literature: 27

- Be attentive to what is happening in the group - to you and the group;
- Observe continuous topics affecting the group;
- Be open to various statements about what affects the group (e.g., why a certain interaction or a certain topic is being repeated);
- Explain clearly what you as a leader are trying to achieve (when you intervene).

The goals of the self-supporting group can be set in these lines: 28

- Reducing the feeling of isolation through contacts with others;
- Providing the opportunity to interact in a way that allows expression and discussion of emotional states
- To achieve the change of parent's mentality so as to have a more balanced and more positive (reality-based) perspective;
- Opportunities to develop or reinforce coping mechanisms by learning from others' experiences;
- To focus on sharing personal experiences (as opposed to ordinary conversation);
- To receive and provide support

Responsibilities of the group leader: 29

- Administrative duties: group development, organization of meetings;
- To ensure that the group is clearly informed of the goals, expectations and rules of the group;
- To discuss the rules (for example, confidentiality);
- To ensure that everyone has a safe space to explore their issues;
- To intervene to achieve the group's effectiveness (for more intervention skills, consult the sources in the list of references).

Example of rules that can set for groups (adapted from Nichols & Jenkinson, 2006).

**Objectives** - Our meetings will have these objectives.

- First, to support each other by sharing time and effort to listen to each other's experiences in parenting children with disabilities.
- Secondly, to help each other examine at a slightly greater depth how they can address the difficulties in parenting children with disabilities.

**Group experience** - the group offers the opportunity for you and others to share your experience and feelings, and be open to elaborate and discuss these with others.

We intend to share our immediate and current opinions and feelings with each-other and not treat them as superficial. We appreciate:

* self-reflection - make a constant effort to pause and look for your inner feelings about whatever is the focus of attention at a certain time, talk carefully but openly about it.
* self-revealing - be open for your sincere feelings and thoughts and to try to reveal these.

**Listening** - Make some effort to listen carefully to others in the group. Try to find out what they are experiencing exactly rather than giving immediate response or advice.

**Support** - When other members talk about personal issues and feelings, give them full support, full attention, and a lot of time.

**Confronting and responding to confrontation** - because of the importance of your supporting involvement with one another, it can be uniquely useful if we are direct and sincere to one another. If you have the impression that a member is avoiding an issue or not seeing anything important, gently confront this. Those who receive these communications should pause and explore the feelings involved before rushing to respond.

**The Leader** - The role of the leader is to guide the group towards the development of the aforementioned processes, as well as to care for each individual member. He / she is not an authoritative figure, but can occasionally offer suggestions to help the group.

**Confidentiality** - our group will only succeed if we feel confident and trust each other. The specific content of the meetings and the personal details of the members should be kept confidential. This is vital.
3.3 Thematic content on self-supporting groups

3.3.2. Educational sessions

Some group sessions can have educational purposes, and to achieve this, the guest lecturers may be invited. It is recommended to invite professionals in the following areas: \(^{30}\)

- A doctor to explain the disability and medical implications of the condition.
- A physical therapist to discuss exercises and strengthen regimes.
- A mental health worker who helps with management of child problems and helps parents understand their emotional responses.
- A lawyer to elaborate legal aspects, custody and parental rights, and to assist in the interpretation of relevant legislation.
- A local or state politician to discuss community / state policies related to disability issues and to provide support for the relevant legislation related to disability.

Hornby (1994a) described a typical 2 hour meeting: \(^{31}\)

7: 30-7: 45 P.M. Socialization. Tea and coffee are served while parents speak unofficially with professionals and each other.

7: 45-8: 05 P.M. Presentation of lectures. A 20-minute lecture on a topic that is a matter of concern for parents is presented by a professional.

8: 05-9: 15 P.M. Small group discussions. Parents are divided into small groups to participate in the discussion. It is possible to discuss the applications of the lesson content on the specific problems presented by the parents. Parents are encouraged to express and explore any problems, concerns or feelings about their children with disabilities.

9: 15-9: 30 P.M. Summary, leaflets and homework. The big group is recreated so that issues raised in small group discussions can be summarized and shared, homework assignments can be explained, and materials that summarize the content of lectures can be distributed.


3.3.3 Sessions on emotional support

These sessions can have expressive-supporting forms, meaning group members are able to express themselves emotionally in a more supportive environment (see above for more on the format). Sessions with this aim may be semi-structured, thus a set of topics is predetermined. It is recommended that these sessions include topics such as the following:32

- the meaning of being a parent of a child with disabilities;
- the difficulties of the child with disabilities;
- dialogue between parent and child;
- daily dilemmas within the family;
- parent’s vision for the child's future;
- dealing with the education system;
- parent as case manager;

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