

The background of the slide features a low-angle shot of the St. Louis Arch, a large white concrete structure that curves from the bottom left towards the top right, set against a clear blue sky. The arch's surface shows some texture and shadows.

International Ventilator Users Network (IVUN)

Coordinated by

**Gazette International Networking
Institute (GINI)**

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Independent Living Concepts & IVUN History

**Joan L. Headley, MS
Executive Director**



MARY SWITZER



GINI LAURIE



Gini and her brother
Bob Laurie





National Foundation for Infantile Paralysis- Funded Poliomyelitis Respiratory Care and Rehabilitation Centers

Alameda County Hospital, San Leandro, California

Children's Hospital, Columbus, Ohio

City Hospital, Cleveland, Ohio

Goldwater Hospital, New York City, New York

Jack Martin Respiratory Center, New York City, New York

Jefferson Davis Hospital, Houston, Texas

King County Hospital, Seattle, Washington

Mary MacArthur Respiratory Center, Boston, Massachusetts

Medical College of Georgia, Augusta, Georgia

Rancho Los Amigos, Hondo, California

Saint Joseph's Hospital, Omaha, Nebraska

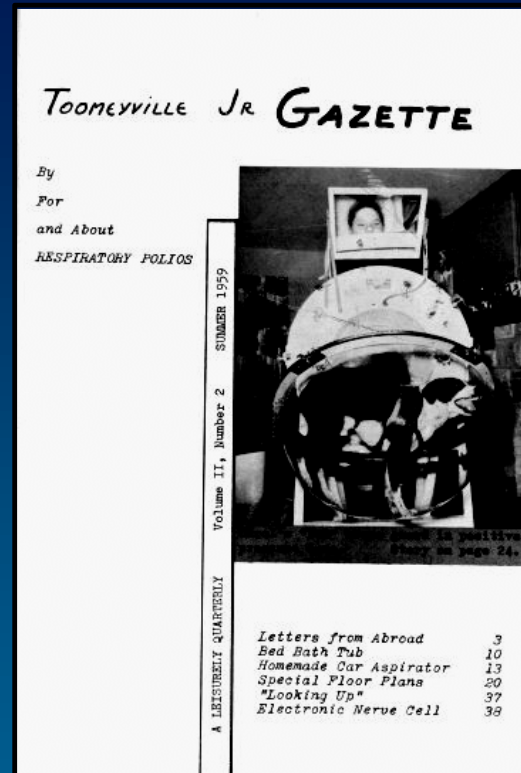
University of Buffalo, Buffalo, New York

University of Michigan, Ann Arbor, Michigan

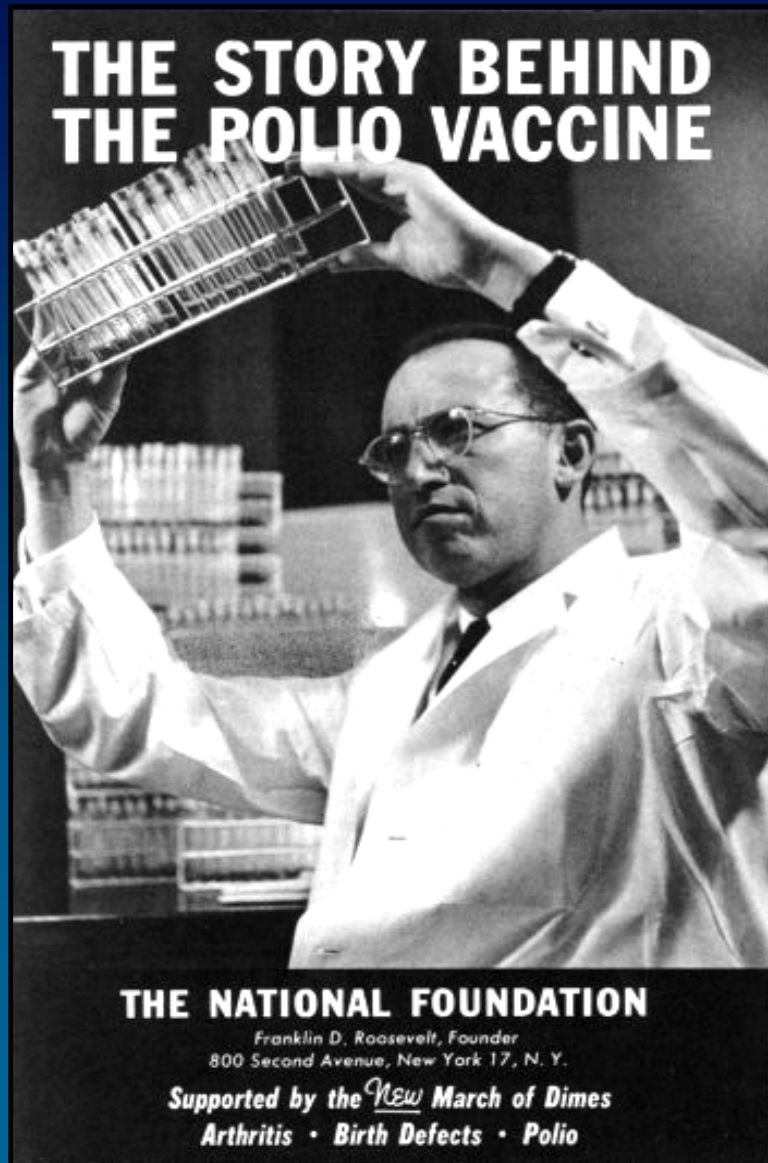
University of Illinois, Chicago, Illinois

Vanderbilt University, Nashville, Tennessee





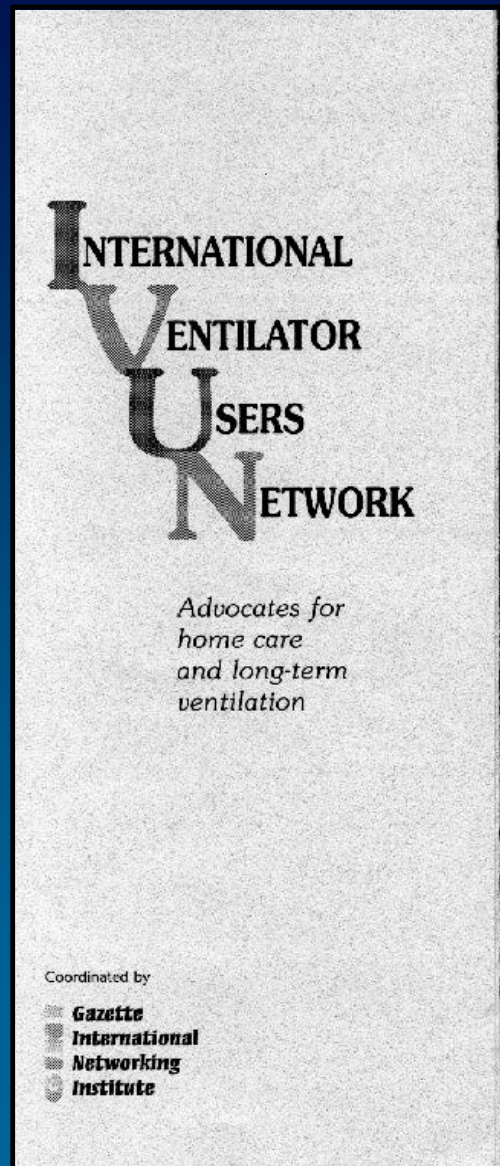
TOOMEY J. GAZETTE



JONAS SALK

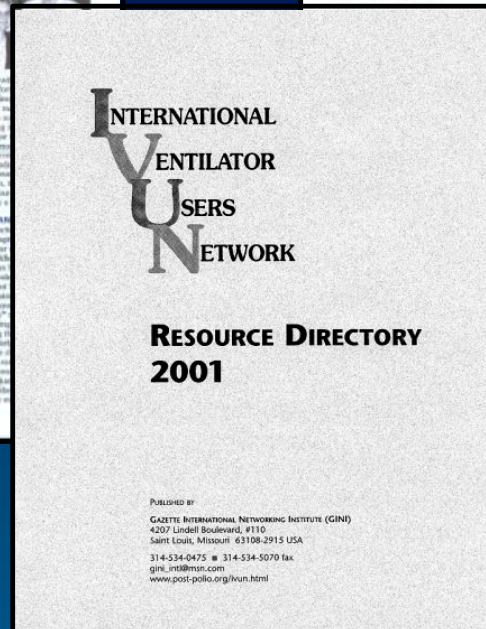
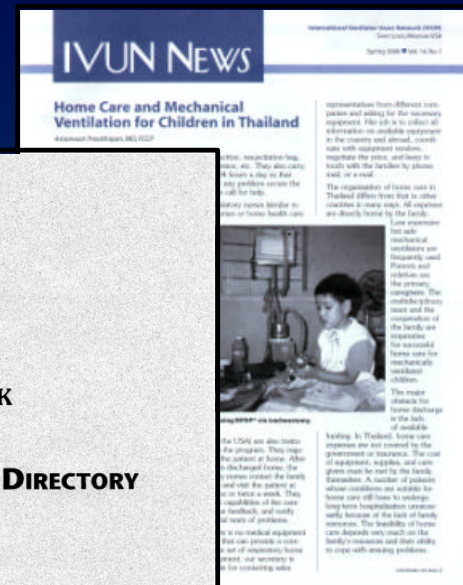






International Ventilator Users Network (IVUN)

links ventilator users with each other and with health care professionals interested in the options available for mechanical ventilation and home care.



Judith R. Fischer,
MSLS

Editor of *IVUN News*

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Gini Laurie and Ed Roberts

Core Services

- Information and Referral
- Independent Living Skills Training
- Peer Counseling
- Advocacy

Other movements during the 1960s and 1970s

- Civil Rights
- Consumerism
- Self-Help
- Demedicalization
- Deinstitutionalization

**Source: DeJong, Gerben. The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research. Paper presented at American Congress of Rehabilitation Medicine, 1978.*

■ Civil Rights Movement

People with disabilities became aware that...

- ...their rights were being denied.

- ...securing those rights could involve social protest.

- ...prejudice against disability is rooted in society's attitudes about youth and beauty.

■ Civil Rights Movement

The awakening was worldwide as evidenced by the United Nations...

...Declaration on the Rights of Mentally Retarded Persons (1971).

...Declaration on the Rights of Disabled Persons (1975) .*

Source: "The United Nations and Disabled Persons: The First 50 Years."
Disabled Persons Bulletin. United Nations, NY, 1997.

■ Consumerism

The concept of a person with a disability as a consumer was counter to the standard practice of professionals making decisions for people with disabilities.

■ Self-Help

Self-help organizations, patterned after Alcoholics Anonymous, sprang up to assist people with disabilities to exercise control over their own lives by providing knowledge and promoting awareness.

■ Demedicalization

Removes the individual from the “sick role.”

Medical model locates the problem in the individual with a focus on cure or “fixing.”

Independent living model locates the problem in the environment with the focus on advocacy to eliminate the architectural barriers and policy barriers.

The “impaired role” results in loss of full citizenship and may result in a child-like dependency.

“Themes of self-care, peer support, empowerment of the individual, and taking one’s rightful place within the family and community does appeal to people who are forgotten or treated as children.”*

*Source: “The Independent Living Movement: Is It Living? Is it Moving?”
Adolf Ratzka, PhD. *Rehabilitation Gazette* (Vol.38, No. 2) 1998.

“A very big problem with traditional rehabilitation, from the point of view of the experienced disabled, is that in their ‘zeal’ to be helpful they don’t know when to stop!”*

*Source: “The Implications of the Consumer Independent Living Movement on Traditional Rehabilitation.” Audrey J. King, MA and Jane Staub, MA, C. Psych.
Presented March 1983.

■ Deinstitutionalization

...results in cost-savings to the taxpayer.

...related to normalization.

“Normalization” emphasizes that independent living allows individuals the dignity to take risks, make their own choices, and the recognition that those choices may lead to failure.

“Normalization” a term co-opted by professionals.
“Right to difference” a term now used by people with disabilities, or consumers.

What is independent living?

“Control over one’s life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities.” *

*Source: National Council on the Handicapped (Disability).
National Policy for Persons with Disabilities. Washington, DC, 1983.

What is independent living?

“Independent living is a lifestyle, with possibilities and limitations common to everyone.”

Argentina

“Independent living is an individual or group attitude against the strategies of protection that generates dependence and passiveness.”

Columbia

What is independent living?

“When people with disabilities can live on their own, with the same rights and responsibilities of others.”

Venezuela

What is independent living?

“Independent living alludes to the fact that people with disabilities are a strategic part of their own development and that their participation is vital for the enrichment of society. Therefore, all necessary resources to acquire the same opportunities as other members of the community must be made available to them.”

Mexico

What independent living is not

“People that ‘in spite of’ their disabilities, are able to live by themselves or with little help from others.”

Argentina

Source: “IDEAS 2000 Latin American Independent Living Survey.”
Rosangela Berman Bieler. International Disability Exchanges and Studies Project
(1996).

What is independent living?

“Independent living is a western concept that has not achieved acceptance in developing countries due to its emphasis on individuality and self-sufficiency, and its lack of consideration of family and cultural norms.”

Source: *Asia Pacific Disability Rehabilitation Journal* (Vol. 12, No. 1, 2001) .



Kimiyo Satoh



“To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a ‘normal’ body.”

Judith Heumann



“I prefer to think of the movement as an interdependent living movement rather than an independent living movement.”

Gini Laurie, 1988

Men who are good by reason – i.e.,
men who, under the guidance of reason,
seek what is useful to them – desire nothing
for themselves they do not also desire for
the rest of mankind.

Spinoza

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