



Parents as Leaders

**Adapted from PCL Module 1 by:
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Parents as Leaders: What's the Vision?

- Leadership is an attitude and a behavior – not a position
- Leadership needs to be based in reality – not on political views
- Leadership can be shared
- Leadership can be collaborative
- Leadership can be learned



Parents as Leaders: A Historical View

Parent Advocacy prior to the Individuals with Disabilities Education Act (IDEA):

- 1933: Five mothers of children with mental retardation in Cuyahoga County, Ohio organize to protest school's exclusion of their children. Result: a special class is created in a public school
- 1949: Parent of a child with cerebral palsy founds the United Cerebral Palsy Association
- 1950: 42 parents and others meet in Minneapolis on behalf of children with mental retardation. Result: Establishment of the Association of Retarded Citizens (ARC)
- 1960s: Parents of children with mild to severe retardation sue the state of Pennsylvania to obtain "free and appropriate education" (FAPE) for all students with disabilities.

- 1974: ARC members, professionals and other parents continue to lobby hard for federal legislation for children with disabilities. Result: The Education for All Handicapped Children Act, now known as Individuals with Disabilities Education Act (IDEA).

Parents rights are born under IDEA:

- The IDEA contains provisions requiring:
 - Parents to be part of IEP teams and to participate as educational decision-makers
 - Parents have the right to due process

Advocacy of Parents of Children with Visual Impairments:

- The National Association for Parents of Children with Visual Impairments (NAPVI) has consistently advocated specifically for special education and related services for children who are blind or visually impaired, including those with multiple disabilities.
- Orientation and Mobility has been included as a related service
- The language related to the decision process for instruction in braille was strengthened in IDEA

What Roles can Parents take as Leaders?

- Policy makers/ advisors/ consultants
- Program evaluators
- Members of task forces
- Advisory board members
- Leaders of parent advocacy groups
- Grant reviewers
- Members of boards of trustees
- Group facilitators

What are the Benefits of Parents as Leaders?

- Benefits to programs and services
 - Providing parent perspectives
 - Bringing a sense of reality to ideas and tasks
 - Improving the quality of services and supports
 - Ensuring that programs and policies meet the needs of families



- Benefits to parents and professionals
 - Enhancing skills
 - Working from a strengths perspective
 - Seeing others' points of view
 - Appreciating the expertise of the other
 - Acting on a vision



What Challenges do Parents Face?

- Professional reluctance and resistance to viewing parents as partners and leaders
- Professional reluctance to “overburden” families
- Fear of the things parents might ask for
- Parents’ reluctance or fear of assuming new roles
- Administrative and organizational barriers

For more information....

See the Parents as Collaborative Leaders website:

www.uvm.edu/~pcl/modules.php

Or contact:

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For more resources, visit www.Perkins.org.

Our on-demand webcasts are presented by experts in the field of visual impairment and deafblindness. View our directory at:

www.Perkins.org/webcasts.