

## **The Place of Experts in Work Processes of the Coalition for Social Change**

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**2014**

The advantages of the general coalition for promoting social change are clear. Combining the resources of organizations and parents allows sharing of knowledge, resources, and contacts each of the partners.

In this article, I will relate to the dilemmas arising in the work of the coalition in connection with professionals in general, and health professionals in particular.

### **Background**

Social change is brought about, among other things, by change in organizational, social, and economic policy. Policy change can be made by the implementing authority, or by the legislative or judicial authority. An individual, organization, or coalition wanting to propose a change must base this change on an infrastructure of professional knowledge. The Coalition of Organizations and Parents for Children with Disabilities is supported by a committee of experts, which convenes in order to provide the professional infrastructure, and from this, to establish recommendations for change. In this article I will relate to the stages of work, from the decision to establish the committee of experts until recommendations are given, and the dilemmas that arise.

### **The stages of work**

#### **Preliminary stage – identifying the need for a change in policy**

Parents of children with special needs who are members of the coalition, or are in contact with organizations that belong to the coalition, or representatives of the organizations themselves, draw the attention of the coalition coordinators to the absence or shortcomings of a service, or the absence of a right, or difficulty in implementing an existing right.

The preliminary stage of the work is to clarify whether this is a broad phenomenon that is known to other parents and organizations, and where appropriate, there is room to check with the care providers as well – the developmental doctors, specialist physicians, developmental psychologists, health professionals, social workers, principals of frameworks,

and so on. If a need is identified – and after a process of study – the subject is brought up for the forum to decide whether this is an issue that will be studied and promoted. If the forum chooses to act on the matter, one of the ways of creating a professional infrastructure as a basis for the change is through the expert committee.

### **The contribution of the expert committee to the process of influencing policy**

The use of a committee of experts makes it possible to raise the lack that has been identified with the appropriate professionals. The professionals discuss the lack, and formulate a professional opinion as to whether it does indeed exist, according to their professional approach, and if so, what response is required. Working together with the committee members leads to the formulation of independent professional recommendations. The committee members sign these recommendations, which are circulated among additional professionals who support the recommendations. The document of recommendations represents the basis for applying to the appropriate authority – legislative, implementing, or judicial.

### **Situations in which it is worth using the tool of the expert committee**

The Coalition of Organizations and Parents for Children with Disabilities has been in operation for around a decade. Over this period, it has dealt with and promoted a variety of issues, for which only two expert committees have been established. We must therefore ask why a committee was established in a few cases, and not in others. It appears that the answer lies in the type of knowledge required, and whether or not the coalition members possess this knowledge. The cases in which an expert committee was established were cases where it was necessary to determine medical or professional criteria, or examine a diagnostic tool based on yardsticks of developmental medicine. In these cases, the assessment of the coalition was that there was a need to gather a group of experts dealing with the subject of the diagnosis, which would also have the professional ability to determine that the service was lacking, which group was in need of this service, and what existing diagnostic tools could be put forward - or even to propose a new diagnostic tool.

#### **Example 1: Expert committee formed for increasing entitlement to rehabilitation day care**

It was claimed that the existing law does not entitle children in need of rehabilitation day care to receive this service. According to the law, those entitled to the service are children defined as backward by the Division for the Care of People with Intellectual Developmental Disabilities, or children entitled to an allowance from the National Insurance Institute. The expert committee of developmental physicians identified that most of the toddlers in need of rehabilitation day care and not receiving this service were children with delayed development. The expert committee discussed the existing diagnostic tools, and eventually proposed a diagnostic tool which, until then, had not been a recognized medical / legal yardstick (DQ – development quotient). The Ministry of Health decided to adopt this diagnostic tool, and after a fight, the Rehabilitation Day Care Law was expanded, the main new clause in the law being based on the DQ index proposed by the expert committee.

## **Example 2: Expert committee formed for determining criteria for the inclusion of children with special needs in regular day care**

It was claimed that many young children with special needs are forced to stay at home because of the lack of support they receive in regular day care. The expert committee was established to define which children need support in order to be included in regular day care, and what type of support is required.

This committee included developmental physicians, developmental psychologists, a social worker, representatives of organizations, the director of the national inclusion program, and even a representative of one of the day care organizations.

The committee, which was much broader than the previous one, heightened the dilemmas of working with an expert committee, which I will detail below.

### **Assembling an expert committee**

#### **1. Selecting members for the expert committee**

The choice of experts to join the committee is clearly of great importance: in terms of their professional approach, in terms of their professional 'seniority', and in terms of their connections and professional loyalty to the establishment.

a. The professional approach of the experts: the professional slant is also based on the ethical world view. As in every profession – the clearer and more unequivocal the subject, the easier it is to select professional committee members, because there will be greater consensus among the different professionals, and fewer and more specific disagreements. With an issue that is less clear-cut, even the definition of the need will be less consensual, and the same will be true for defining the scope of the need and the proposed response. Accordingly, it is important to meet the professionals before inviting them to join the committee, and to invite people who believe, both professionally and ideologically, that there is a failing that needs to be corrected.

b. It is important to turn to 'senior' doctors with considerable knowledge and experience, whose participation in the committee as renowned experts will later help ensure that the decision-makers adopt the recommendations.

c. Contacts with the establishment: the more the doctor is part of the establishment and working within it (Ministry of Health), the more familiar he or she will be with the way the system works, able to give professional recommendations that can also be implemented in the system, and even implement them him- or herself. In addition, someone who works in the establishment can identify its failings and suggest solutions, based on his or her professional experience, 'outside the box'. At the same time, the reverse is also true – sometimes working with the establishment can ossify ways of thinking and hamper the presentation of innovative ideas.

d. Professional loyalty to the establishment. Due to the nature of their work, care providers are usually employed by the Ministry of Health and/or the health funds. Sometimes their professional approach is shaped with a view to protecting the system and its ability to function.

## 2. Independent committee

It is very important for the committee members to participate on a voluntary basis, without sponsorship or support from any source. In this way the committee recommendations will be seen as purely professional, and not biased in favor of any body. When we are talking about senior professionals, contributing their time for the benefit of social change, a considerable effort is required to schedule meetings in the experts' free time, taking into account their crowded schedules – meaning a very protracted work process.

## 3. The make-up of the committee

Should the committee include only health professionals, or other professionals as well, such as social workers, day care principals, and integrators, and should it also include parents?

a. **There is no doubt that a heterogeneous professional committee is harder to manage**, since professionals from different spheres do not necessarily 'speak the same language'. Furthermore, each one identifies the problem from a different angle – a doctor sees a problem differently from a psychologist, and sometimes the boundaries between the spheres are unclear and the responses are different. In addition, when there are also care providers (such as day care principals and social workers), once again the problem is viewed from another angle.

A heterogeneous committee also demands joint and sometimes complex thought, with world views that may be in opposition to each other, and this is very important. The recommendations of a multi-disciplinary committee, in which there are professionals from different spheres who have thought and discussed the points of contention with each other and succeeded together in coming up with recommendations – these are recommendations that can more easily be accepted, since many aspects of the subject have been brought up and deliberated over.

For example: in the expert committee on inclusion, the participants felt that there was a group of infants that would actually benefit more in a segregated framework, and therefore thought that a separate class should be created in the regular day care center, in which they would spend most of their time apart from the other classes, with a special nursery teacher and with health profession treatments. All the professionals on the committee thought that it would benefit this group – but after clarifying the matter with the different day care principals, it emerged that it would be hard to implement this recommendation, and perhaps it would be preferable for these children to join a rehabilitation day care framework, in which there is the infrastructure and framework for providing the necessary response.

**b. It is necessary to ask whether an expert committee should also include parents.**

On the one hand – the parents have expressed their opinion by bringing up the need that initiated the process as a whole. On the other hand, it appears that the decision as to whether parents should be participants in the expert committee is an ethical one. In practical terms – hearing the parents’ position with regard to the criteria that are determined and the proposed responses is important – because they can testify, as parents, as to whether they feel that the proposed responses will be beneficial, and whether they can be implemented as proposed. On the other hand, since the recommendations will be brought up before the wider forum of organizations and parents so that the forum can express its opinion on whether to promote the recommendations as they stand – the expert committee should perhaps be purely ‘professional’.

**c. It seems that ideologically, we must ask who decides what is right and who should participate in shaping policy whose main consumers are the parents and children.**

On the one hand, it can be said that it is the professionals who have the professional knowledge – the doctors or care providers, and so they are the ‘experts’. On the other hand, the parents have the basic right to decide what is good for their children, and they do so in every sphere of the child’s life, including deciding with regard to health and education. So why not define this right broadly and allow the parents also to be partners in shaping the appropriate policy, on the basis of the community approach of ‘nothing about us without us’? After all, the significance is that the parent is part of the team, the parent’s viewpoint is heard in the process, and his or her position is considered in the same way as the professional opinion. It seems that putting the professional recommendation into practice must be done in a way that is both accessible to the families, and possible to implement.

For instance, see the example given in section 3a above. The recommendation of the professionals was that there should be a group of children in a separate framework in regular day care centers. However, apart from the technical difficulty (day care centers are not set up for this and the recommendation would be hard to implement), there is another difficulty arising from the viewpoint of the families – if this group is in regular day care, opening such a class would depend on a sufficient number of children living in the area of the day care center, and in the absence of a sufficient number of children, the class would not be opened and there would be no response. On the other hand, if this group were to be included in rehabilitation day care, the child entitled to rehabilitation day care would also be entitled to transport, and so could be assured of an appropriate framework.

**4. Number of committee members**

The greater the number of committee members, and the greater the differences between the professional fields – the harder it is to schedule meetings, manage discussions, and reach agreed conclusions. On the other hand, as mentioned above, this brings different approaches to the discussion and makes it possible to think about the subject from many different aspects.

### **The stage of formulating recommendations**

In the case of the expert committee on inclusion, where professionals from different fields were involved, the stage of formulating the recommendations was, in the nature of things, no easy matter. Here the committee coordinator plays a very significant role in writing up the recommendations and clarifying positions with each of the members, in order, as far as possible, to reach an agreed form. In our case, the committee succeeded in drawing up recommendations that were agreed by all but one of the committee members. At the same time, one item remained the subject of disagreement among the committee members. Accordingly, and for the sake of transparency, it was decided to write the report in a manner reflecting the agreements, and also mention the issue that was the subject of contention among the experts. The summary report also related to the fact that one of the committee members objected to the recommendations as they stood. It was clear to everyone that the recommendations were only the beginning, and that change through legislation will in any event require many discussions – whether in the Knesset committees or in the ministerial committees, in order to formulate the final text of the proposed law. But when the basis for the recommendations is almost complete agreement by a multi-disciplinary, heterogeneous, and independent expert committee, this provides a solid foundation for continued work.

### **Circulation of the report and signing up supporters**

This stage of circulating the report among professionals who were not part of the expert committee is a very important part of the work. The more professionals support the position proposed in the report, the easier it will be to persuade the establishment of the necessity for the change and the proposed arrangements.

### **Additional methods**

Other ways of making use of professionals for the benefit of social change in the framework of the integration law in particular and social change in general:

## מה הרופאים יכולים לתרום לקידום חוק שילוב לפעוטות



מה רופאים יכולים לתרום לתהליך זה:

- יידוע המכונים להתפתחות הילד לנושא השילוב ולאפשרות הפניה – על מנת ליצור לחץ על המערכת;
- לתת מידע – מחקרים או מקרים, רעיונות, פתרונות, הסדרים מקומיים;
- פגישות עם נציגי משרדי הממשלה והשתתפות בוועדות בכנסת;
- מתן מידע להורים על האפשרות לפנות לפורום ואו לקדם ואו למצות זכויות;
- הפניית הורים שמתמודדים עם הבעיה שמנסים לקדם אל הפורום.

### What doctors can contribute to promoting the Early Childhood Inclusion Law

What doctors can contribute to the process:

- Informing the child development institutions of the subject of inclusion and the possibility of referral – in order to put pressure on the system;
- Providing information – research or cases, ideas, solutions, local arrangements;
- Meeting with representatives of the government ministries, and participating in Knesset committees;
- Giving parents information on the possibility of making contact with the forum and/or promoting and/or taking advantage of rights;
- Referring parents coping with the problem and trying to move ahead to the forum.

## מה הרופאים יכולים לתרום לשינוי חברתי



- העלאת נושאים ורעיונות לקידום/שינוי ולהביאם בפני הפורום
- השתתפות בתהליך לימוד הנושא
- השתתפות בוועדות מומחים
- תמיכה בהמלצות של ועדות מומחים
- השתתפות בפגישות במשרדי ממשלה/בכנסת
- להציג מקרים התומכים בנושאים שמבקשים לקדם
- לקרוא ולהגיב למיילים
- לחתום על ניירות עמדה

### **What doctors can contribute to social change**

- Raising issues and ideas for promotion / change and bringing them up before the forum
- Participating in the process of studying the subject
- Participating in expert committees
- Supporting the recommendations of the expert committees
- Participating in meetings in government ministries / the Knesset
- Presenting cases supporting the issues that are being promoted
- Reading and responding to emails
- Signing position papers