

Advocacy Dimensions

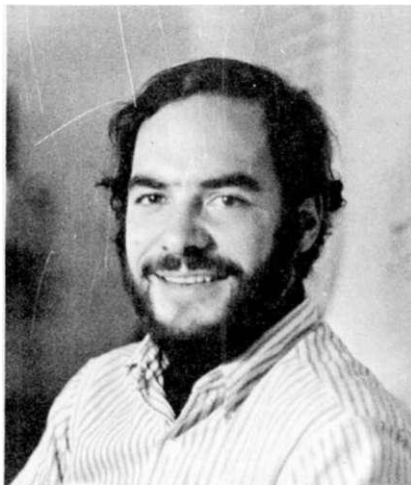


VOLUME 1, NO. 1 FALL 1979

Minnesota State Planning Agency

Developmental Disabilities Protection and Advocacy Network

Biklen Keynotes Advocacy Conference



Douglas Biklen

"It feels good to be a donor, hell to be a recipient." That was the comment of Douglas Biklen, keynote speaker at the statewide Conference on Advocacy for Developmentally Disabled Persons, held February 20-21 at the Sheraton Inn, N.W. in Minneapolis.

Biklen was referring to the fact that services to the handicapped in the past were delivered with the connotation of 'charity' which required a response of gratefulness.

An assistant professor and Director of the Center on Human Policy, Syracuse University, and an author of many publications on advocacy, Biklen went on to point out that retarded adults are too often treated as children, patronized by adults 'supervising' them.

He was addressing over 200 participants from Minnesota and neighboring states at the Advocacy Conference sponsored by the Developmental Disabilities Planning Council, the Developmental Disabilities Planning Office, Minnesota Protection and Advocacy System, and Continuing Education in Social Work, University of Minnesota.

Biklen maintained that slogans such as "mainstreaming" "rights, not privileges," "normalization," and "least restrictive" are effective catch words which help the public gain a vision of an alternative view.

Would-be advocates for developmentally disabled persons must be unequivocal in their stand that a change in attitudes is needed, he said. Deinstitutionalization, with the resultant move toward community, would never have come about if advocates had not been uncompromising and adamant about the negative living conditions forced on residents in state facilities.

Any push toward 'change' challenges the status quo and power inherent in the system, Biklen added. Controversy is an inevitable and to-be-expected result.

Biklen to p. 4

Advocacy Network Becomes Reality

Attention Advocates! What issues and activities are you involved in that others would like to hear about?

What can others in Minnesota's Protection and Advocacy Network do for you?

These questions are being asked and answered as reports come in daily to the P & A Network office in response to a July mailing to advocates across the state who serve persons with a developmental disability.

Results of a requested needs assessment, to this date, give Public Information & Education topmost priority, followed by the need for Technical Assistance and Advocacy Training. These are the areas some replies indicated as being focus areas for the central advocacy office.

This input has helped the Minnesota Protection and Advocacy Network become a reality. The Amended Developmental Disabilities Act, Title II, Section 113, mandated the establishment of Protection and Advocacy Systems in every state and territory. Minnesota's perspective of that office is as a facilitator to what is going on locally across the state. Staff will provide technical assistance upon request and

Network to p. 2

Advocacy Program Highlights

Health Office Investigates Complaints

Can an Ombudsman Office perform freely and judiciously within the system it is set up to monitor?

Jean Donaldson, Director of the Minnesota Office of Health Facility Complaints feels that it can and that office, located within the Department of Public Health, may even be considered a "model" for the nation. Certainly, it places Minnesota in the forefront in the country in guarding the rights of persons residing in health care facilities.

The Office of Health Facilities Complaints was established by the Legislature in 1976 in response to public pressure and growing concern about the administration and quality of health care in nursing homes.

Principal responsibility of the office is to investigate complaints by any person, known or anonymous, on care provided by any licensed health care facility in the state. This includes hospitals, nursing homes, board and care homes, supervised living facilities, state hospitals, etc. In addition, the office assists in public information programs and may recommend legislation and rule changes to the Board of Health, the legislature, Governor, administrative agencies, or the federal government.

The office performs an "ombudsman," rather than a true patient advocacy role in that it is to act in an impartial, judicious capacity in monitoring compliance of health facilities with the Patient's Bill of Rights, state licensing regulations, and Minnesota statutes.

Suspected mistreatment of patients due to physical abuse or neglect must be immediately reported to the Health Dept. under State law (Chapter 626.55, Sect. 2) by any physician, surgeon, nurse, administrator, pharmacist, or anyone engaged in the practice of healing. Failure to report such information is a misdemeanor.

Investigators have full access to facilities, and to patients' charts and have the right to interview all staff. They record and document all evidence and write full reports kept on file in the Minneapolis office. These files are open to the public and may be photocopied. Names of complainants and staff interviewed are not recorded.

Complaints against doctors and nurses working within health care facilities are also investigated. A verified complaint against a doctor might go to the Board of Medical Examiners. Evidence of non-compliance with regulations or patient's rights may lead to a correction order, a penalty assessment, or a hearing before the State Hearing Examiner. Other departments, such as Public Welfare, might be notified. A recommendation for certification or decertification of the health facility would be sent to the Health Systems Division of Licensing and Certification.

Nine hundred thirty-nine complaints were accepted for active on-site investigation in 1978. An additional 300 calls requested aid or information provided in the office. For the first six months of 1979, 418 complaints were formally investigated.

Persons with concerns on health care in facilities anywhere in the state are urged to contact:

MINNESOTA OFFICE OF HEALTH
FACILITY COMPLAINTS
717 Delaware Street, S.E.
Minneapolis, MN 55440
(612) 296-5562 (Collect)

Network from p. 1

seek out means to enhance communication, cooperation, and coordination among advocates serving developmentally disabled persons.

Feedback is vital to the process. Advocates are interested in hearing what is being done elsewhere in the state, successes or failures, innovative ideas. The central office and its newsletter can facilitate that kind of communication and linkage.

A full tally of needs replies in order of priority is as follows: public information & education, technical assistance, advocacy training, information and referral, demonstration, advocacy directory, newsletter, information clearinghouse, mini-conferences, statewide conference, evaluation, and data collection.

Informal comments accompanying the replies touched on some provoking questions: "Is the MR service delivery system overfed and underproductive?" "Are MR and MI mutually exclusive? If not, why can't I find psychiatric help for my client?" "Define advocacy. (How service providing conflicts with advocacy.)" "Provide a mechanism for complete independence from political pressure, particularly from state owned and operated state hospitals."

Advocates who have not done so are urged to become a recognized part of the informal state network by mailing in their Statement of Mutual Obligation, sent out in the July survey. This Statement outlines the concept underlying the structure and suggests the contributions both the state advocacy office and local advocacy projects might make to the network, to the benefit of developmentally disabled persons.

Need for Citizen Advocacy Grows

The success of "expressive" citizen advocacy in Minnesota may be viewed much as one does a glass of water. Depending on the perspective of the onlooker, the glass will be considered either half-empty or half-full.

In like manner, optimists on citizen advocacy in our state will point to the many alive and thriving programs as evidence of success. And pessimists will point to the long waiting lists of proteges, the inadequate list of volunteers, and maintain that things are not going too well. Both views are accurate.

Many good things are indeed going on in citizen advocacy with such established programs as those initiated by A.R.C.s (Association for Retarded Citizens) around the state, by United Cerebral Palsy, and Epilepsy leagues. Foster grandparent and senior companion programs are making meaningful changes in the lives of many developmentally disabled persons, as are Big Brother and Big Sister friendships, benefiting both

community is made easier by the presence of a friend.

Add to this population a new one, the estimated 30% of persons now residing in state hospitals who are projected to move into community residences over the next five years according to the new DPW role and function policy.

Based on Minnesota Individual Information System figures, this could be some 800 persons facing community adjustments after years of institutional living. It is not too difficult to imagine what an expressive advocacy relationship could mean to those individuals who often have no ties with a family or indeed, any person in the non-handicapped world.

The prognosis, then, is not too bright, unless a major push is made to educate the general public to the existing needs. Without public education, the funding base for programs is not likely to improve, however necessary.

The public has to know what a citizen advocate is, and what

With many programs the volunteer "friend" is asked to make a commitment of one year. Reports are that many support friendships go on for years or even for a lifetime.

Duluth A.R.C.'s enterprising, expressive advocacy program, which matches from 120 to 150 "pairs" at times, sees public education as basic to success. Staff members utilize T.V. slots, radio, newspaper ads, (free-courtesy and one full page annually), speakers, movies, brochures, hand-outs and helium filled balloons and are seriously considering the advertising power of billboards. They have made good use in rural areas of "key individual" recruitment system to recruit volunteer advocates, which relies on word-of-mouth and individual referrals.

The Duluth advocacy program has applied for an HEW grant, hoping to initiate a "family-to-family" support system, based on the premise that the entire family of a child with a developmental disability is under stress, with the

An Aim of the Minnesota Protection and Advocacy Network is to open doors of Communication . . .

the protege and volunteer.

Such positives, however, do not change the reality of the long waiting lists and the shortage of volunteers. All indications are the waiting lists are going to get longer, much longer.

The developing impetus for more semi-independent living units for persons now living too restrictively in group homes is certain to increase the number of individuals needing a one-to-one supportive relationship. The "art of survival" in the

she or he is capable of doing for another human being, often to one's own enrichment. Wolfensberger has defined citizen advocacy as a one-to-one relationship between a capable volunteer (advocate) and a developmentally disabled person (protege) in which the advocate defends the rights and interests of the protege and provides practical or emotional reinforcement, or a combination of both. Simply stated, the volunteer becomes a "friend."

marriage and all relationships affected.

An aim of the Minnesota Protection and Advocacy Network is to open doors of communication between citizen and other advocacy programs in the state for mutual sharing of ideas and resources. Technical assistance is available from the state office, located at 200 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101 (612/296-4096) (TTY No. 296-9962).

HEW Approves Duluth Legal Advocacy Funding

Word has been received from the Department of Health, Education, and Welfare that the Duluth Branch Office of the Legal Advocacy Project will receive third-year funding beginning October 1, 1979.

Earlier this year a decision had been made to withdraw third-year project funds of all Developmental Disabilities National Significance Projects.

This would have resulted in the closing of the Duluth Legal Advocacy Office which was beginning to have an important impact in Northeastern Minnesota.

The decision was reversed thanks to the many citizens in the Arrowhead Region and throughout the State who wrote letters to protest this action and in support of

the project. These many letters spurred the Minnesota Congressional delegation into action as well as educating decision makers in HEW as to the value of the project.

The Duluth office is a branch of the Legal Advocacy for the Developmental Disabilities project administered by Central Minnesota Legal Services.

Biklen from p. 1

However, he said, advocates can create their own power base to counter that of the system by cooperating with each other and coordinating activities.

Whistle blowers working within the system must know how to preserve themselves. They should record evidence of unjust practices or denial of rights, know and cite the law, make an appeal through the system and keep a record, assess who might most be affected by a change in the situation and where these people

are, and build allies and supporters within and without the system.

The present conservative political trend does not change the "rights" issue, he said. Economists must be brought into the human service field to show the rationale and economics of opening opportunities for normal living to persons who are developmentally disabled.

Persons interested in obtaining a copy of Biklen's full address may write to the Developmental Disabilities Planning Office.



Conference participants review exhibit materials

ADVOCACY DIMENSIONS

200 Capitol Square Bldg.
550 Cedar Street
St. Paul, MN 55101

Bulk Rate
U.S. Postage
PAID
Permit No. 171
St. Paul, Minnesota

Return Postage Guaranteed

Advocacy Dimensions is a publication of the Minnesota Developmental Disabilities Protection and Advocacy Network of the State Planning Agency. Staff members include:

Marylee Fithian, Director
Roger Strand, Advocacy Planner
Helen Boddy, Advocacy Intern

The staff welcomes reactions and input from the readers.
(612/296-4096, or TTY 612/296-9962)