Continuity, Transition and Governance in Parent Groups
Notes on the workshop at the ICCCPO Conference, Geneva; Sept 2006
Organiser: Julian Cutland, with contributions by:
Marianne Naafs-Wilstra; Simon Lala; Anders Wollmen; Gerlind Bode

Introduction
All organisations must go through periods of change and transition. Sometimes these can be traumatic; sometimes they can be planned; sometimes they are forced on the organisation by circumstances.
Parent groups are no exception to this. Old leaders will step back, and new ones will take over. Sometimes these will be parents, and sometimes they will be paid employees. Sometimes a group will grow and expand because it identifies that there are many needs of the children and families that it wants to satisfy. This may require a major rethink of how the group operates and is managed.

Why should we think about continuity and transition?
They are issues that all groups will inevitably face at various times in their existence. One recognises that there can be a potential conflict between maintaining continuity and ensuring transition, and it is often a matter of getting the right balance between the two. We believe that it is better to go into things forewarned, rather than by accident, and that it can be important for parent groups to be aware of the sort of issues that will arise at various times in their lives.
We want to ensure that our groups have: long term continuity of delivery of services; effective development of the group and its activities; smooth transitions between leaders; and maintenance of the focus and objectives.

Some Basic Assumptions:
The main focus is on what we may term “traditional” parent groups, ie groups established primarily by parents, and with ongoing control by them. Probably much of what is covered is also applicable to other, “professionally run”, groups, but we believe that the issues can be rather different in traditional parent-run groups.
All groups will go through transitions in leadership; no-one is immortal, and new people must take over. Each organisation is different, and there will not be a case of “one size fits all”. However there are probably similar challenges faced by many groups.

Aims of the Workshop
The intention of the workshop is to:
- highlight the different types of parent groups;
- identify some of the transitions that Parent Groups may face;
- highlight some of the issues that may need to be addressed;
- pose some questions that need to be answered;
- pool the experience of ICCCPO members, and ultimately to develop some guidelines for groups.
Maybe it won’t provide many of the answers, but the discussion will hopefully provoke people to think about the issues in their own context.
**Types of Parent Groups**
To provide a framework for the discussions, we have identified three main types of parent groups. While the split is not necessarily exact, it does provide a convenient way of identifying some of the issues involved.

**Type 1: Support Group**
Many groups have started off in this way, with a primary focus on mutual support between parents. There is probably no significant emphasis on raising funds, and possibly all of the people involved are parents, with maybe some hospital staff.

**Type 2: Fund Raising Group**
Many groups decide to raise and manage money, to fund a range of programmes that they have identified as being necessary or desirable to support the children and families. There are probably some paid staff, for such areas as secretarial, fund raising, admin, and accounting. However the ongoing control and running of group remains firmly in the parents’ hands.

**Type 3: Professionally run organisation**
For some groups, there might come a time when it has become much larger, it is achieving much, and is handling significant funds. It may well be that not all required skills are available within the parent group, or that they do not have the time available to do all the work that is now required. Because of the nature of a group of this type, there will be the need to run it much more as a business, taking more cognisance of such things as branding, marketing, delivery of services, and accountability for the use of public funds. It is likely that it will become necessary to hire a “CEO”, and probably other staff, to run the organisation.

**Comments on types of group**
In some cases, a group may be able to fulfil what it sees is required while it remains as basically the same type of group. In other cases, a group may grow and make the transition between the types of group, because they identify the need to address a wider range of issues and programmes. We do not mean to imply at all that a group should inevitably aim to make the transitions through the various types. Each group will be different, and it works within the environment in its own country (with the social support structures that are available there), and will presumably do its best to meet what it sees as the needs of the parents and children in that context.

**Different and evolving requirements**
Sometimes there will be a definite progression in the development of a group over several years. In some developing countries, there have been models for the development of Paediatric Oncology (eg the St Jude / SIOP model), to first become established in a pilot centre; then progress to a centre of excellence; to regional treatment centres; and a then to a national specialisation. The support structure around this development and progression, including parent groups, will inevitably have to evolve as the needs of the treatment centres develop. Perhaps it will change over time from one group focused on the pilot centre, to several regional groups, and maybe to a national group, or a set of co-operating groups. It is felt that the issues that are covered in this workshop will have relevance at all the stages that these types of groups may go through. The scope and details will inevitably vary in each situation and country, but the general principles will probably be very similar.
**Types of transition**
There will be a transition when there is a change in leadership, whatever the type of organisation. There will be a different type of transition, which could potentially be a much greater change, when the organisation changes from one type to another. This type of transition may take a lot more careful thought and planning to make it really successful.

**Leadership requirements, and developing the next generation**
Any organisation needs leaders, and parent groups are no exception. However normal businesses can select from the whole population, but parent groups have to manage with the random selection of people that nature has chosen.

Good leaders develop good successors, and hand over at the “right” time. Good leaders develop good successors, and hand over at the “right” time. Good leaders develop good successors, and hand over at the “right” time.

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It is recognised that different types of organisation will require different leadership skills. During the formative years of the group, it is typically a set of passionate, entrepreneurial, and empathetic parents who will get the group established. However business skills become increasingly important if the group develops into types 2 and 3, with the need to address such issues as: business planning; finance; marketing; fund raising; legal; etc. So the role of the parent group leaders may well change over time, and particularly if there is major evolution / development / transition of the group.

There will always be the need for committed parents, to take leadership roles, possibly in conjunction with paid staff and volunteers, but there may not be all of the required skills, or time available, among parents.

How does a group develop the next generation of leaders? There are no simple answers!! But some simple suggestions would be:
- The group should think about succession, and consciously plan for it on a regular basis.
- They should think clearly about what skills the organisation needs, at its current stage of activities and development.
- They should consciously identify potential people among the parents, encourage them to get involved, and maybe also look among wider family members or dedicated volunteers.
- They could send potential new leaders on courses or seminars run for the NPO sector, eg on governance, fund raising, marketing, etc, and maybe give them wider exposure by attendance at the ICCPO / SIOP conferences.
- They could give them responsibility for some specific areas of the group’s activities, such as fund raising, or a support programme, and mentor them during this process.
- They could think about having limited terms for office bearers, in order to force them to encourage and develop new leaders.
- It may be useful at times to bring in some outside “experts” (eg management consultants) to assist the group to develop their plans. Having an outside perspective can be very useful to help people to think clearly about where they want to be going, and how to get there.

**Maintaining the “ethos” of the organisation**
(Contribution from Marianne Naafs-Wilstra - Netherlands)
Parent groups start off with some ideals as to what they wanted to achieve. They will normally have a passionate commitment to achieving certain things, and will probably develop a group ethos as to how things are done. The objectives and vision will probably evolve over time, but there should be some core values of the group that remain constant for the long term, during transitions between leaders, and also during major transitions between the different types of organisation.

Some useful insight can be found in the paper by Mark Chelsel’s paper (1998 – see ICCPO web site) on the differences between Parent Groups and Cancer Societies. He highlights the passion and commitment of parent support groups as against a more bureaucratic / business approach that professionally run charities adopt.

Some of the ways in which an organisation can maintain its fundamental ethos are as follows:

1) **Defining your goals:**
   - Define what is really needed. Make your goals comprehensive, but don’t go into details.
   - Examples of defining your goals could be:
Narrow: To improve treatment and support scientific research
Wide: To support families of children with cancer by 1, 2, 3, 4, etc

2) Defining the way you work
   Are you a Parent organisation? Or a Volunteers organisation? Are volunteers parents or outsiders, or both? Do you seek collaboration with professionals? Etc.

3) Goals and methods
   Make sure every board member, volunteer, and staff member knows and “feels” the goals and method of the organisation. And make sure the outside world knows what the organisation stands for.
   How do you share your goals and methods?
      Internal: by interviews; with manuals; by holding strategic planning sessions; etc. The aim is to build a “family”.
      External: in letters, on pamphlets; posters; website; etc.

4) Goals & method and activities
   Check your activities with your goals, and define who is responsible. Set priorities.
   Work with a long-term business plan, and a one-year plan.

5) Review your goals and methods
   Consider: Are they still valid? Do we want/need to do more/less? Does it work well? Can we do better? How can we do better?
   How do you review - or even redefine - your goals and method?
   When defining year plan and business plan:
      Through questionnaires among: parents / children / survivors / siblings / professionals; etc
      Through strategic planning sessions of board, staff, volunteers
   Remember - that the overall aim is: To make the world a better place for a child with cancer and its family.

Governance issues (Contribution from Anders Wollmen - Sweden)
As a type 2 organisation, and particularly as type 3, the organisation will be handling money raised from the public, and with some organisations this could be many millions per year. The governance and public accountability required in this situation becomes paramount for the ongoing credibility of the organisation. It may be very desirable for the group to review its governance structure and processes as it goes through major transitions, especially between the types of organisation.
Some notes from the experience of the Swedish Parent Organisation:
   Ensure good governance:
      - External board members: To add skills to the board that the parent members don’t possess.
      - Competent chairman: It’s important to have a competent and skilful chairman; also it is easier to get publicity with a well-known chairman.
      - Competent leader of paid staff: The leader of the secretariat must be a good leader in order to get an efficient job done.
      - A clear line in responsibilities between board and secretariat: The board should make all the strategic decisions, but leave the operational decisions to the secretariat.

   Accountability
      - Fundraising control: In order to assure the public and other donors that the money is spent for the organisations purposes.
      - Auditing
      - Chartered accountant
      - Ethical guidelines: Guidelines on what purposes the organisation can spend money, and from whom they can accept money. Also guidelines on which type of companies the organization can buy shares in.

   Utilisation
      - Charters
      - Ethical standards
      - External committees: The board doesn’t possess the expertise or competence to decide which project is good or not. Therefore an external committee is essential.
Handing over / letting go  (Contribution from Gerlind Bode - Germany)
The transition between different leaders can go smoothly, or can be somewhat traumatic for both the old and the new people.
Some leaders will want to depart and have no further involvement, but some will be willing to continue to be actively involved. It could be a problem for some people to fully let go of the reins and allow the new people to really be in charge. It could also be a problem if the previous leaders feel excluded and ignored, while wanting to continue to contribute. One wants to get the right balance of utilising the knowledge of the “old guard”, while truly handing over the control and direction to the new people.
There will be many personal relationships built up (with donors, medical staff, community, etc) over time; handing over and maintaining these relationships for the best benefit to the organisation could be a potential problem area.

Some questions for consideration:
  When is the right time? How to prepare for it? Is there a “right” time? Who determines that? The statutes? The leader him/herself? The members (Board / General Assembly)?
I. Worst case: Leader does not realize that his/her time is over
  They may give reasons why not to step down, eg: Nobody is willing to take over; Nobody is able to take over; He/she is the only person willing to do whatever is needed …; Times have changed - people are no longer grateful …; No respect for the achievements … etc…
  Such a leader did not let anybody “grow” next to him/her.
  This scenario has to end with a disaster:
    Either the health situation brings a natural end
    or the leader makes a very blunt mistake (e.g. wrong financial decision etc.)
  It can mean the breakdown of the organization, the end, nobody prepared to take over …
  But it can also be a new beginning (completely new group)
II. The leader prepares the “handing over” process:
  By choosing a person as a “descendent”; who will be introduced at all occasions; as the possible follower; who works along side with the current leader (within the board); and who is involved in all decision making processes.
  This can be a very smooth handing over process.
  But it also holds the danger that there is no change at all (eg with no innovation and no growth).
III. The statutes regulate the handover:
  The statutes determine the years of a leadership term; which means that all board members have to think about the transition (as well as their own position in the board)
  Is there a “right” time span for a board office? Such as two terms (depending on how long each term is)? Or a maximum of 8 years / 10 years??
  It will be dependant on cultural / economic or other circumstances.
  But one should bear in mind: that many things can have changed within 8 years; and such a position is very demanding and exhausting.

Handing over Process:
  All board members have to watch out for potential “leaders”. Candidates can be prepared by assuming responsibilities. They should be made acquainted with all situations / people / officials, etc. Should be sent to “training” (such as ICCCPO meetings, etc.).
  Democratic voting process in General Assembly.
And last but not least:
  If possible, the organisation should utilise the skills of the “old leaders” for special purposes. Thus, a large “pool” of expertise can be built up, to which the organization can relate. With Internet connections the “old” ones do not have to be physically present, involved in all meetings.
  They can be informed and asked for advice; they can be sent on special missions in their local area, or their field of expertise; they can contribute by organising and keeping up important contacts; and they can get special assignment according to their (professional) skills (e.g. book keeping, graphic design, website organization, newsletter editing, printing ….)


Working with the CEO  (Contribution by Simon Lala, New Zealand)

Probably the biggest change that an organisation will go through is when they first appoint professional staff to manage the organisation, ie the transition to type 3. The “CEO” is a crucial person in this type of organisation. They could possibly be a parent, but they (and other staff) would be hired primarily for their professional skills, and not because they happen to be a parent. Delivering on the programmes and services to the families and children will probably require a harmonious combination of staff, parents and volunteers. Understanding and effectively managing the dynamics and interrelationships of this can be critical to the ongoing success of the group.

Maintaining the “balance of power”, and congruence of objectives, between the parents and the staff can be a critical factor in running the organisation. There need to be clearly defined relationships and roles between all the different parts of the organisation.

There will probably be legal rules set by the Government, and the organisations policies must conform to these.

One must recognise the distinction between Governance and Management. The Board of Governors to appoint & monitor CEO; the Board does not manage but it ensures that the organisation is managed. The CEO & Management actively do the job of running the organisation.

It is necessary to educate volunteer committees, and to define the roles of staff, both paid and unpaid. Every staff member must report to the level above, to ensure consistency of standards and service. There must be a clear Management structure in place.

A possible organisational diagram for the organisation with a CEO is given below.

Management Organisational diagram

It is suggested that the Board of Governors develops a strategic plan every three years. The CEO must enact and achieve the points in the strategic plan, and his performance is measured against this every year. The CEO reports regularly to the Board, probably each quarter.

Planning for the future

All organisations will face the issues of transition and continuity at some time, and really should think about how they can best be handled in their situation. It is better to go into them prepared. We would suggest that they should form part of the group’s business plan (which one assumes will exist, and be reviewed and updated annually). This business plan should identify:

- What you want to achieve – ie the deliverables that one can see are achieved.
- When, and how, these are to be done.
What resources you need to do it. This will include: people, money, and equipment. The people involved will be a combination of: parents, volunteers and paid staff. They will all contribute their skills, expertise and experience, but with possible constraints on the time that they have available.

Some suggestions that we would make regarding this process are:

- Make the issues of continuity & transition part of your (annual) planning cycle.
- Identify the skills, etc, that you will need into the future, looking at least 2 to 5 years ahead.
- Think about who your future leaders could be, among parents and volunteers, as well as within the staff.
- Develop them to be able to step forward and take over.

**Concluding remarks**

We have covered a range of issues that all parent groups will face, in some way or other, at various times. There are no definitive answers that will apply to everyone. But if one is aware of some of the potential problems and challenges, hopefully they can be met in a rational way and be a positive experience for the group, rather than one which causes significant disruption to what the group is doing.

We hope the session was useful, if not in providing all of the answers, at least in making people think about some of the issues and questions, and how they relate to their own context and situation.