



Leadership/Advocacy

September, 2001

Leadership

The life-changing event of having a child with special needs will draw some individuals out and move them to take on a leadership role they may never have had if life had been different. They may discover an interest, passion or skill for leadership in themselves, that they were previously unaware of. Leadership is for some people. There will be a small number who will take on the mantle of leadership. Some individuals may have acted in a leadership capacity before; for others this may be the first time they have ever taken on such a role.

Leadership can come in many forms:

- facilitating a meeting or a support group
- organizing and overseeing an event
- educating other parents and individuals through presentations and speaking engagements
- rallying the support of other parents and individuals around issues through calls and personal contacts
- sharing their personal story
- participating on committees, boards and task forces at local, state and national levels
- drafting letters and documents
- testifying before boards and legislators

Leadership does not only come from the person who is standing at the podium speaking. Remember, sometimes it is the person behind the scenes who gets the most done.

Advocacy

From a family's perspective, advocacy provides information or a person who is an independent resource working only on the family's behalf and not someone who is beholden to the same system for their job.

Professionals may have a negative perception of advocates and advocacy for a couple of reasons. Historically, advocacy had the connotation of being combative, challenging or litigious in nature. In recent times, advocates can be viewed more as negotiators and mediators. A negative perception may also be present because of those few situations where there were bad experiences with an advocate. It is easy for feelings from a bad situation to linger and be carried forward to other situations.

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An advocate's job is to be informed and to fully inform families of their rights, responsibilities and the existing laws. It is also the role of an advocate to let families know the reality

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of whether the laws and outcomes favor them or not. An advocate should work with the family to be good negotiators. For parents and individuals who are ready to advocate for themselves and other families, it is important that training in advocacy, negotiation, mediation and leadership skills is available.

As you think about supporting families and individuals in gaining and enhancing their advocacy and leadership skills, there are several state and national forums in which parents can participate:

- Governor Council on Developmental Disabilities – Partners in Policy Making
- Council on Parent Leadership
- PACER Center Training
- Learning Disabilities of Minnesota – Leadership Conference
- Local Trainings

Consider providing advocacy and leadership trainings locally. For some parents this will be their only exposure because of constraints such as time, family, money and careers. You may also find the hidden leader in the room who may have otherwise remained in the background.

Note:

Parents who are strong leaders and good advocates do more than support the rights of their child and family. History has shown that it is those parents who have impacted and created change that has benefited children, families and professionals, such as: TEFRA (Katie Becket Waiver), inclusion, Arc organization and the removal from institutions of people with disabilities.

Critical Questions:

Am I avoiding sending parents to advocacy and leadership trainings because:

- *it may cause “problems”?*
- *parents may know as much or more than I do?*
- *there may be militant parents there that will give our parents ideas?*

How much of a leadership role am I willing to take on?

How do I support leaders who are just emerging?

Is there any issue that makes me want to take on a leadership role?

