KIDS AT CEEP

ALICE BLACKSTONE INTERVIEWS EDDIE FELIX
BARRY ROBERTS ON RESIDENTIAL SERVICES
AND MORE INSIDE...
Table of Contents

GOARC's Roots ................................................................. 1
Corporate Guardianship ..................................................... 2-3
General Membership Meeting ........................................... 3
Legal Services ............................................................... 4
Abuse at Beatrice? ........................................................... 5
What's He Do, Anyway? ..................................................... 6-7
Rights: Human and Legal .................................................. 8
In's and Out's of SSI .......................................................... 9
Help Wanted! ................................................................. 10
Spotlight on Eddie Felix ..................................................... 11-12
GOARC's Great Gunn ......................................................... 13
Moving Day ........................................................................ 14-15
Eastward Ho! ..................................................................... 16
Making It Thru Winter ....................................................... 17
Alice in GOARCia ............................................................... 18-19
Schooling for the Mentally Handicapped .............................. 20
The Residential Mystique .................................................... 21-22
A Few Words on Self-Esteem and Children ............................ 23-24
Youth: Fall In Behind New Leader ........................................ 25
A CEEP Peek ..................................................................... 26-27
Pilot Parent Banquet ........................................................... 28
Looking Forward ............................................................... 29-30
Letters To The Editor ......................................................... 29-30

INSERTS: GOARC Awards Night Nomination Form
Booklet: SSI For Retarded People

GREATER OMAHA ASSOCIATION
GOARC
FOR RETARDED CITIZENS

Cathy Campbell, Editor
3812 Dodge
OMAHA, NE 68131
(402) 348-9220

Ed Sharnulis, President
Perhaps much more than any other organization, the Greater Omaha Association for Retarded Citizens has had a history of grass roots activism, a history of involving numerous people to do a variety of tasks for the purpose of improving the quality of life for mentally retarded persons. When one thinks of GOARCs beginnings one must think of the parents. It was parents who volunteered without recognition. Parents whose concern went far beyond their own child to encompass other children. Parents who weren't afraid to speak out for what they believed. One thinks of parents who worked tirelessly to begin the Omaha Opportunity Center, one of the first direct services in the city for mentally retarded children who were denied public education programs. In Bellevue, CHAP (Children Have A Potential) began as a counterpart of the Opportunity Center.

I find it easy to mull over GOARCs history because 1978 marks the 15th year of GOARCs existence. During those years GOARC has experienced many phases. At one time GOARC was providing direct services to several hundred mentally retarded children and adults in a variety of innovative community-based programs. The staff was approximately 100 persons. Since the early 1970's, GOARC members have been active in different forms of advocacy. GOARCs volunteer structure has also changed over the years. There have been numerous committees, some of them ad hoc and some of them long term. These groups were organized around specific concerns to better the lives of mentally retarded persons.

Some GOARC members have a greater sense of our history than others. Among us are parents, professionals, and interested citizens who remember the early formative years of the Douglas/Sarpy Counties Association for Retarded Children. They remember the planning of the very active years of the late 1960's and early 1970's and the services that came from it. Since then, they helped describe what advocacy roles GOARC would be taking throughout the 1970's.

It is GOARCs anniversary. Since in that short period of time many memorable things have happened, I am appealing to members who have experienced GOARCs history to come forward so we can record those events for future members. I'm sure that some of you have pictures of our past that may be of interest. Bits and pieces of historical knowledge about GOARC exist that would be advantageous for us to preserve.

May 9th is GOARCs Awards Night. Numerous GOARC members will be recognized for their volunteer efforts in various categories. On that evening we will also be celebrating our first 15 years together. Many members could contribute to telling GOARCs story that night. Please call and share your part in that history.

Tom Miller, Executive Director
Several requests have come in for GOARC to become corporate guardians for mentally retarded persons when the parents are no longer able to do so. If we provide such a service we want to do it right and it should be available to all who need it. This subject is being discussed now by our Board and we would like thoughts from the membership-at-large. Here are some things to consider:

**PRO**

1. It would be a way to answer the age-old question asked by parents: "What happens to my child when I'm gone?"

2. It could relieve brothers and sisters (and other relatives) of responsibility for their mentally retarded brother or sister.

3. What people or agency would be better qualified or more trusted to watch over the welfare of mentally retarded children or adults than other GOARC parents?

4. It could enable mentally retarded persons to remain eligible for public agency benefits (ENCOR, Welfare) if insurance policies, trusts, etc., were in GOARC's name.

**CON**

1. It does expose GOARC to some risks that won't be known until we can get some attorneys to advise us.

2. It will require volunteers or staff to personally be involved with the mentally retarded child or adults. Someone will have to watch finances, living situations, food, clothing, etc.

3. It still will cost GOARC money to retain attorneys, figure out how to serve people who cannot pay for the services, etc. Where will we get it?

These are just a few of the things that come to mind. Let us know what you think.

**A FINAL WORD (AT LEAST FROM ME) ON COUNTY HOSPITAL**

My somewhat facetious proposal for returning 250+ of our friends and neighbors to their hometown from Beatrice, by converting Douglas County Hospital into a temporary holding facility generated more interest than I've seen around here in a long time.
PRESIDENT'S ARTICLE (cont'd)

It resulted in some constructive criticism of the idea, provided an opportunity for people to re-affirm their beliefs, and for this I'm grateful. There were a few of the predictable petty remarks, like: "Well, you know of course that Skarnulis used to work in an institution." But by and large the response was: "I may not agree with what you say, but I'll defend to my death your right to say it." And that my friends, is healthy.

NEW FACES NEEDED

I was happy to see more than 80 people at the General Membership Meeting in January. It was a below zero, cold, blustery night so the response was especially good. I also think that, in spite of some provocative remarks from one of our guest speakers, we "comported" ourselves admirably. But we need to get more guests and new members to these meetings, and we need more parents there. When it comes to recruitment there's simply no substitute for personal contact. Bring a friend, co-worker, or relative to the March meeting -- the warmth and enthusiasm of GOARCs members will do the rest!

Ed Skarnulis, President

General Membership Meeting

THURSDAY, MARCH 2, 1978
7:30 P.M.
FIRST FEDERAL OF LINCOLN
2101 South 42nd Street

PRESENTATIONS BY: Dr. Owen Knutzen
Superintendent of Omaha Public Schools
Pilot Parent Program
"What's New For 1978"
January 31, 1978, marks the end of the Legal Services Project for the Mentally Handicapped. It is therefore with a sense of sadness that I write this article. I was asked to write about the Project and its accomplishments, and this I shall do, but only briefly. Instead, most of what follows are reflections on legal advocacy.

The Project's accomplishments have been small. Most of those persons involved with the Project at its beginning envisioned important law suits with great precedent-setting value. For whatever reason, this vision was not realized. Almost all of the Project's cases involved somewhat minor legal disputes. But many people were helped on this individual basis.

It has been questioned whether there was a need for the Project, since most of its cases did not require any expertise in mental disability law and therefore could easily have been handled by Legal Aid and private attorneys. When the Project first began, I was firmly convinced that there was such a need; now, I do not know.

I am, however, convinced that there is a need for more legal advocacy - advocacy which strives to enforce and protect the legal rights of mentally retarded persons - which is practiced by parents, friends, mental retardation professionals, and mentally retarded persons themselves. This is not said in derogation of the role of the legal profession. Obviously, there are many occasions when only an attorney can effect the enforcement of a legal right. But the sole responsibility for asserting the legal rights of mentally retarded persons cannot rest in the legal profession. Professional legal resources are simply too limited.

Parents, friends, mental retardation professionals, and mentally retarded persons must recognize that without their legal advocacy efforts, the legal rights of mentally retarded persons will frequently be denied. These persons have a responsibility to become knowledgeable about legal rights, to carefully monitor service providers, to strenuously assert the legal rights of mentally retarded persons when there is the slightest indication that such rights are being abridged, and, finally, to seek the assistance of others (including attorneys) when necessary and appropriate.

Christine Smith
Her hands were tied together with the strings of an institutional diaper. The strings on the other end were tied around a bathroom stall support. She was about 15, thin with messy hair, several bruises, no speech. At the time she was residing in Building C, Unit 3 at the Beatrice State Developmental Center.

Karma Sparks, a Beatrice ward attendant from August 22 to December 20, 1976 was recalling this moment and others as a part of her testimony in federal court before Judge Albert Schatz. The hearing, which began on December 5, was called at the request of the plaintiff and plaintiff intervenor to decide whether the Agreement entered between the parties in 1975 had been violated by the defendants.

Karma is now a resource room teacher in a Montana elementary school. She returned to testify regarding several instances of brutality of Beatrice residents that she observed. The one listed above was observed twice. On the second occasion the staff member who tied the resident into the bathroom stall was observed saying, "Get back on the toilet" and kicking twice toward the resident.

On another occasion, in December 1976, Karma testified that the same staff person gave her a board as she was leaving and said that she was going on break, to take the board and hit them if they gave Karma any trouble. She left saying "that Karma would not have to hit them, just wave the board in the air and they will know what it means".

Ms. Sparks testimony included similar incidents in cottages 414 and 415. She also testified regarding several occasions when she was, at night after the residents had gone to bed, directed to fill in program books as if the programs had been run.

Admitting that she did not report each incident to the administration, she then told about complaining to a woman in the Personnel Department who said, "All I can do is sympathize with you". With that Ms. Sparks resigned.

The hearing before Judge Schatz is not yet complete. It recessed on December 13 until February 6. The main witnesses on behalf of the plaintiffs have been presented. Bruce and Annette Mason did an excellent job of preparing and presenting Phil Roos of the National ARC, three current Beatrice employees, a State Health Department employee, and a former Hastings Regional Center employee.

Additional witnesses have now been presented by the United State Justice Department including Jerry Griepentrog, Ms. Sparks, Linda Glenn, and Jerry Nedrow.

During the recess Kevin Casey and Mr. Griepentrog, at the direction of the attorneys, are attempting to develop a process which would by the end of the year result in an acceptable Plan of Implementation.

Dave Powell, Executive Director of NebARC

(For additional discussion on the first week of the hearing, see FOCUS on Mental Retardation, January, 1978).
After three years and three months, the ENCOR/GDARC Ombudsman position ceased to exist on October 1, 1977. In the place of the former ENCOR/GDARC Ombudsman position now stands the Developmental Disabilities Ombudsman Program which is funded by GDARC and the Nebraska Developmental Disabilities Council for a one year period ending September 30, 1978.

The Developmental Disabilities Ombudsman has been established to provide for the adequate, appropriate, timely and effective protection and promotion of the human, legal, civil and service rights of persons with developmental disabilities (epilepsy, cerebral palsy, autism and mental retardation) as citizens of this country and this state. The primary service area is the five county area consisting of Dodge, Washington, Cass, Sarpy, and Douglas Counties.

The primary consideration for the Ombudsman is the welfare of citizens with developmental disabilities. The Ombudsman's only sanctions for intervention are demonstrated consumer need and consumer requests for assistance.

The Ombudsman receives and responds to individual contacts (complaints, requests for assistance and information, etc.). Individual case contacts should be used to support change efforts that aim at improvements of a general nature and contribute to the development and improvement of systems affecting developmentally disabled persons as a class.

Any individual may contact the Ombudsman on matters involving the human, legal, civil, or service rights of developmentally disabled persons. Upon receipt of a contact (complaints, requests for assistance, consultation requests, etc.), the Ombudsman:

- Seeks to obtain documentation necessary to pursue a resolution to the contact.
- Determines the action which appears to be most necessary and/or appropriate for the contact.
- Provides (for) that action which appears to be most appropriate and/or necessary for the contact.
- Follows up on the action taken for the contact in order to determine the effectiveness of the action taken and, as necessary, provides (for) additional action on the contact.

Insofar as the law will allow, the Ombudsman holds the identities of contacting parties as confidential. On those occasions that confidentiality might serve as an obstacle to achieving a resolution, the Ombudsman may remove confidentiality but only after the possibility of removing confidentiality has been discussed with the contacting party or parties.

The Ombudsman, on the basis of observations, informal notification of concerns, identification of patterns of problems, etc., may initiate action on his own (Independent Action).
The Ombudsman monitors, and advocates for, the adequacy, appropriateness, responsiveness and quality of services delivered to developmentally disabled citizens by visiting services, maintaining communications with consumers, advocates, service providers, etc., and reviewing plans, proposals, and programs relating to services provided developmentally disabled persons.

In addition, the Ombudsman:
- Provides for education regarding the rights of developmentally disabled citizens.
- Provides assistance and serves as a resource to personal advocacy programs throughout the State of Nebraska as requested.
- Coordinates and cooperates with the Nebraska Developmental Disabilities Protection and Advocacy Agency and system mandated by federal legislation (P.L. 94-103, Section 113).

The Ombudsman is restricted to the "powers" of inquiry, notification, referral, inspection, criticism, persuasion (negotiation), reporting, publicity, and recommendation.

To date, sixty-two contacts have been made with the D.D. Ombudsman Program:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>4</td>
</tr>
<tr>
<td>Dyslexia</td>
<td>1</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>2</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>1</td>
</tr>
<tr>
<td>Hearing Impaired</td>
<td>1</td>
</tr>
<tr>
<td>Mental Retardation and Epilepsy</td>
<td>5</td>
</tr>
<tr>
<td>Mental Retardation and Cerebral Palsy</td>
<td>3</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>29</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
</tr>
</tbody>
</table>

Remaining contacts consist of requests for assistance, requests for consultations, information requests, etc., that do not involve individual consumers. Issues that have been received include: abuse, neglect, sexual exploitation, employment discrimination, denial of medical services (discrimination), housing discrimination, and denial of educational services.

Developmental Disabilities Ombudsman - Carl V. Sullivan
Deputy Developmental Disabilities Ombudsman - Michael R. Curue

Carl Sullivan, Developmental Disabilities Ombudsman
At the November meeting of the General Membership I was approached by Ed Skarnulis about assuming the chair position of Human and Legal Rights and Legislative Action. Since I have always been very vocal in professional circles about the way things "should be" and so I was immediately interested. I spent December (before the holiday rush) talking with Tom Miller about how the previous committees had functioned; Carl Sullivan about his perceptions, recommendations and priorities as well as several other committee chairmen in this case. I was also approached at this time about considering a Board of Directors position. I was pleased that my professional efforts at individual and systems change agentry were in a sense being acknowledged while at the same time I was amused that all this attention should occur now that my membership was up and I was having to consider re-activation!

Now that I am a Board member it is even more important to meet all GOARC members so that I can get to know and represent your views and priorities. I strongly believe that unless every person in our general membership is aware of our actions as an agency and believe in the underlying philosophical concepts, we are not reaching our full potential. Through this monthly column I hope to educate everyone in some aspect of Human & Legal Rights as well as to let everyone know what activities our committee has accomplished and to constantly recruit new members.

I consider myself to be a strong independent woman with a lot of energy and a varied background from which to draw a great deal of strength and experience. As well as being a professional in the field of developmental disabilities, I am preparing to become a foster and eventually an adoptive single parent of a delayed child.

In order for this committee to accomplish its goals, all of our membership must be educated in the goals and philosophy as well as aware of the current activities underway. I need 25-30 people interested in volunteering 6-8 hours per month to concentrate on an area of interest (pre-schools, schools, medical services, portrayal in the media, ENCOR, institutional confinement, guardianship, employment, etc.)

The February meeting will be held on Tuesday, the 28th at 7:30 P.M. The place is to be decided. Please call the GOARC office (349-9220) to get your name on the committee list. A packet of information will be provided to you as well as a tentative agenda prior to the meeting.

This committee is crucial to the purpose of this agency but it can ONLY WORK IF YOU HELP!

Jamie Kelley
Many parents have expressed their frustrations in getting correct information on the eligibility requirement for SSI and the information about their child or family income they should bring when they are applying for services.

A meeting was held with officials at the Social Security Office to express these concerns and receive clarification on the information provided on page 6 of the attached booklet, "SSI For Retarded People." This booklet was provided by the Social Security Office "to distribute" to the membership.

Social Security cards: Each person applying for SSI will need a social security card. You will not be denied an application if you do not have one for your child. The application process will be slowed down until you receive one.

Birth Certificates: If you do not have a birth certificate, you may still apply for services. There must be some proof of age. Again, application process will be delayed until proof is provided. If a parent cannot afford to purchase the certificate, the Social Security Office can refer the family to an appropriate source for the certificate.

Records: Bring with you a list of doctors, clinics, schools, or names of other persons who have had contact with your child. The Social Security Office will write to these individuals, with your permission, to obtain the information they need to process the application.

The term "applicant" refers to the handicapped child or adult. "Ineligibles" refers to other children in the family who are not handicapped.

The attached sheet "Basic Eligibility Conditions for Children" is provided for your information on income guidelines. It is important that you contact the Social Security Office to determine if you meet the eligibility requirements.

The Social Security Office can also take an application over the phone, if the parent or handicapped adult person is unable to come to their office. An application for SSI is filed at the Social Security Office, 215 North 17th St., or telephone 221-3771.

What's Cookin'?  

"SPECIAL EDIBLES" (120 pages of recipes, hand-transcribed by the students at the Westside Learning Resource Center at Arbor Heights.) These recipes have been prepared and served by the students for special occasion meals at the Center. The cost is $3.50 (including postage) or $3.00 (if not mailed). If you are interested, call 391-2332 - Westside Learning Resource Center to reserve your copy.
Help Wanted!

Recent MAKING MILLION DOLLAR DECISIONS
Focuses every two months on the life of a local advocacy association. GOARC Gazette Editor reviews submitted articles, decides on priorities, and develops layout. Requires some free time, but not too much. Call Tom Miller, GOARC Director, 348-9220.

INVESTMENT GROUP COUNSELOR Parents, professionals and interested citizens investing time and energy in local advocacy group. Need leaders to guide committee active on behalf of mentally retarded citizens. Committee chairman positions available. Contact President-Ed Skarnulis, 541-7903 or 348-9220.

COMMUNITY CONSCIENCE Human and Legal Rights Committee needs members to prod service agencies to actually provide the quality of services they have promised. Requires highly conscientious individual with thick skin. Must be able to look at services and evaluate them from the viewpoint of client or student needs. Prefer applicants who can listen well. Call Jamie Kelley, Committee Chairperson, 351-4073 or 391-4780.

RECRUITER Join GOARC and see the world at least, see it in a new light. New members will find this opportunity largely through the enthusiasm of current active members. Dreams available to be developed into a reality of good things for mentally retarded citizens. Recruitment Committee has been formed for true believers to organize this effort. Call Dan Mcgee, Membership Support Team Leader, 541-7928 or 348-7487.

PHOTOGRAPHER Youth activities wait to be skillfully captured on film. The GOARC-Youth needs photos for public awareness projects. People experienced or interested in publications or media call: Bev DeMey, Youth Public Awareness Committee at 391-7499 or Robert Coleman, Membership Development Coordinator 348-9220.
Eddie Felix is a mother who believes in "Parent Power."
What Eddie preaches, Eddie practices.
She speaks out for causes she knows won't win her a popularity contest.
She attends meetings when she'd rather play Bingo.
She refuses to slack off when the going gets rough.
She's happy when she gets services for her own son but bothered when she knows other kids aren't getting help because their parents won't push.
She wants productive participation, not token involvement of parents, including members of minority groups.

To tell it like it really is — she is (or was) so busy advocating for the mentally retarded she failed to catch on that GOARC was about to name her "Volunteer of the Year" at their Annual Awards Night last May.

A mother of five, it's not easy to give so much time to working for the retarded. Despite a staggering load, Eddie maintains a lively interest in her four normal children. When she says "All my children are important to me," she's not just mouthing words, she's busy by illustrating action.

"It's a lonely life," she confided, "trying to understand how to help a mentally retarded child. But I guess I've always been a complainer. If I've got a problem, I'm going to be sure somebody listens one way or the other."

Why don't other parents speak out?
Eddie suspects many don't know where to go or what to say. Others believe no one will listen; others don't realize their children aren't getting what they need.

Frustrated by her role as GOARC representative to the Advisory Committee on Special Education to OPS (Omaha Public Schools), Eddie thinks the basic idea is good. "A lot of parents will talk with other parents but not with professionals," she says. Direct communication between parents and their representative and then through the representative to the OPS administrators, would relieve the bottleneck.

Critical, but not pessimistic, Eddie says she will continue unless she's replaced.
A first-time member of GOARC's Board of Trustees, she asks: "Where are the Indians? The Mexican Americans?"

"Just because I'm black doesn't mean I can represent everybody out there. Some
SPOTLIGHT ON EDDIE FELIX (continued)

blacks have problems a lot different than mine. People assume if you're black, you know every other black. That isn't true. No one can represent a large segment of people."

She looks on GOARC as a monitoring agent. Wise in the weaknesses of volunteers, she understands that some fail down on the job. Nevertheless, she thinks every effort ought to be made to effectively monitor the quality of services available to the handicapped, especially ENCOR and OPS.

"Every parent wants his kid to become as self-sufficient as possible," she says, referring to the older children in OPS. "One of the hardest things is wondering what your child can do when he's finished at OPS." As a member of the Education Advisory Committee to ENCOR's Five Year Plan, she would like more emphasis on programs for the adult handicapped. Preschool education is only part of the program.

For Eddie, Pilot Parenting other black parents makes sense. "In most cases," she says, "the blacks are more eager to communicate with other blacks." Parents helping other parents is a very important service in her estimation.

Work done on the Committee of Poverty and Mental Retardation on which she serves is also important. Getting information to low-income parents and holding meetings at convenient locations is helpful. She thinks the Committee would benefit from greater variety of minority-group membership as well as low-income whites.

Her soft voice grows softer as she talks with pride about her children.

"They all love school," she says. "Keeping them home when they're sick is a real problem."

Ronald, 17, a student at North High, loves basketball and usually has an outside job in addition to keeping up with his school work. Cheryl, 15, chose being bussed to Burke High; Lisa, 14, attends Nathan Hale. Andre, 13, mentally retarded, began at Project Chance and is now at Hartman.

Eddie's eyes took on a give-away-sparkle as she mentioned Dennis, 11, a student at Castellar.

"Dennis, the Menace?" brought a laugh.

"He's always into something. Last week he decided to run away, but he came back in a little while. I guess he decided home wasn't so bad after all."

Summers, she and the children love to go fishing—"anywhere there's a hole in the water."

Asked about the future, Eddie seemed to find her answer in the past.

"When they told me my son was retarded and that I should put him in Beatrice, I didn't know what I would do. I just knew I wouldn't do that. I really don't know what I'll do when he's finished at OPS. I just know I'll do everything I can to keep him from sitting at home."

Alice Blacks tone
I am thankful I have a job and an opportunity to learn new things. Without ENCOR, I would not be here today. Roger Gunn has made those statements many times and those who have met him know he means every word. "Thankful"? Yes, but not passively so. Roger is a very active participant and strives to be his own advocate.

Although he is a quadraplegic and is almost totally dependent on others for physical needs and assistance, Roger is one of the most active employees at the Bellevue Industrial Training Center. Even with the very limited range of motion of his arms and hands Roger has mastered almost all of the contract work which has gone through the center. He accepts his physical handicap, which would be unbearably frustrating to most of us, as a minor problem which can be overcome with perseverance, hard work, and creative thinking.

Those who work with Roger have learned not to underestimate his abilities or potential. He actively participates in his own Industrial Program plan meetings by reviewing his own progress, setting his own goals, and presenting them to the IPP team. He states, "I have made good progress since I started at the Bellevue ITC and have met all my goals". He is quite proud of his accomplishments and wants to do and learn more.

Since starting in the ENCOR program in 1975 Roger has been very active in local organizations and in bowling. He is the consumer representative for the Sarpy County Chapter of GOARC and on the ENCOR 5 Year Plan Recreation Committee and is primarily interested in solving the transportation problems for the handicapped. He is past president of the Bellevue ITC Employee Union and was quite outspoken in representing the wishes of all the employees. He won GOARC's Membership Drive Contest by soliciting the most new members to include the Mayor of Bellevue. He participates in a bowling league in Bellevue and has won many trophies for his bowling skill to include a first place trophy in the International Handicapped Bowling Tournament. One of his most cherished achievements was being chosen as adult with the most progress at last year's GOARC Awards Night.

Roger spent most of his life in institutional settings and knows quite well how one with his kind of handicap can be overlooked and ignored. Now he is experiencing a great deal of personal growth and self actualization and won't allow himself to be put away and ignored. He continually advocates for the rights and interests of others and is very well liked and respected by those who know him. Roger states, "If people would wake up and give the handicapped a chance it would be a better world for everyone".

Roger has shown us all that physical or mental handicaps do not have to stand in the way of living a full, interesting and productive life.
MOVING DAY

PHOTOGRAPHY BY:
PAT HENRY

Almost like the Marines planting the flag at Iwo Jima, a gang of volunteers struggle to stand a tall file.

Tom Miller is on an end of a desk, and it must be the heavy end.

At Right: Office furniture rolls with the help of a dolley and Norm Stava.
Swing For The Retarded provided a truck and three generous helpers: Ted Haines, Chuck Shanahan, and Don Sorensen.

Below: Gene Smith, whose mother directs Pilot Parents, negotiates the last doorway at the old office.

Larry Davis brings 3 cases of lunch.

Dan Mcgee (below) complains that he usually is doing something else this early on Saturday mornings.

With a shoulder into a heavy load and feet on slipping ice, Don Grimm moves carefully.
EASTWARD HO!

At Right: Ruth Thode, GOARC, checks out new office.

No longer will the GOARC office be found next to a world famous restaurant (with golden arches). As of February 4th, there will be no such thing as the GOARC basement to meet in. GOARC is moving East.

The lease was up for renewal at the South 40th Street location. Several added staff members couldn't be absorbed into that space without extensive renovation. No agreement could be reached with the landlord to bring up the office to an attractive and useful location.

A long search began for an alternative. A West Omaha location had many things to offer. But the Executive Committee insisted on remaining in the Central area. As an advocacy agency, GOARC would remain close to all segments of the community, particularly those generally hampered by lack of transportation.

GOARC will need to invest in changes to the building to enable access by physically handicapped members and visitors. Plans have been developed to ramp the front entrance and provide a bathroom that is barrier-free.

Look for GOARC on Dodge, across the street and just east of Mutual of Omaha. An Open House is planned as soon as all is in order. Plan to come then, or any time before, to see your office.

TAX TIME

The National Association for Retarded Citizens has provided a summary of tax rulings that relate to mentally retarded persons and their families. It deals with earned income credit and with deductions for fee schedules, transportation, medical expenses, and the like. Would that be helpful right now? Call GOARC at 348-9220, and ask for Pat Henry.
Hundreds of birds gathered at the bird feeder of the Fontenelle Forest Nature Center for Sunday dinner. Among the other creatures was a large flock of GOARCs Youth. A volunteer naturalist offered to let everyone handle one of the large snakes. But some grew reluctant when he turned and asked another employee "Which of these snakes is it that doesn't bite?"

The GOARC-Youth meet regularly, sometimes to hike. It is an integrated group of adolescents, some having problems with mental retardation and others who don't. Winter is here for a few months but they still find imaginative things to do. Jill Nagel (330-4327) is the youth leader for activities. Call, and come along.
CINDI RAY SPELLS MONEY

An old-fashioned spelling bee for third and fourth graders at Waterloo, Bennington, and Springfield elementary schools in mid-December raised $1,400 for GOARC.

Cindi Ray, a fourth grader at Springfield, spelled 38 words and won the grand prize - a ten-speed bike.

"I really wanted to help the retarded," Cindi said, "but it was exciting and fun too." A "go-getter", she enrolled 25 sponsors.

Her teacher, Mrs. Fern Hlavac, said the children used a Thanksgiving theme and focussed on being grateful.

**

ALLEYS CONCENTRATE ON PIN MONEY

Posters at Vinton, Skylanes, Kelley's North, and King Louie Rose Bowl attracted about 40 teenage bowlers to raise another $1,500 for the GOARC general fund. Ten-speed bikes were awarded to the top four and smaller prizes to others.

**

HODEN LIVES THINGS UP IN IOWA

Don Hoden of Council Bluffs, an active member of Pilot Parents recently was appointed as a member of the Special Education Advisory Board for the State of Iowa. If Don has his way, handicapped children will be getting ahead instead of falling behind come next Summer. Summer school, he thinks, would do just that.

**

POVERTY AND MENTAL RETARDATION COMMITTEE PROVIDES ANSWERS

On January 25th, the Committee presented panel of representatives from agencies who serve mentally retarded adults 18 years or older. Agencies represented were CETA, Nebraska Vocational Rehabilitation, ENCOR, and OPS.

**

PROJECT II IS ON THE MOVE

July 14 and 15 will be red-letter days for Project II when they launch the first state-wide convention for the mentally retarded. A poster designing committee and speakers' bureau, are just two of the enthusiastic groups getting ready to spin into orbit.
KATHY JOHNSON TRIES OUT SHOES FOR FIT

Recently appointed GOARC's Citizen Advocacy Coordinator, Kathy is busy pre-piloting a program to find out for herself how advocacy works. For a short while, before the Committee gets going, she plans to spend time playing the advocate's role with a variety of clients.

GOARC PEOPLE LIVE IT UP

Wine and cheese parties flourish among the faithful GOARCians. No wine turned up on December 4th at Pilot Parents Annual Children's Christmas party at St. Paul Methodist Church, but Santa was there, a puppet show and Jodi Derby brought her now famous big cheese balls for those who couldn't indulge in cookies. Word spread to her Mother who arrived with two handsome Christmas Gingerbread Houses. Wish I'd been there, don't you?

Project II had a Christmas Dance. Inez and Harold Edwards won the dance contest again. Those of you who got left off the list, please forgive. Just concentrate on remembering what a good time you had and remember, in GOARC, there's always another party just around the corner.

PILOT PARENTS KEEP PRESSES ROLLING

An attractive new blue on white Pilot Parent brochure is ready and into circulation. As usual, the photography by Robert Coleman is a come-on.

Fran Porter's Training Manual for Pilot Parents has made it up to Bob Perske who is editing it and writing the introduction. Dr. Frank Menolascino will write a cover page and see that they go out to 50 State ARC's as gifts. Fran will be famous, Pilot Parents will be famous (Omaha variety) and Omaha will become even a brighter spot on the map.

BIG DAYS AHEAD FOR PILOT PARENTS

February 25 and 26 is the date for the 4 State Area Pilot Parent Workshop. Not enough room to give you the low-down here, but Patty Smith will fill your heads with details and your spirits with enthusiasm.

HAVE HAMMER WILL TRAVEL: The rough spots remaining at the new GOARC office would soon fade away with help from a volunteer practiced in 'around-the-home' carpentry. Would you be willing to put your skills to work for all of us? Please call Pat Henry at 348-9220. Thanks!
Since the time we were told of our son's mental handicap, I have heard the terms "educable and trainable." He was eventually put in the trainable class of the Omaha Public Schools, while other children were placed in the educable classes. I always wondered how much difference there really was in the two... after spending two hours in Val Kessinger's class I found out there is a lot!

Val teaches the TMR-EMH Transition Program at Columbian Elementary School. There are two such programs in the Omaha Public School system...Columbian and Sherman. It is a three-year transitional program for the children from the Trainable Mentally Handicapped program who show academic ability, and for other special education children who need more of the individualized curriculum. Mrs. Kessinger said, "It's like a country school because I have all grade levels. My ten students range in age from 6-12, so you can see that it's necessary that each one has individual attention." During the day the children are mainstreamed to regular classes with their age peers for physical education, music and art.

Four of the students came to Columbian from a TMR program a year ago and have all shown exceptional progress in reading and spelling. Mrs. Kessinger said that one of the boys entered a third grade spell down and did very well. She has one little boy who had been to kindergarten but didn't know the alphabet and just couldn't keep up with the rest. He is now able to count to 100 and write his name.

During my visit, the thing that impressed me the most was how well the students worked on their own, without supervision. Some were reading into a tape recorder, others were filling out a workbook, and the two youngest boys were using the vox-con, a special hear and see recorder.

The biggest difference between EMH and TMH is that the trainable classes teach functional academics while the educable program teaches academic subjects such as reading from books, math, and spelling. Mrs. Kessinger said the children learn phonics and can spell many words just by sounding them out.

The program for Educable Mentally Handicapped is coordinated to serve the needs of students who cannot meet the demands of the regular curriculum and schedule for the entire school day. Parent involvement is a very important part of this program, as they are included in the planning of their child's curriculum. Each child's future placement will be determined at an annual review, with supervisors, teachers and parents contributing to the evaluation.

Jan Novicki
The Residential Mystique

President Carter made one of the more significant statements of his admin- istration some months ago when he stated that most current Federal approaches to social problems tend to weaken or penalize rather than support strong family structures. While various welfare programs are the most infamous examples for the general public, the same tendency pervades many local and state as well as Federal programs to assist the mentally retarded. By their nature and history, residential services present the most delicate and difficult challenges in maintaining healthy family systems while delivering needed services.

INSTITUTIONAL PLACEMENT represents the greatest disruption of the retarded person's role in a family system by removing him or her from both home and community. To the extent that they maintain a person in the community with easy and regular access to the natural family, community alternatives are certainly an improvement. Yet improvement often blinds us to underlying assumptions and omissions which we should question and correct before concluding that we have done our best. In the case of residential services we continue to assume that only specialized staff and facilities can successfully manage sophisticated or complex developmental needs, while our services to families omit many of the very supports which make successful management possible in a residence. Thus I see great danger that systems of community-based residential services, as progressive as they are, may perpetuate the "residential mystique" of the institution.

HOW DID WE ARRIVE at the curious delusion that the mentally retarded are by definition better off away from home and family? Dr. Wolfensberger, in his brilliant paper, "The Origin and Nature of our Institutional Models," traces clearly the development of residential facilities for the retarded from small, special boarding schools to giant warehouses for segregating "the unfit". Part and parcel of the notion of mental retardation as a menace to society was the false conclusion that most retardation resulted from "bad genes," thus making whole families suspect in professional eyes. While enlightened persons have long since abandoned the genetic alarm, biased interpretations of other data are still used to justify removal of retarded persons from home. For example, the concept of "cultural-familial" mental retardation, while slippery and probably overgeneralized, does describe some real situations in which lack of developmental stimulation leads to retarded intellectual development. Professionals, however, tend to use such evaluations as pretexts for placing persons away from home rather than as indications for special assistance to families.

To be sure, WE NEED AN EXTENSIVE SYSTEM of alternative residences in our community both to serve persons from the institution, most of whom cannot return to their families, and to serve persons from the community who are endangered by abuse, neglect, rejection, or situations of overwhelming need beyond any one's control. But few of these situations develop so rapidly that we have no inkling of trouble before a crisis forces residential placement. More often community services (of which ENCOR is only one) accumulate long histories of problem incidents and pressing needs which neither case workers nor the family
can handle alone and for which no other resources are provided. The family, who earlier may have wanted very much to stay together, wears down over months or years to the point that placement of the retarded person away from home appears as the only alternative. Once the person is placed in a residential facility, many of the same training, staff and material resources which were identified as needs but unavailable to the natural home are employed by the services system to serve the retarded citizen in the system's facility.

Eventually then, THE SYSTEM DOES RESPOND TO PREVENT institutional placement but only after needless and expensive delay. Small problems identified early must fester and grow into major crises costing much time and everyone's mental health. Institutional residents must wait still longer to come home because crises in the community fill residential places meant for them. Willing parents, rewarded by love, are replaced by paid employees. No one, parents, professionals, or retarded persons, plans or wants such chaos but the residential mystique, the idea that retarded citizens do better under constant professional care, feeds on itself in a vicious circle. Lack of resources for families leads to crises which lead to residential placements which lead to commitment of more resources to more residential placements and even less to families.

This gloomy state of affairs NEED NOT CONTINUE FOREVER IF we begin to test the residential mystique by placing similar resources at the disposal of families. In the next issue I will suggest some ways we should try.

Barry Roberts

---

NEBARC AWARDS

This is the time of year to think about those individuals who have done outstanding things to better the lives of mentally retarded persons. In this Gazette, there is a form to nominate individuals for GOARC's Awards Night which will be held at the May 9 General Membership Meeting. This is also the time to begin thinking about individuals who are eligible to receive awards from the Nebraska Association for Retarded Citizens. The categories that NebARC has this year are Special Education Teacher of the Year, Citizen of the Year, Organization of the Year, and Employer of the Year. If you are aware of anyone who you would like to nominate in those categories, please call the GOARC office for a nomination form.

All nominations must be in NebARC's Western Nebraska Office no later than February 17. So, please call us as soon as possible with those persons you would like to nominate.
"Low self-esteem": we use the phrase often to describe a common problem people have. We use it to describe both cause and effect, which is, I think correct: low self-esteem predisposes a person to failure, an experience which consolidates the negative self-concept. There are people who believe low self-esteem can be reversed if you read their books: How To Be Your Own Best Friend, Your Erroneous Zones, How To Be The Person You Were Meant To Be and so on. Maybe, maybe not. But these writers seem to have fastened on a basic truth, that high self-esteem is a basic key to one's happiness, productivity in work, and success in relationships.

Nevertheless, there is a scarcity of material designed to tell parents how to encourage high self-esteem in their children. Surely it would be better for the child if we saved him from the mental habit of self-devaluation in the first place; parenthood would be an easier, less stressful and more fulfilling state besides. Nevertheless, high self-esteem is seldom addressed as a goal for parents and teachers. We speak of maximizing intelligence, motor skills, and social adaptability, but we seldom approach self-esteem in that spirit. Dr. Spock and company no doubt would expect high self-esteem to be a residue of good parenting, but they don’t address it directly. Perhaps because self-esteem is less measurable, both cause and effect, an element that depends much more on other factors, we overlook it as a quality we want our children to have. And surely we want them to value themselves, for whatever their “objective” qualities—their intelligence, skills, talents, looks, and limitations—they cannot and will not do all they are capable of unless they recognize their resources and value them.

One aspect of the self-esteem system is body image: a child must, over the years, learn to accept his or her body and like it. I think parents can draw two ideas from this: 1) The child’s need for much affectionate touching, hugging and contact: low self-esteem predisposes a person to failure, an experience which consolidates the negative self-concept and 2) The child’s need for physical exercise—sports, dance, gymnastics, swimming, games. The body is the place where each of us lives. To the extent that one feels that his or her body is good, comfortable, attractive, capable of meaningful action, one’s capacity for self-esteem is deepened. Our bodies in a sense “remember” early parental affection in a basic way our minds cannot. Even without the findings of research, we know that boys and girls are treated differently in these areas. Male children are touched far less frequently than female children; boys are encouraged to develop physical grace, skills and strength while girls are not. Would men be better fathers, husbands and persons, would they have less need for praise and admiration if they were affectionately touched as children? Would women be more secure in their grace and physical presence, more confident and assertive, if they had experienced their bodies in childhood games and sports? I would guess yes on both questions.

One way to estimate one’s self-esteem is to review one’s childhood “do’s and don’ts”, “shoulds and musts,” and to listen to those subconscious messages and evaluations and predictions we tell ourselves in times of stress. The person with low self-esteem, for example, is constantly hearing “You won’t make it. You fall short. You will fail short again,” and hence prepares himself for defeat or for excusing himself without trying. Children hear these messages, too, and since they will inevitably fail or fall short on some things, parents should try to help them gain a realistic notion of their strengths and weaknesses. High self-esteem is based on all not on blind arrogant faith, but on a realistic and useful trust in their own capacities and talents. An optimistic willingness to test them
Further, parents should avoid transmitting the negative estimates of the child that one is apt to use in anger. Particularly in disciplining the child, by being very angry, the parents tends to shift the focus from the act to the child. Instead of learning that he should not break his toys, the child learns that he is "always such a rotten kid." A sentence like that, engraved in the child's memory by the parents' dramatic anger, can linger a long time in the subconscious mind and can condition him to a negative self-esteem.

One research psychologist, after studying low and high self-esteem children, found some interesting associations between the children and parental practices. Permissiveness and lack of parental demands, he found, were more often associated with harsh punishment and consequent low self-esteem in the children. High self-esteem was more frequently associated with the parents use of reward, their tendency to use restraint and separation (rather than corporal punishment and withdrawal of love) as a mode of discipline, and the level of demands made by the parents of the children. As long as the parents are fair and tolerant, and not dominating and stifling, parental demands represent increased attention and increased interaction for the child. For the child, the parents' demands become tasks and guidelines at which he can succeed. They also become a definition of reality in which he can more clearly develop a realistic view of himself, his skills, qualities and limitations. This sense of realism about oneself is a necessary part of the child's self-esteem system.

Touch. Encourage. Guide. Demand. These are some of the varied forms of communication that should pass between parent and child. The developing child presents many selves to his parents, and only in a parent/child relationship based on many kinds of supportive, affectionate, and guiding communication can the child bring these selves together into a whole identity that he can accept and value.

by Robert Coleman

**CELEBRATE**

**IT'S VICKI KELLY DAY!**

The Mrs. Jaycees of Omaha have discovered one of our own, and indeed she is one of our best. Mrs. Kathy LaRoe announced that Vicki Kelly will be named one of this year's outstanding volunteers. Vicki's recognition will begin at a luncheon in mid-February. Soon will follow the designation of a day in Omaha as Vicki Kelly Day.

Vicki has been a leader in GOYARC's involvement at ENCOR's Developmental Maximation Unit. Vicki will likely be found on her day - as on many others - active there in the lives of the children she has found to be so important to her own.
Meet Chris Beem...new GOARC Youth President!
There should be no problem recognizing Chris. He is usually right there - in the center of the action - rallying people around him. His smile and spirit spread as easily as a late winter cold. GOYARC's shaker and mover is now the group's President.

This change in leaders came about in the middle of Heidi Davies' term. She is into her freshman year at UNO, busy part-time as Wards Department Store, and leading the local Rainbow Girls Chapter. Reluctantly, she came to terms with the fact that GOYARC's President's role demanded more than the 24 hours a day mere mortals are given. Heidi asked to continue as a Youth member, but not as its leader.

Chris Beem can be found in many places. That's him at half-time beating a drum in the Warrior Marching Band. He is traveling with the Westside High School Dance Club as a cast member performing in various parts of Nebraska hoping for honors in competition. His junior year studies keep him busy during the school day. Chris is active at the Lutheran Church of the Master, currently serving on a search committee to find a new youth pastor. But during part of the Summer he maybe hard to find. Chris has found an interest in canoeing the Boundary Waters National Canoe Area in the wilderness of Northern Minnesota.

The youth didn't elect a rookie. Chris has served this year as the youth member of the GOARC Board of Directors. At home there is a tradition of involvement in mental retardation causes. Ray and Marilyn Beem are long time GOARC members and past leaders of the parent group at the Westside Learning Center. His older brother, Steve, has been a GOYARC member for 6 years. It was Steve's interest that sparked Chris's.

The support at home is probably what has fostered Chris's positive and reality-based attitude towards people with handicaps. It was Chris who wrote in a letter that everyone is actually handicapped in one way or another. But what is different about people with mental retardation is many people focus only on the person's weaknesses, ignoring his/her strengths. This can become an added "handicap". Chris' letter is used in the materials for staff training at ENCOR.

The Youth have found a leader, and GOARC has another reason to be proud.
ENCOR's Coordinated Early Education Program, begun in 1973, now serves 67 developmentally delayed children in regular community pre-schools in the Omaha area. For these children, integrated pre-school gives them many experiences necessary to their full physical and mental development: speech and other therapies, individualized learning with an ENCOR teacher, and especially play and learning with their peers. As the CEEP program is proving, the delayed child can make great developmental gains through contact with, and acceptance by, his or her age-mates.

The photographs, taken at the Early Learning Place, feature Skippy Richardson (on cover), Kyle Simpson (at sink), Scott Greenwood (finger painting), and Sherry Simpson (with ENCOR teacher Ann Ericson).
PILOT PARENT

On a cold and blustery night in January, a large group of Pilot Parents turned out for a lovely banquet to celebrate another year of the Pilot Parent Program. The place was Gorat's Steak House, the food was excellent, the company was great.

The Pilot Parents had their first opportunity to see the new Pilot Parent brochure and to be updated on the news of the regional grant. This was followed by many Pilot Parents sharing their experiences in piloting new parents.

Many stayed late to continue the visiting, and then back out into the sub-zero temperatures after a good evening.

Patty Smith, Tom Dean, & Jane Sherratt enjoy banquet.

Above: Jack Dolley and Catherine Williams joking around.

At Right: Chris Christiansen, Tom Porter, and Dick Bauer relax after a good meal.
Although the daily temperatures still hover around zero, a group in GOARC has July on their minds. The Nominating Committee will be soon proposing a slate of leaders to fill positions then open on the Executive Committee and Governing Board.

They ask that everyone think ahead to the new year, and of candidates to lead. Nominations are needed for all offices: GOARC President, First Vice-President, Second Vice-President, Recording Secretary, Corresponding Secretary, and Treasurer. The By-Laws call for parents to comprise 50% of the Board of Directors. Factors such as this will come into play in the Nominating Committee decides from among the candidates offered to them.

The grass roots character of GOARC demands active input from all. Members can call any of the seven on the Nominating Committee to suggest a leader. July is distant, but their deadline is very close.

Bill Wills 333-4359
(Acting Chairperson)
Bill Montooth 734-2195
Shirley Olson 558-8661
Fran Porter 451-0564

Bob Fox 344-4094
(alternate)
Jack DeMay 391-7499
Fe Hankerson 731-5475
Bob Schroeder 493-3930

TOOTSIE ROLLS for the retarded, in my opinion, does little to enhance the lives of our developmentally disabled citizens. Although the supporters of Tootsie Rolls for the Retarded have their hearts and minds in the right place, their perspective for meaningful social change is far from adequate or progressive in relation to the most misunderstood of our society, the developmentally disabled.

Services for the developmentally disabled should be a right not a privilege. Soliciting funds to enhance our developmentally disabled citizens' lives by means of charity reinforces the cultural misconception that those who are developmentally disabled are objects of charity rather than developing human beings entitled by law to the same rights and privileges as all citizens. Those of us who are "normal" would be humiliated by the notion that even our most basic human needs, out of lack of alternative resources, be met through charity. To quote a national advocacy group, "you gave us your dimes, give us our rights".

Rather than spending time and resources to entrench outdated notions in the mind of the public, i.e., developmentally disabled citizens as objects of charity, advocates should actively spend time and resources to fight for basic services as a right rather than a privilege.

Daniel P. McGee
LETTERS TO THE EDITOR (cont'd)

MY NEW POSITION as director of the UNO Center for Children has changed my relationship with mentally retarded persons from "professional in the field" to "interested citizen". After nine years of close association with retarded children and their families, I am looking at mental retardation from the vantage point of an outsider. I see evidence almost daily of the changing attitudes toward retarded individuals within our community. I think at times parents and professionals see the unmet needs which still exist, but fail to recognize the great strides which have been made.

Ten-twelve years ago, just before GOARC implemented its plan for serving mentally retarded citizens in their community as an alternative to institutionalization, I also worked in a generic early childhood program. I believe the following examples illustrate the successful integration of mentally retarded children in our community and the accompanying changes in perceptions which have occurred in those intervening years:

- Lila, one of our teachers, previously worked in a day care center which integrated mentally retarded children through ENCOR's CEEP program.

- When Mrs. S. came to enroll her three-year-old daughter, I recognized her as the mother of one of the first children to return from Beatrice through ENCOR's residential programs. She spoke openly about her feelings, then and now, and her concern about telling her other children they had a retarded brother. As it turned out, their attitude has helped her to accept her son and his handicap.

- Cece, a UNO student majoring in Special Education, has a brother with Down's Syndrome. She speaks with pride of Michael, and of their mother, who is receiving training at MCRI which will help her provide support at home for Michael — and the rest of the family.

- Jeanette, our head teacher, related an incident involving one of her friends whose mother had just had a baby. When the family learned that their infant has Down's Syndrome, Pilot Parents were called upon to help.

- Debbie, mother of four-year-old Roben who attends the Center for Children, is also an ALU parent to Craig, age 3, who formerly lived at the Developmental Maximation Unit (DMU).

- Five-year-old Vanessa kept saying she wanted to go to the "C.C. room". An explanation was in order, so our staff would know she was referring to the Cooperative Classroom, CEEP's pre-school setting for severely multiply-handicapped children. Vanessa's mother has a friend who is a "C.C. room" teacher.

Many other incidents come to mind, but these demonstrate to me that public attitudinal change is taking place. Mentally retarded individuals are being accepted into the mainstream of our community. And it is happening because of the advocacy of organizations such as GOARC. This advocacy takes many forms, and the results occur in different ways, but I believe there is tangible evidence of its success. All I have to do is look around me!

by Phyllis Chandler
By-Laws Review Committee, GOARC Office, 11:30AM.
Awards Committee, GOARC Office, 7:30PM.

Awards Night Program Committee, GOARC Office, 7:30PM.

Awards Night Program Committee, GOARC Office, 7:30PM.

Pilot Parent Mother's Coffee, at JoAnn Volcheck's, 9515 Spencer Street, 9AM-Noon.

GOARCs General Membership Meeting, First Federal of Lincoln Bldg., 2101 South 42nd Street, 7:30PM.

Pilot Parent Training, First Session, GOARC Office, 7:30-10:00PM.

GOARC Executive Committee Meeting, GOARC Office, 7:30PM.

Pilot Parents' Mom & Dad's Evening Coffee, Beacon Hill Apartment Clubhouse, 9315 Maplewood Blvd., 7:30PM-9:30PM.

Pilot Parent Training, Second Session, GOARC Office, 7:30-10:00PM.

GOARC-Youth Leadership Retreat at Notre Dame Academy, Saturday at 9:30AM til Sunday Noon.

Pilot Parent Training, Third Session, GOARC Office, 7:30PM-10:00PM.

GOARC Board of Directors Meeting, GOARC Office, 7:00PM
Self Assertiveness Workshop - 5 sessions. March 31, April 7, 13, 21, and 28. Time: 9:00 A.M. Place to be announced. To register please call Barb Bishop at the GOARC office - 348-9220.

February 27 "Reading and Writing Ain't Everything"
March 6 "Eddie"

The films will be followed by discussions led by Tom Miller and Al Stark respectively. Meet from 7:30 till 9:30 at MCRT (444 S. 44th St.) Adult Education (Room 1020).

A presentation of the GOARC Education Committee.
LOOKING AROUND for new GOARC members. Many people join us because of the interest they see in people who are already members. Who is there that you can talk with about taking part in enriching the good life of Omaha and Bellevue for all citizens? We, in GOARC, need you...and your friends, too.
GOARC GAZETTE

June 1978

GOARC CELEBRATES ITS 15th BIRTHDAY

(Story on pg 4-5)

John, Gina, & Rick Clark
## Table of Contents

- A Farewell to GOARC ........................................... 1
- I Never Promised You A Rose Garden ....................... 2
- Sarpy County On the Move ..................................... 3
- What A Night! .................................................. 4-5
- An Introduction to ENCOR Policies ........................ 6
- Advocates, Are You On The Right Track? .................. 7
- Spotlight on Helen & Joe Schultz .......................... 8-9
- Alice In GOARCia ............................................. 10
- Protect The Children .......................................... 11
- GOARC-Youth On The Road ................................... 12
- Vicki Kelley - Youth Volunteer of the Year ................ 13
- Organizations Raise Funds/Project II Plans for Convention 14
- Pilot Parents Grow ............................................ 15
- Close Encounters of the Nordic Kind ...................... 16-17
- Five Year Plan ................................................ 18
- Many New Faces .............................................. 19
- Sibling Day .................................................... 20
- In England Spreading the Word .............................. 21
- Position Opening/An Open Invitation ...................... 22
- A Man to Remember .......................................... 23
- Letters to the Editor ......................................... 24
A Farewell To GOARC

My last day at GOARC will be July 31, 1978. I am resigning my position as Executive Director of GOARC. It was not an easy decision for me to reach since I have enjoyed my position as Executive Director of GOARC and have been excited about GOARC's present and future.

The reason I am resigning is solely personal. As long as I can remember I've been interested in learning about people in foreign countries. As a child I "devoured" all the books on travel in our local library and thoroughly read National Geographic. I've been fascinated with the manner in which other people have coped with handling their "world". I have been especially interested in learning about developing countries since their familial, social, cultural, and economic ways are so much different from our own.

Over a year ago, I rekindled a friendship with a person I had known since I was 13 years old. We discussed what we were doing and our future dreams. Both of us discovered that we had a desire to travel. For a period of time, I had intended on taking a leave of absence from GOARC. On further thought, however, I felt I wanted to be free to accept other alternatives that might develop. For instance, I wanted to have the freedom to stay a month or longer in Ethiopia, Tunisia, or some other exotic country if the chance to do so came along.

I view my trip as an opportunity to learn more about myself and the world and also to continue my professional interest and knowledge in mental retardation. I am planning on visiting programs and services for retarded persons during my travels and have a chance to talk with parents and professionals from other countries.

I have enjoyed working at GOARC the past three years (almost) as its director. I have enjoyed knowing numerous parents and other volunteers who have committed their time and their energies working on committees, and tackling issues that will make for a better GOARC and will provide for a better life for mentally retarded persons. I have enjoyed knowing two presidents - John Clark and Ed Skarnulis - who even during the difficult times continued to lead GOARC in constructive ways. GOARC has been very fortunate to have their leadership. I have enjoyed knowing a dynamic staff that has been willing to spend time and effort because they sincerely believe in what they are doing. Although, the job has not been without its headaches and frustrations, it has been overall a very positive, growth producing and enlightening experience for me. After my travels, I plan to return to Omaha and be an active GOARC volunteer.

I wish the best for GOARC in the future. I hope GOARC continues to exercise its role as a strong support organization that advocates for the rights, needs, and full development of all mentally retarded persons.

It is impossible to thank each and every one of you personally and individually for what you have done for me in my personal and professional growth, but I'll try anyway . . . THANK YOU.

Thomas Miller
Executive Director
When I give "show and tell" presentations to people from other parts of the U.S., they predictably want to know "How did you get so many interested parents?" "Where did you find the money?"

I'm often asked what our "secret" is. How was it possible to bring together so many dedicated people; parents and professionals, in a relatively small community in North America? The parents and mentally retarded persons of Eastern Nebraska got the services they enjoy through a very simple formula called "hard work". We grew because puny mortals cared enough to swallow their pride and beg, borrow, or steal whatever they could get from politicians and the taxpaying public.

We grew because employees of GDARC and ENCOR taught themselves how to write federal grants, because parents who weren't trained public speakers told county commissioners in their own words what they needed for their sons and daughters. And their sincerity was obvious. There was nothing magical about the thousands of hours spent in trying to raise money for programs, or in hashing out new ideas for providing better services.

It didn't come easy. If we weren't fighting with "outsiders" who blocked our efforts to get a new residence, we were at each others' throats in bitter quarrels about how the residence should be furnished and staffed. If we weren't fighting off an arrogant governor who wanted to destroy everything that had been built, we were suffering through bleary-eyed Board meetings trying to figure out how to make up a deficit from our Honey Sunday drive.

It's been the history of GDARC and ENCOR. Nothing's changed. It still boils down to each individual member pulling his or her own weight, not looking for easy solutions to complex problems, not expecting somebody else to do the work, and not throwing in the towel when the going gets rough. It means maintaining a united front when we talk with other parents and professionals about our accomplishments, but it also means being honest with ourselves about our deficiencies.

We've come a long way and lot of us got burned-out during the journey. Sometimes this happened because selfishness set in. It doesn't end, of course, and none of us have been able to sit back and relax. Every new program, every new building, every new staff member -- means just that much more that has to be maintained. And when we're not busy holding on to what we've gained, we're busy trying to fill the gaps that still exist.

The point of this sermon is that during the last year or two we have had a significant decline in number of members. All of us have explored possible reasons, some having to do with internal problems and some having to do with outside forces. There has been a lot of breast-beating, self-recrimination and even more pointing the finger of blame at others. Some people say we're too vocal in our advocacy, others say we're not vocal enough.

Obviously, none of these exercises is terribly productive. I would humbly suggest that we return to the formula we know to be successful -- hard work. We can wring our hands until hell freezes over, and we can hurl insults at one another until we're blue in the face, but the organization will not be helped one iota.

Your new Board will be first in line when work is handed out. Some of its more creative members will be in the vanguard, meeting new challenges and hammering out solutions for them. So at the very least we can be assured that the organization will have 30 hard-working people to perpetuate and improve on the volunteer movement we have today. Wouldn't it be nice to have 300? or 600? Will you join us?
Sarpy County On The Move
by Ona Mayer

Nearly 200 people were in attendance at the 5th Annual Awards Banquet held at the Miner's Camp Saturday, April 29th.

The banquet, co-sponsored by the Cass and Sarpy County ARC's, highlights a year of significant achievements by the bowlers of the Tuesday Sundown Mixed League.

Ona Mayer, organizer of the league, stated, "The league, which consists of handicapped and non-handicapped bowlers, has had one of its best years." This was evidenced by the presentation of over 100 awards and trophies to the participants.

Bellevue's Mayor Haworth assisted in the ceremony by presenting corsages and boutonnieres to 12 people who were honored for being in the league since its beginning in 1973.

Among the many trophy winners were Perry Diltz and Marilyn Stander for high averages, and "The Afternoon Delight" for the first place team. Shirley Rotundo accepted a plaque on behalf of Space Lanes.

Though the season has officially ended, many of the league participants are looking forward to the National Handicapped Tournament to be held this summer.
Candles glowed, and joy was shared by the GOARC members and their guests at the party for our 15th Birthday. It was this occasion chosen for Awards Nite '78. The winners each added a lit candle to the birthday cake which all shared at the end.

Another 15 years of active support of mentally retarded citizens and their families is assured if the strength of the people honored on Awards Nite is an indication of what's ahead. Here are GOARC's winners:

Volunteer of the Year: Ray Loomis founded and continues to lead as President of a group called Project II. These mentally retarded adults have learned to become their own best advocates and a ready support to one another.

Employer of the Year: Mr. Steak Restaurant (South 121 & Center) employs several young mentally retarded adults during the last years of their formal school program.

Employee of the Year: Dr. Jack Stark, Director of Meyer Children's Rehabilitation Institute, has been responsible for developing alternatives in vocational training.

Citizen of the Year: Eugene Conley of Guarantee Mutual Insurance for work in organizing community efforts to assist handicapped adults.

Outstanding Progress-Adult: Terri Kelley was nominated by the ENCOR staff who serve her at her residence and at the Benson ITC.

Outstanding Progress-Youth: Ann Tamisiea is the daughter of Dr. Paul & Judy Tamisiea. She has demonstrated remarkable growth in her ability to communicate despite handicaps in this area.

Parents of the Year: Tim & Judy McGuire have a handicapped child in their family.

Outstanding GOARC-Youth: Sue Halvorson kept a journal last Summer which she & other Youth members developed into a project which drew national recognition. Also cited was Steve Beem who has served GOARC-Youth seven years.

Teacher of the Year: Mary Cole is a special education teacher in a program at Hartman School of Omaha Public Schools.

Special Teacher of the Year: Mike Nuschy is an instructor in the UNO Dept. of Education who has focused extensively on developing a curriculum to teach children with severe and profound mental retardation.

At right: Terri Kelley (right) shares her award with Barb Martin, the friend who nominated her for most Progress-Adult.
Pilot Parents of the Year: Tom & Pat Heeren have assisted several other parents whose children have recently been identified as handicapped.

Human Rights Advocate: Carl Sullivan has worked diligently to solve problems which relate to the rights of handicapped people.

Organization of the Year: Redman Nursing Home provides vocational opportunities for students of Madonna School.

Distinguished Services Award: Karen Faison has originated a training program at Metro Area Technical College to prepare students for careers in child care for children with handicaps.

Distinguished Service: Pat & Connie Jung have served as a guardian for a multi-handicapped child.

Distinguished Service: Bonnie Shoultz has a long history of support and concern for people at-risk in society.

Special Award: Tom Miller will be leaving as GOARC Director. He was commended for three years of service to the agency.

Tom Heeren and his award-winning (Pilot) Parents.

Bonnie Shoultz is recognized for her advocacy thrusts.

Ray Loomis, Volunteer of the Year

Sarah Creek joins Paul & Judy Tamisiea in admiring their daughter Ann's award.
An Introduction to ENCOR Policies

By Carl V. Sullivan

The following are examples of policies in effect at ENCOR:

1. "ENCOR Policy Guideline: Policy on Eligibility for ENCOR Services"
2. "Addendum to the Policy on Admission into ENCOR"
3. "ENCOR Policy: Residency Policy for Mental Retardation Regional Services"
4. "Referrals from State Institutions"
5. "Procedure for Contracting for Services between Mental Retardation Regional Agencies"
6. "Waiting List"
7. "Admission Priorities for ENCOR Residential Services"
8. "Addendum to ENCOR Residential Service Admission Priorities"
9. "ENCOR Policy on Individual Program Plans"
    A. "Missing Clients"
    B. "Sexual Assault on Children or Adult Clients"
    C. "Severe Weather"
    D. "Answering Service/Pageboy System"
    E. "Emergency Planning"
11. "Client Health Policy and Procedures"
12. "Policy on Safety"
13. "Guidelines for Client Supervision"
14. "Statement on the Use of Consumer Participation and Representation"
15. "Statement on the Use of Alternative Communicative Systems"
16. "Policy on Appeals and Grievances"
    A. "Procedures for Appeals and Grievances"
17. "Reporting Abuse and Neglect"
18. "Mental Health Treatment and Commitment"
19. "Guardianship"
20. "Discipline"
21. "Right Not To Be Deprived Of Life"
22. "Policy on Research"
23. "Record Policies for Release of Information"
24. "Policy for Incident Reporting"
25. AC/MR - Developmental Disabilities Standards on Rights

There are others. ENCOR has a Client Policies Manual that will soon be available. Bonnie Shoultz (444-6571) is the appropriate party to contact for copies of policies and information about them.

You have a right to copies of ENCOR's policies and information about them as they state parents' and clients rights.
Advocates, Are You On The Right Track?

As parents, friends, and professionals involved with developmentally disabled individuals, we are advocates for the very best possible services. Unfortunately, we are never experts in all the areas in which an individual may need support. This leaves us with nagging questions that often go unanswered. The questions aren't even formulated, you just have the "feeling" that something was left out, or not quite right.

As members of the Human and Legal Rights Committee, we would like to spend the next several Gazette issues sharing some different types of questions that are designed to get the information you need to understand the services in which your daughter, son, or friend is currently involved.

Changing an individual's behavior is something which becomes an issue sooner or later. "Behavior" may mean what is typically labelled as "bad". Behavior may be something like a person's range of motion. Sometimes the decision to "change" means teaching a skill that the person currently doesn't exhibit such as eating with a fork and knife or writing checks. Sometimes the change is to eliminate something a person does. In any case, a decision must be made to intervene.

By law, no publicly funded program may attempt to change just any behavior it desires. Every program has its area of concern and should have specific goals to accomplish.

When considering the decision to intervene, we must recognize that intervening in someone's life may deprive that person of some rights. Therefore, several key questions should be kept in mind.

1. What is the cause of the behavior? Is there a medical condition, something scaring the person, or some physical discomfort?

2. Is the behavior disrupting a good portion of the "normal" daily routine?

3. Will the behavior cause danger or lead to potential harm to the individual or to others?

4. Does the behavior make the person seem greatly different from others of his/her age?

Every advocate must also be confident that "the bottom line", when working to change a behavior, is really to benefit the person's growth. Convenience of teachers, line staff, and even of parents should never be the motivating factor.

Lastly, we need to keep in mind that we have the right to all information surrounding a plan of behavior change. We need to ask questions until we feel confident we understand everything before we give our consent, it is our job to make decisions based on as much information as possible.

If you have any questions, please write the Committee a letter at:

Human and Legal Rights Committee
C/O GDARC
3212 Dodge Street
Omaha, NE 68131

Please sign your name and we will respond personally to your questions. Any material will be printed with permission.
Near midnight on July 2, 1972, Gary Schultz waited anxiously in the driveway of his parents’ neat, one-story home, wondering where the senior Schultz’s might be. It wasn’t like them to go away without telling someone where they could be reached.

Earlier that evening, his sister, Judy, had kept watch while he patrolled the exit from the highway near their home, hoping to spot the returning pair before they accidentally heard the numbing news. About 3:30PM that Sunday afternoon, their younger brother, 18 year old Ronny, had been drowned in a multiple tragedy at Indian Cave State Park near Nebraska City.

It had been a typical, humid, summer afternoon. A group of care-free, sweaty young men were cooling off in shallow water in the Missouri River at a spot for wading. Splashing and calling back and forth, one of them suddenly stepped into an unexpected hole and stumbled. No one knows why the others followed. Perhaps, they thought the leader was playing a prank. Moments later, Ronny, his four companions from the ENCOR Burt Street Residence and their counsellor, Tom Madsen, were dead. Their contagious laughter, swallowed up suddenly by panic had ceased forever.

"We couldn’t imagine what Gary was doing in our driveway that time of night," said Helen. "We’d been having such a good time visiting our cousin in Fremont we hadn’t even turned on the evening news. Our first thought was something had happened to our home. It never occurred to us it might be Ronny."

Already Ronny’s lifeless body had lain several hours at a Falls City mortuary waiting to be brought back to Omaha.

Six funerals in five days plus visits to each of the bereaved families remain a blur in the Schultzes mind. "We never left Ronny’s body alone," said Helen, explaining the Polish custom she and Joe observed. "One of us was always with him." Memories of the more than 400 people who crowded into the mortuary and the overwhelming stacks of cards that arrived continue to bring comfort.

This wasn’t the first time Helen and Joe had mourned for Ronny. Nineteen years before when the doctor told Helen and Joe their six week old infant was “mongoloid”, that he would never be a normal child, they had felt their dreams blow away.

"The doctor told us", said Helen, "no one knew how far such children could go, so we took him home and taught him all we could." Eight years later, when it was necessary to place...
him in the Beatrice State Home, they were heartbroken. With love, they promised to visit him weekly.

"Mommy, Daddy, come," Ronny would say each Saturday as he eagerly waited for his Omaha family to arrive. They skidded and slid on ice; once on a Sunday when garages were closed, they lost a wheel. Only twice in 8 years did the unpredictable, outrageous Nebraska weather succeed in keeping them from their weekly 200 mile drive.

On blue-sky days, they picnicked and played in the park. Ronny enjoyed shopping for comic books and new toys. Sundays when stores were closed they strolled up and down main street, memorizing every crack in the sidewalk.

Touched by the loneliness they saw in the eyes of those whose parents never visited, they were determined Ronny should not forget his Omaha home or what the world outside was like. Perhaps, some day—

"The best Father's Day present I ever had," said Joe, his brown eyes moist from remembering that Friday in June, 1970, when Tom Miller brought Ronny back to them.

"He was so happy," said Helen. "We'd go to watch him bowl. Afterward, we'd stop at the Dairy Queen. He loved to go there—he'd start telling us when we were getting close." "Sometimes," added Joe, with a teasing smile, "we'd kid him and pretend we weren't going to stop."

From the ENCOR residence he could telephone home; his parents visited twice a week. Camping, bowling, going to wrestling matches and stock car races, working at the Benson Workshop broke his week up into exciting patterns.

The Schultzes often wonder how far he might have progressed. Their hopes were high. He would have been 25, next December 21st.

"What if?" is a question they don't ask. The many pictures they treasure spell out the answer.

Ronny, as a cuddly toddler, reaching up in a natural-admiration-society pose to give his big brother a kiss. Helen's voice trembled as she lingered and looked.

Nine year old Ronny, a fashion model in his dark suit, tie, and man-like felt brimmed hat, posing with the family after confirmation. "We were afraid he'd never make it but he made his first communion too," Helen said proudly.

Athletic Ronny, assuming a heroic stance at the Special Olympics where he'd thrown the softball. Already he was planning to enter as a runner the next year.

Happy Birthday Ronny, lips forming an "O" to blow out the candles. Camper Ronny, giving his buddies a hand with unloading their truck at the campsite.

They remember and treasure their last conversation. "Hey Dad," Ronny said over the phone, "they're loading up to go camping. Can I go with?" Plans to celebrate the 4th of July as a family evaporated. This was Ronny's chance to follow his dream.

Sorrow remains but the Schultzes have no regrets. They admit they might have refused consent had they known Ronny was going wading. But it didn't happen that way. The important thing—the thing that matters—is that Ronny's last camping trip was exciting. Life was holding out promises; dreams were being fulfilled. While some parents feel bitter, the Schultzes remember the dedicated staff who gave their son opportunities he might otherwise have missed. In particular, they remember Tom Madsen, the young counselor who gave his life trying to save his friends.

Sorrow remains but hope and joy abide. The same spirit that motivated them to spend hours selling candy, candles, and chances to provide playground equipment and gifts for the forgotten ones at Beatrice reminds them of the special work waiting to be done. Since Ronny's death they have helped bring two other men back to the community. They love to see them progress and find satisfaction in reuniting them with their parents.

Perhaps the words printed on the award given to the Schultzes in 1973 when GOARC named them Parents of the Year best express the underlying faith that sustains and gives them peace.

"Happy are they who dream dreams and are ready to pay the price to make them come true."

To Ronny, the Schultzes gave more than life itself; they have him a chance to live in the mainstream where life is real and dreams have a chance of coming true.
Alice in GOARCia

by Alice Blackstone

COFFEE, COOKIES and A BABYSITTER provides a much more relaxed atmosphere for mothers to exchange ideas. "We just sent the children off to the playroom," says JoAnn Volcheck, describing the good time about 20 mothers had at her home on the morning of April 20. Dawn Brennan, the Volcheck's 6 year old foster child, missed out on the fun. She was in the hospital undergoing tests for San Filippo disease, a rare affliction (only 2 cases in Nebraska) that causes hair to grow abundantly over the body.

SHERRY NOLEY SUFFERS CULTURE SHOCK - Our new Pilot Parent Outreach Specialist loves being back in the Midwest where bag boys carry out her groceries and services for the handicapped and mentally retarded are way ahead of those back East where she lived and worked for several years. She's been getting her feet wet with Glenda Davis doing Pilot Parent workshops at Storm Lake, Iowa and Columbia, Missouri. Her 3 daughters, Lisa, 14; Kimberly, 9; and Miki, 4 will be joining her soon. Kimberly (Down's Syndrome) is one of the reasons she wants to live in Omaha.

NOBODY WANTED TO GO HOME from the Sibling Day Workshop held May 6 at St. Timothy's Lutheran Church says Barb Bishop. 20 to 25 participants, ages 10-30 years, enthusiastically listened and discussed talks by Anne Marie Alta Mulligan (The Dignity of Risk), Margaret Brink (Feelings and Resentments) and Christine Smith (Planning for the Future). One woman, whose husband's brother is in Glenwood, attended, hoping to better understand so she could be helpful in her family situation.

GOYARC MEMBERS SHINE - Chris Beem, President, and Jill Nagel, Peer Making Leader, were chosen by District 66 Superintendent, Vaughan Phelps, to attend the National Youth Helping Youth Conference at the Boys Town Study of Youth Development.

WHAT'S AHEAD - concerned parents of children 13 and over want better services for graduates who are mentally retarded. Interested persons are invited to join their discussion each Wednesday at 7:30 PM at the Commercial Savings and Loan, 11207 West Dodge Rd. Ed King, Vice-President of the group lists their interests as driver training, residential services, training in handling money and anything else young adults need. Primary interest is in jobs for the future. Barb Bishop is liaison person from GOYARC.

THE POT'S STILL ON - on April 20, parents of clients in residences met to discuss their special problems. Jenny Friend and Wilma Wills talked to parents about their feelings and experiences. They both have sons in ENCOR residences. Bonnie Shultz and Tom Wave informed the group about human and legal rights. Information about further meetings can be obtained from Barb Bishop (348-9220).

SEXUALITY WORKSHOP begins Thursday, June 1 and continues for 5 consecutive weeks from 7:30 to 9:00 PM. They will be held at Benson Presbyterian Church. Anne Marie Alta Mulligan will be in charge. Cost is $10.00 per parent. Registration required. Call Barb Bishop.
MISS TWINKLETOTES DEBUTS - Friday, June 2, Randi Christiansen, daughter of Chris and Peggie Christiansen will dance her way into the hearts of the audience at Millard High School in her first recital. Just goes to show ya!

OMAHANS AT NEBARC - Glenda Davis, Ron and Kathleen Sorensen, Shirley Dean, and Sherry Noley presented a Pilot Parent workshop. Sara Persons from the Fremont Pilot Parent group participated, in a Respite Care Panel.

GLENDA DAVIS REPORTS - three new chapters of Pilot Parents: Kansas City, Kansas; Lincoln, Nebraska; and Storm Lake, Iowa; have completed training.

TEMPUS FUGIT - and so does Patty Smith. Only yesterday, it seems, some 50 friends were wishing her Bon Voyage and presenting her with a check before her departure to England. OK, Patty, now that you're back, how about giving us a party and telling us what went on in merrie olde England?

BE PREPARED - Next time you spot a car wrongly parked in a stall for handicapped, let 'em know. Call the Mayor's Committee on the Handicapped, City County Building, they will mail you official stickers. The telephone number for the Mayor's Committee is 444-5001.

Protect the Children by Billie J. Cook

You should check now to make sure that your youngsters have been immunized against the following dangerous childhood diseases:

- Polio
- Measles
- Mumps
- Rubella (German Measles)
- Diphtheria
- Tetanus (Lockjaw)
- Pertussis (Whooping Cough)

Why should you check? Because many pre-school children have missed one or more of their immunizations against childhood disease. These children face a needless risk of serious illness and devastating, perhaps fatal, complications.

In recent years, the percentage of children immunized against childhood diseases has been declining. As a result, polio, measles, and other preventable disease continue to strike.

Worse still, health experts warn that unless more young children are immunized, widespread epidemics could take place once again, spreading particularly among pre-school children.

Anyone who remembers the polio epidemic of the 1950's, when many children died and thousands more were seriously crippled, understand the importance of immunization. More recently, measles and rubella were brought under control. Before vaccines were available, measles complications claimed hundreds of young lives each year. The last rubella epidemic took place in 1964-65 and resulted in the birth of 20,000 deformed babies and 30,000 miscarriages. Epidemics must not be allowed to strike again. Parents are urged to check their records to make sure their children have received all their immunizations. Unimmunized children should be taken to their doctor without delay. Remaining unimmunized from childhood diseases is a risk no child should face.

(The above information is from the brochure, "Protect Them From Harm", Omaha-Douglas County Health Department.)
GOARC-Youth

On the Road

To Valley, Nebraska. On a Sunday after the flood, GOARC-Youth took part in the drudgery of the clean-up. They shared some sad experiences with a family who they helped sort through a lifetime of possessions; discarding most. Molly Sorensen scrubs mud from a window sill of a farm house just East of town.

To Waubonsie. Spring and GOARC-Youth arrived in Iowa at the same time. Sue Sutherlin isn't as sure as Cathy Bogacz about how good the cold drink will be.

To Church and to Westside High School. Rev. DeMay takes questions from a study group at St. Paul Methodist Church. She also coached three GOARC-Youth who concluded the mental retardation sequence of the Westside sociology courses. Tough assignment: to address 150 seniors on their very last day of school. Yet, Chris Beem, Jill Nagel, and Vicki Kelly won a round of applause — well done.
Vicki Kelly is into her 18th year and has a career of volunteer work and advocacy that someone twice her age would be proud of. The United Way of the Midlands has taken note of her work with GOARC-Youth, and particularly of her leadership of the Youth efforts at ENCOR's Developmental Maximation Unit (DMU). They couldn't miss, the fresh spirit in what she did with children having such noticeable handicaps. Many may lament asking "what can they do?" Not so with this youth whom United Way picked as Omaha's Volunteer of the Year. Vicki has led people to realize that there is little that kids with handicaps couldn't do.

Vicki Kelly may well be among a new breed of volunteers. She has given countless hours of help. But with her involvement comes tough demands. Children are to be cared for generously, sensitively, and with the profound belief that they will grow. She won't back off or be compromised when even "good intentions" fail the children, much less when someone has been simply petty.

A review of the past months of Vicki's life would provide a moving account of advocacy. It would be complete with warm moments of joy over the increments of growth in a child. But just as true are the stark, lonely moments. These are filled with fear when a young advocate stands toe-to-toe, trying not to flinch, with someone of stature who has failed to serve a child well.

Vicki has turned to Child Protective Services for help with a situation of abuse. Another concern led her to return to them over a child who was seriously neglected. Granted, she was obliged to report these under Nebraska statutes. But for Vicki, her motivation to act came from a prior, deeply felt struggle to do "what is right".

Others have grown because of Vicki's efforts. But what about Vicki herself? Her interest in GOARC-Youth began six years ago when she was in junior high. It was important then to do things for other kids. Later this matured as she realized that handicapped youth don't need someone to do things for them, but rather to simply be their friend. As Youth President, she learned that good ideas do more when youth are led to live them intensely.

Despite the pressure of being a student at Creighton, Vicki is finding a new way to continue her involvement. The ENCOR staff have recognized her ability and honest concern. They have asked Vicki to be part of Bobby Murphy's planning team. She had singled out Bobby months, ago to provide for him what even the best service system can't.

Congratulations, Vicki! We have known you to be a winner, now all of Omaha knows that too.
Organizations Raise Funds

Two groups within the Omaha area were active in fund-raising events, which will benefit GOARC. The Knights of Columbus Councils throughout the State participated in Tootsie Roll Weekend, March 31 through April 2. I assisted Dan Lynch, County Commissioner, in selling tootsie rolls at a grocery store on North 30th Street. The participation was superb. Two out of 3 gave donations. Last year GOARC received approximately $2,500 from the Knights of Columbus Tootsie Roll Drive.

Another very energetic and successful fund-raising event was Swing for the Retarded. Last year Swing for the Retarded gave GOARC $2,500 for the purpose of public education. Swing for the Retarded is a non-profit organization which holds a golf tournament for men and women and a tennis tournament to raise funds to support programs for mentally retarded persons in Omaha and throughout the State. The golf tournament was held on Monday, April 24th. Swing for the Retarded is run by numerous volunteer businessmen who meet weekly to plan the golf tournament. The tennis tournament is held the latter part of August. The target for this year’s event is $60,000.

Project II Plans for Convention

In August, Project II will sponsor a statewide convention for developmentally disabled people, announced Ollie Rector, convention chairperson. This will be the first annual convention of a new statewide organization entitled "People First of Nebraska".

Project II members, Ray and Nancy Loomis, Ollie and Lowell Rector, and Robert Fox are accepting speaking engagements from all over the State to tell interested persons about the convention and about how to form their own local groups. They put on a very successful workshop for the NebARC Convention in April.

The theme of the convention is "All persons with handicaps have the right to speak out." In the past, people with handicaps often have not known how to speak out. Project II realizes the importance of coming together to achieve the strength that people may lack as individuals.

The convention will be held from noon, August 26, to noon, August 27, at the Kellogg Center for Continuing Education, Lincoln (33rd & Holdridge Sts.). It will cost approximately $25.00 per person. It is recommended that those who wish to go start saving now. One or more ENSHA vans will provide transportation for conventioners from the ENCOR region.

Project II members have identified four purposes for the convention: to explore self-advocacy, to identify common goals and strengths, to meet old friends and make new ones, and to have a good time (there will be a dance).

Groups or individuals who would like to know more about the People First of Nebraska Convention may write to Ray Loomis, c/o GOARC, 3212 Dodge Street, Omaha, Nebraska, 68131. Project II will send information and registration forms or when possible, speak in person to a group.
Pilot Parents Grow

Despite another rainy night, about 30 Pilot Parents met at Barb Bishop's house on April 24th. It was like most pot-luck dinners: four times as much food as we could eat, all of it delicious, and several of us talking about starting that diet "tomorrow".

All the Pilot Parents who just completed the Spring training session were there and received certificates. They are: Lenis and Kathy Schoepke, Connie and Mike Scasny, Connie Holcomb, Marilyn and Bruce Dale, Dwight and Ellen Meyer, and Lula Sigler.

This brings the total number of Pilot Parents to 47. Besides piloting parents here in Omaha, several persons from this group are now assisting staff in responding to requests from 22 communities within Region VII to establish parent programs. A special thanks to those who helped so much while Patty was in England.
DATELINE: Stockholm

What does Sweden mean to you? To some people it brings to mind pictures of Viking trading boats sailing the North Seas. To others, images of tall, tanned, and blonde women...movies that are curiously yellow and blue...Dag Hammarskjold, Ingmar Bergman, and Bjorn Borg.

Having come from an all Swedish background, I have returned to the land of my ancestors. My time and energies have not been spent looking for my roots. They have been channeled into coming to an understanding about the society that has received so many judgements from afar.

Sweden, the land famous for the 3 s's: socialism, sex, and suicide. I'm not going to dwell on these well-known but poorly substantiated aspects of Swedish Society. Instead, I shall focus on another "S" which is not just rumor, but the reality of services.

I would be inclined to wager that Allstate comes nowhere close to keeping people in good hands, as compared to the Swedish welfare system. "From Cradle to Grave" is no exaggeration, and in actuality, no nightmare either. Swedes have a collective out-look in their way of viewing the welfare system. "From Cradle to Grave" is no exaggeration, and in actuality, no nightmare either. Swedes have a collective out-look in their way of viewing the welfare system. That viewpoint being that it is everyone's duty, and in some way, shape or form, everyone will receive something. Sure, taxes are high (but those in Belgium and the Netherlands are higher), but "that is the price one has to pay", the typical Swede will say.

Magazines and newspapers often print articles on U.S. medical and educational costs that Swedes find hard to believe. "Do you mean to say that chronic medicines such as insulin and digitalis are not free in the U.S.?" Swedes often ask in astonishment, "Who can afford to be sick?!" or "Who can afford to send their children to a university?"

Nearly everyone in Sweden is a recipient of human services. Parents receive quarterly child allowances, regardless of financial status. Most people receiving housing allowances. Everyone has nationalized health insurance as opposed to a system of socialized medicine such as in England. University tuitions are non-existent and students over 16 receive monthly study allowances.

An adult unable to work due to mental or physical handicaps or injuries, receives a monthly "future" pension, which is his or her old-age pension advanced to begin at an earlier date. Another newly initiated pension (known by its abbreviated name ATP) for those over 65, provides 60% of one's annual salary earned during the ten best years of one's life. A person over 65 might receive 2 pensions; ATP and the standard "folk" pension. At the moment ATP is not extended to women who have been housewives all their lives, but there exists a strong movement to change.
A recent class in Social Policy gave me the opportunity to get out into the community to examine one type of human services agency in the Stockholm area. I chose the agency that provides programs and facilities for the "Omsorgsnämnden", people who are mentally retarded.

The class didn't begin until the second semester of the school year. Before that time, I tried to make contacts on my own with mentally retarded persons. My attempts were not met with much success for the sole reason that it was difficult to find mentally retarded persons in Stockholm. No large groups of mentally retarded children or adults did I meet downtown while shopping. There are no large signs posted on buildings saying that this was a sheltered workshop or group home. A few other students in the Social Policy class also noticed this apparent absence of mentally retarded persons in Stockholm. No large signs were posted on buildings saying that this was a sheltered workshop or group home.

"They're there, you just don't notice them," was his answer. His succinct statement later became the title of a paper, written by myself and two other students, on a type of group home for mentally retarded adults in Stockholm, known as Inackorderingshem. The principle of normalization is the basis of all programs for the mentally retarded in Sweden, and Inackorderingshem seems to be one facility where normalization can make its furthest strides. It's usually located in a suburban apartment house. A type of housing in which the majority of Stockholmites live. One would have to look close to see where the differences between these and a normal Swedish apartment lie. Two to a dozen people sometimes live in a normal Swedish apartment. Two people sometimes live in a normal Swedish apartment.

During the weekdays the people are away at work or at vocational training centers. For those physically unable to use public transportation, taxi service is provided and the fee is paid by the "Omsorgsnämnden". Adult education is as Swedish as herring, and the majority of those living in Inackorderingshem are enrolled in at least one evening course each week. English is one of the most popular courses.

Sad to say, there is a shortage of Inackorderingshem in Stockholm today—due to the fact that housing for adults is hard to come by. According to a report that I've seen, over 100,000 people are on waiting lists to move into new dwellings in Stockholm alone. Institutional or "parent care" was the prevailing norm before the advent of normalization and a great many mentally retarded adults are still in one of these two types of facilities. The largest institution in Stockholm's area has 250 residents and there are a half dozen or so "vardhem" (care homes) ranging in size from 12 residents to 85. Twenty three percent are still living in parents' homes while 12% have their own apartment or house.

Great emphasis is placed on keeping the mentally retardada child in his or her natural parents' home. If this is not possible, a number of alternatives exist. There are "Korthdshem" (short term homes), where the child can go in a time of "crisis", or foster homes, "ekevgen", which are Inackorderingshem for children. Finally, there are large "vardhem" - of which there exist two in Stockholm. English is one of the most popular courses.
Five-Year Plan

by Karen Knudsen

Members of the Eastern Nebraska Community Office of Retardation's Five-Year Planning Council attended a comprehensive workshop Monday, May 22nd. The purpose of the workshop was to inform the council of the progress made in planning ENCOR's goals and objectives for the next five years.

An informative general assembly topped the workshop's agenda. Council members were updated on subjects and research relevant to the Five-Year Plan. The historical, political, and present situation of ENCOR was capsulized by Ed Skarnulis, Dave Powell, and Kevin Casey.

The group was divided into committees and each member of the Planning Council was presented with a plan. Revisions and suggestions were requested from each committee and individual.

The Five-Year Plan is going out to the public the first week in June. Public forums will be held in a different county each night beginning June 5th through June 9th. It is hoped that people in the communities ENCOR serves will offer their suggestions regarding the Five-Year Plan.

After public input is obtained, the final draft of the Plan will be written and presented to the ENCOR Governing Board.

A year ago, the Planning Department of ENCOR, under the direction of Lois Rood, set out to tackle a monumental task: to organize and involve the community in deciding the future goals of ENCOR.

Members of the community, along with ENCOR and GOARC staff have worked together to plan for better, more comprehensive services with the philosophy of normalization apparent throughout the Five-Year Plan.

ENCOR's future direction might be summed up by ENCOR's Director, Kevin Casey, "I am firmly committed to the Five-Year Plan."

A NEW VOICE . . . Doreen Ludemann, GOARCs new receptionist.

Doreen is a recent graduate of Creighton University where she received her bachelors degree in Modern Languages. Doreen will be leaving in September for Bonn, Germany where she will study German Literature at the University of Bonn on a Fulbright-Hayes Scholarship. Next time you call the GOARC office...say hello to Doreen.
GOARC has re-elected Ed Skarnulis to serve as President for a second term. Ed is employed by the University of Nebraska Medical Center as the Director of Family Practice Clinics. His thoughts on residential alternatives for mentally retarded children and adults have had an impact in our area and many parts of the world. Only last month, Ed traveled again to Oxford University to present what is widely accepted as the most innovative family-based plan that enables everyone to live in the middle of things.

As a parent of a youngster having a developmental disability, Ed shares a responsibility common to all the officers elected this year.

Elections continued until a full complement of 30 Board members was decided on. This year’s Board has youth and mentally retarded citizens as members. Nineteen parents will serve as Directors along with six interested citizens from Douglas and Sarpy Counties. Five members are professionals-in-the-field of mental retardation. The proportion of men and women Directors is nearly even. The most remarkable change is likely with the election of eighteen new members to the Board.

Many New Faces
by Pat Henry

Tom Upton  First Vice-President
Gerald Paes  Second Vice-President
Fran Porter  Secretary
Don Grimm  Treasurer

Joy Barfield  Roger Gunn
Sherry Bauer  Rev. Charles Harmon
John Clark  Pat Jung
Shirley Dean  Jamie Kelley
Tom Dean  Liz Lankford
Jack DeMay  Ray Loomis
Bev DeMay  Ona Mayer
Margaret DeVore  Ellen Meyer
Lewis Diltz  Dan McGee
Sr. Mary Evangeline  Bill Montooth
Craig Fecker  Gene Nicholson
Eddie Felix  Betty Paes
Joy Barfield  Norm Stava

19
Sibling Day

The Sibling Day workshop held on May 6th, was an effort to support persons who have a retarded or handicapped brother or sister... ages ten to over thirty years attended.

Topics covered included: "Stress in the Family", "Dignity of Risk" and "Attitudes" by Margaret Brink and "Planning for the Future" by Christine Smith.

During one session, siblings tried writing with their teeth and toes to experience what it would feel like if you could not use your hands.

One teenager expressed her thanks for the workshop and said "she was glad to meet others who had the same problems she did. And that they don’t always handle some situations well either."

Craig Focker was Master of Ceremonies for the day. Some of the presenters who are pictured are: Dr. Ken Keith, Anne Marie Aita Mulligan, Chris Beem, Bev DeMay, Connie DeVivo, and Kathleen Sorensen.
In England Spreading the Word

by Patty Smith

My exciting trip to England and Ireland began with a Bon Voyage party at Barb Bishop's home. To begin a trip with family and friends, members of GOARC, members of Pilot Parents, and so many people from the community was a great thrill. "Thank you to all of you who were there."

My journey began with a flight into New York City. I was welcomed at the airport by the new staff member at GOARC, Sherry Noley. I had the opportunity to receive a very fast overview of New York City. It was highlighted by a ride on the Staten Island Ferry, visiting the United Nations Building, going to the top of the Trade Mart, Greenwich Village, St. Patrick's Cathedral, and many other things.

Flying on a gorgeous jet, I arrived in London, Sunday morning, April 2nd. After a rest in my hotel, we were graciously entertained by James and Anita Loring, my host and hostess in England. The following two days were filled with sights, sounds, and smells of London.

Bright and early Wednesday morning, I was off to Oxford. I stayed at the University College, and slept in the students' rooms, ate in the grand hall and drank in the students' pub.

The participants in the conference had come from many countries. I will describe some of the papers that were presented that I felt were the most outstanding. The Wessex Project which was a respite care "sch" eme, as they called it which would remind us somewhat of the ENCOR respite care. This care is provided for all parents of children in their public schooling system. The respite care was provided by trained parents in the community.

An excellent paper was presented by a young man named Paul Williams giving his perceptions as though he were a mentally handicapped person himself. This was a very sensitive and moving paper.

Anne Marie Alta Mulligan captured the audience with the key note address talking about attitudes and perceptions of mentally handicapped persons. Skarnulis did a beautiful job talking about residential alternatives and how a system like this can be developed and maintained. Jim Mulligan finished the conference with the most "put level" talk of the entire conference.

The presentation by the gentleman from Sweden was on all the services available in Sweden for mentally handicapped persons and it was absolutely excellent. It's great to hear a person say that the services in an entire country are planned on the philosophy of normalization.

There were two presentations by brilliant young Englishmen who are endeavoring to do some creative things in and out of institutions. The presentation from the gentleman from Germany outlined the complete service system in their country.

The Pilot Parent Program and my presentation about our parents from Omaha was extremely well received by the English people. I have had numerous requests for information while I was there and since I've come back. Many of the things the Americans presented to the English were questioned; yet the idea of serving the parents seemed to be completely acceptable. It was a great thrill to present a program that I feel strongly about and have it well received.

The last night of the conference there was a grand banquet that was attended by the Master of the College and Lady Wilson, wife of former Prime Minister Wilson. This was a very formal and grand affair with outstanding food and beautiful toasts.

The following week Anne Marie, Jim and I spent five days in Ireland. It was a beautiful opportunity for me with my Irish heritage. We met a number of handicapped persons as we travelled and tried to visit programs that were there. The highlight for me was a visit to Mary of the Angels at Beaumont in Killarney, Ireland. I met with their leaders and discussed with them many of their plans for their upcoming
In England...

The Mulligans returned to England and I headed back to America on the following Saturday.

It was really great to be back with my family and filled with so many memories.

A word of gratitude to all the persons who helped me in preparing my paper and all the materials that went to England.

Also, my gratitude to all the parents who have shared with me so that I could share with the people in England. I received a very beautiful note last week from Anita Loring thanking all the Pilot Parents for sharing their program.

The GOARC Executive Director position is available. If you are interested in applying for the job, please send a resume to:

GOARC

3212 Dodge Street

Omaha, NE., 68131

Include in the resume your experiences in mental retardation, administration, and supervision.

An Open Invitation by Anne Marie Mulligan

Being a parent of a potentially sexually active teenager, or being a young adult is a great challenge in today's living. Knowing what to say, what to expect and how to respond are of constant concern. Few parents have the confidence to get themselves and their sons and daughters through the stage in a healthy or meaningful manner.

For the past three years, I've been providing support programs for parents of persons with a handicap. Once again, through GOARC's Pilot Parent Program, I will present a 5-week evening course for parents of teenagers and young adults. The topics will include: social aspects, developmental stages, modeling behavior, menstruation, wet dreams, masturbation, heterosexual and homosexual relationships, birth control, family planning, sterilization, venereal disease, and any other topics the group wishes to discuss.

The dates of the five Thursdays of June 2, 9, 16, 23, and 30 from 7:30-9:00 PM. The cost is $10.00 per parent - couples are encouraged to attend together. Single parents welcomed of course!! To sign up contact Barb Bishop at GOARC (346-9220) by May 30th.

Looking forward to the opportunity of sharing with you.
A Man To Remember

Bill Tetrault was a gentle and affectionate man. His spirit and his will to live enabled him to conquer, time and again, the multiple insults his body received. Originally diagnosed as a child with hyssarrhythmia, he survived the early years. When this condition of chronic, continuing seizures lasts into later childhood and adult life, it is called Lennox-Gastaut Syndrome. The diagnosis is immaterial—except that the description of the seizure difficulty itself illustrates the overpowering will to live when a man is in his 20's.

Bill survived a good many other trials—long years in an institutional setting; the ignominious and immobilizing physical conditions brought on by consignment to a wheelchair; the lack of family and on-going personal support systems. (If it is true that the Lord only gives us as many troubles as our shoulders can bear, then Bill's must have been awfully broad.)

I shall always remember Bill. He taught me as much or more than any one of my college professors.

I learned—that in spite of an EEG which showed seizure activity ninety-seven percent of the time—that Bill learned and developed. I had never thought before that learning took place during seizures. And we all learned that the "incurable" syndrome was vastly alleviated with care, programming...and love.

I learned—that it is possible to re-instate cognitive development even when it has been disrupted for many years.

I learned—to improve my own communication skills in order to communicate with Bill. These, in turn, led to better communication—for me—with a host of other persons.

My reaction when I found out that Bill was dying—was to cry out, "It's not fair!" This one person who has done so much to stimulate me and my intellect, is going to die before some of the harvest of the intellectual planting can be reaped.

I asked to be allowed to speak because of my respect and affection for Bill Tetrault—and because I was concerned that, to some outsiders, his life could be viewed as a "misery" and his death "a blessing"—that the full value and quality of life were not his. I don't believe that.

I believe that the experiences now in store for Bill Tetrault far exceed the life he lived here on earth—but I also believe that his indomitable will and spirit have left a charge to us, so that, in the words of the Old Testament prophet, Isaiah, we—"trust in the Lord; mount up with wings like eagles, run and not get weary, and walk and not faint"—in our pursuit of excellence in human services.

Bill is safe now, and at peace.

God, help those of us who are here.

by Karen Faison
Letters To The Editor

Two articles in the April GOARC Gazette raise several concerns in my mind about the relationship between GOARC and ENCOR. I fear that we are beginning to define advocacy and adversary as identical terms.

First let me clear up several items. (1) ENCOR does have a waiting list and to my knowledge has not claimed otherwise, (2) having just worked on the ENCOR budget, I can assure you that we are not in any way in an enviable financial position. In fact our commitment to keep people out of institutions through the Red Alert process has put us in a difficult budget situation, (3) I agree with several of Mr. Sullivan's points among them that ENCOR is not perfect, and that it needs massive parental input to improve its services. Please, please, call us, write us, send telegrams, communicate with us. If you don't like what we're doing, tell us, and let us know what you want and need.

ENCOR does not desire a confrontive relationship with GOARC. Rather, we desire that the two organizations work together in a cooperative manner to develop and improve the services for the mentally retarded. ENCOR is ready for, is offering, is pleading for, this level of cooperation. Is GOARC ready?

Sincerely,

Kevin T. Casey
Executive Director
Eastern Nebraska Community Office of Retardation

Legislative Bill 574, relating to issuance of drivers' licenses, is now a law. But more importantly to some, the new law also provides for special identification cards for non-drivers. This provision will go into effect January 1, 1979.

As a sponsor of the amendment that added this provision to the bill, I share your satisfaction that the benefits of the new laws will be enjoyed by aged, blind, and physically handicapped persons who — even though they do not drive — still need a widely acceptable form of identification comparable to an ordinary driver's license. As a matter of fact, I felt so strongly about the amendment that I added my name as co-introducer of the bill with the adoption of the amendment.

Working with you and your agency in promoting this piece of legislation has been a pleasant experience for me, and I am glad to have been of some small service to those who are less advantaged.

I hope we may cooperate in many similar projects in the future.

Sincerely,

Neil Simon
Senator
Nebraska State Legislature
TO BE INFORMED

There will be copies of this, the GOARC Gazette, sent to you. Also you will be getting publications by the Nebraska ARC and the Mental Retardation News of the National Association.

TO FIND THE HARD ANSWERS

Nearly every parent agonizes, "what will happen when I'm not around to care for my handicapped son or daughter?" Maybe GOARC has found an answer. Some members are now drawing the blueprints for a Corporate Guardianship program. They need help.

TO STAND FOR WHAT'S RIGHT

While there are services for people in our community, many handicapped people and their families aren't being served well. Some not at all. The Human Rights Advocacy Committee will be challenging those gaps. GOARC's Ombudsman has a track record as an active spokesman and problem solver.

TO MOVE INTO ACTION

People-to-people opportunities. Parent groups are active, especially in Pilot Parents and the Parent Support Program. GOARC-Youth are proud of their emphasis on a fully integrated gang of peers. The grassroots strategy of the Poverty and Mental Retardation Committee is designed to break that cruel cycle. The Public Attitude Change groups envision a community that will find a rightful place for all citizens.

GOARC needs artsy photographers, crafty business people, informal speakers, determined recruiters, gracious masters of ceremony, casual callers, detailed accountants, spirited youth, tested-by-fire parents, expressive retarded citizens, visionary service-providers, and good listeners.

We need believers ... that it all can be better.

USE HEED YOU

I Would Like To Be A Part Of The Greater Omaha Association For Retarded Citizens:

Name__________ Phone__________

Address__________ Sig__________

I AM:  ○ A parent of a handicapped person  ○ Interested  ○ Professional Citizen in the field

ENCLOSED:  ○ $9.00 Individual/Family membership  ○ $100 Life Membership

Donation to further GOARC efforts $__________

3122 Dodge, Omaha, NE 68111 (348-9220)
Calendar

JUNE

19 Pilot Parent Pot Luck Dinner at Pat & Larry Heeren's (5276 Clay St.) from 6:30 gather and at 7:30 dinner.

21 Parents meeting with Mike Nuschy from UNO at 10:00 AM at GOARC office. Any parent interested in working with him to develop a curriculum for the severe and profound is welcome.

23 GOARC-Youth Ethnic Dinner. What's for supper? Call Sue DeMay (391-7499), Joe Davis (453-8466) or Sue Halvorson (571-2507).

28 GOARC Board of Directors Orientation Day - Boys Town Center for Youth Development, for information please call the GOARC office (348-9220).

28 Normalization Training - Training for ENCOR staff and all interested; Downtown Library from 9 til 3:30 PM. For more information call Pat Henry (348-9220 or 397-3315).

JULY

2 GOARC-Youth Sunday Swim - L.D. Davies (391-0669) and Steve Beem (333-8169) plan to find a cool spot on a hot day.

4 Fireworks - GOARC-Youth will be doing many things with the kids from ENCOR's DMU. They'll be up late tonite. Call Vicki Kelly (397-1054).

7 GOARC-Youth - Three-way night, Want to go to supper...to a movie...to swim? Decide and call L.D. Davies (391-0669).

9 GOARC-Youth Square Dance

15 GOARC-Youth vs. Douglas County Young Republicans. The youth have been challenged to a softball game. L.D. Davies (391-0669) and Bev DeMay (391-7499) intend "to show no mercy". Be on the winning side.

17 Pilot Parent Program's Annual Summer Picnic at Cooper's Farm, 8705 Mormon Bridge Road. More information at a later date.

24 GOARC Board of Directors Orientation Day - Boys Town Center for Youth Development, for information please call the GOARC office (348-9220).

28 GOARC-Youth Ethnic Dinner. What's for supper? Call Sue DeMay (391-7499), Joe Davis (453-8466) or Sue Halvorson (571-2507).

28 GOARC Party - GOARCs staff and membership will wish Tom Miller, GOARCs Director, good bye and the new Board of Director's hello. All interested persons are invited. Details on time, place, etc. will follow.

The plateMag K the GOARC GameXY 4-I & nance it, in part, by a donation from SWING FOR THE RETARRED.
Table of Contents

Full Steam Ahead ........................................ 1*
Tom Miller - A Man For All Seasons .......... 2
Getting To Know You ................................... 3
Spotlight on Dr. Larry Rice ......................... 4-5
Alice In GOARcia ...................................... 6
Aloha Hawaii/Outreach Specialist Returns Home... 7
Pilot Parents Do It Again ......................... 8
Carl Sullivan - A Man Of Action ................ 9
Randi Growing Up ...................................... 10-11
ENCOR Policies Given .............................. 12-13
A Unique Approach ................................... 14
Convention Drawing Closer ....................... 15
GOARC Youth Outdoors ......................... 16
Etc.................................................. 18
On several occasions I’ve heard discussions on whether or not GOARC should be a strong outspoken advocacy organization or whether GOARC should take a low profile in the resolution of issues. I personally think that tackling problems of retarded citizens head on is the only genuine response to retarded citizens in need. Taking a soft-sell approach and holding our hat in our hands as though we were poor miserable beggars is not the approach we should take when we are defending and fighting for rights.

There are situations which demand a firm approach toward a resolution, which need follow-up and monitoring, and which sometimes might need publicity or even legal action. In these situations, the approach should be “full steam ahead” in order to resolve the problem.

Most neglectful situations which need monitoring by GOARC don’t seem to be as blatantly denying of rights as those abusive conditions which have occurred in institutions. However, in the Omaha area there are life and death situations and other harmful events occurring to retarded persons. At hospitals in Omaha retarded infants are denied medical services because they are retarded. Some have died. How many? We don’t know, but we are aware of those situations occurring. There are public school programs where retarded students have been restrained, and where the quality of services is far from satisfactory. How many children are in substandard programs? We don’t know, but we know that they exist.

Within ENCOR there are mentally retarded adolescents and young adults who’ve been on waiting lists up to 15 months for vocational services while ENCOR has a surplus of over $750,000 and at one time during the year had over $1.1 million. How many are waiting for services and don’t get them? No one knows for sure because the word is out that it is useless to apply to ENCOR since you won’t get the service anyway.

There are ENCOR clients who have been abused, neglected, and not given quality programs. How many? No one knows for sure since there’s been so little systematic effort in monitoring the numerous dispersed ENCOR settings.

In a nursing home in Omaha a man is restrained and allowed to sit in his own urine day after day because no one cares. How many other persons are in like situations in nursing homes throughout the Omaha area? No one knows for sure since there are no groups evaluating and monitoring nursing homes where retarded people live.

Not all persons who are mentally retarded are living in situations like those I described above. I pointed those out to exemplify the fact that monitors are still desperately needed within GOARC so that quality services, and humane and dignified services are delivered to all persons who are mentally retarded. Although the Omaha area is recognized internationally for providing progressive and innovative programs for retarded persons, there are still retarded persons who are the victims of discrimination, abuse, neglect, and dehumanizing situations.

There will always be a continuing need for a strong advocacy organization whose major concern is the monitoring and watch dogging of programs and services to retarded persons. Only pressure from without can change dehumanizing, inhumane treatment. GOARC must continue to provide the pressure that is needed in order to change negative situations for retarded persons and to spark innovativeness and creativity within the present bureaucratic structures of the public schools, ENCOR, and other service providers in the Omaha area.

—

Executive Director
On rare occasions an agency is fortunate enough to attract an executive director who is willing to devote his every waking hour to the agency. If an agency is really lucky it can sometimes recruit a director who is a national leader. Other times agencies have been known to seek and find a director who has the ability to write grant requests, charm wealthy patrons into donating to the agency, or otherwise generate new dollars to help improve its services. Finally, an agency can occasionally hire a director who is respected and admired by staff and consumers, by sister agency personnel, and by the general public...someone who has enormous warmth and enthusiasm, integrity and sincerity.

But it is almost unheard of to find one person who has all of the qualities described above. Tom Miller is that kind of person, and GOARC will be hard-pressed to find another who can fill his shoes.

In the past four years Tom has helped engineer a twofold increase in the budget, from $125,000 to $250,000 and an increase from 6 staff to 15. We have new office space thanks to his efforts and those of other volunteers and staff. Our relationship with the other chapters in NebARC, and agencies like United Way are excellent.

But most of all, Tom's been a unique personality who has the ability to make all of us laugh and enjoy our work. He can prick our bubbles of arrogance and pomposity without insulting our motives or intelligence. He can convert a boring party into a lively one. He is a master at doing the unexpected, using earthy language but not offending anyone, at regaling others with jokes, at making people feel important.

He is the kind of guy who kicks off his shoes in the presence of royalty, who laughs loudest at his own mistakes. Tom cares about others and it comes through. He intuitively knows what to say to people who are hurting. He can "disagree without being disagreeable".

He may show up at your house on Halloween or as Santa Claus at Christmas. He is one unforgettable character.

Above all, Tom Miller is an advocate and friend to mentally retarded persons. Project II owes its existence to Tom as much as anyone, and mentally retarded persons are quick to acknowledge that debt. GOARC, Pilot Parents, Poverty and Mental Retardation, the Ombudsman, and other programs have all been helped by Tom, at one time or another.

We'll miss you, Tom. When you grow weary of your wandering mission, we hope you'll return home to GOARC. And if any of us can help you, we'd like to make your life as warm and worthwhile as you've made ours. Thanks!
Getting To Know You

Most of the newly elected GOARC board members as well as GOARC staff rather grudgingly committed themselves to a full day of orientation on Saturday, June 24. We met in the very comfortable fireside meeting area at Boys Town Center for the Study of Youth Development.

Over coffee and sweet rolls the 33 participants were asked to fill in questionnaires which revealed intriguing and little known facts about each other.

After a brief welcome and some introductory statements by Tom Miller on the purpose and the agenda for this meeting, we were reminded of the purpose of GOARC: to provide a strong support organization for all mentally retarded citizens by advocating for the rights, needs and full development of these citizens.

Marnie Miller was extremely helpful as our facilitator for this portion of the orientation. She reminded the board members of the confidence that has been placed in them to be leaders in the ARC movement. We identified some of the issues that currently face the board of directors such as funding, meeting the needs of special interest groups, and providing programs by geographical area.

Ed Skarnulis presented a brief history of GOARC and an outline of its structure. Tom Upton reminded board members that they are representatives of a grassroots membership. He also said everyone who was involved in GOARC needs to be free to share input and have it considered by board members.

John Clark spelled out what the relationship between board and staff should be. People were asked to consider both the positive and negative effects of a low, middle or high advocacy position on the issues that face the board of directors. This is a challenging time for GOARC. The board is off to an interesting year.
by Alice Blackstone

Spotlight on Dr. Larry Rice

"He's my Dr. Welby", said Mary (Mrs. John) Clark referring to Larry Rice, the doctor who first began caring for her daughter Gina at the Developmental Maximation Unit (DMU) at the Douglas County Hospital and soon after became the Clark's family physician and friend.

"Last May when GOARC presented him with an award for distinguished service, I introduced him as a gen¬tle man," she continued. "That's the way I think of him—a gentle, understanding man. He takes time to listen—a quality not easily found in the busy modern doctor."

Growing up in Lincoln, Nebraska, Larry took his pre-med on the local state campus, received his medical degree from the Medical School in Omaha, spent a year at Cincinnati Children's Hospital, and served as a resident in pediatrics at the University Hospital. About 3.5 years ago he was appointed medical con¬sultant to DMU and opened a family practice office in West Omaha. His decision to specialize in mental re¬tardation was partly influenced by the fact that his wife had a brother born with Down's Syndrome and partly because of his admiration for Dr. Jack Trembath, a staff member at Meyer Children's Rehabilitation In¬stitute. He spent three years at MCRI.

Parents, staff members, fellow workers agree; he's not just a super doctor; he's a super-person-one who makes parents feel comfortable about their children. They say he takes time to get acquainted with them and their families. With an introduction like this, you wonder if you're about to inter¬view a man or a myth. Dr. Rice is far from being a myth. He's low key, reflective per¬son-one who doesn't hit you over the head with his professionalism. His answers are simple and direct; he doesn't express himself in big words. He has the rare quality of being able to take himself and his work seriously, yet with a grain of salt. A youngish man, some¬where in his 30's; his eyes seem almost black, but soft, not piercing. You get the feeling he's done his homework. He's sorted out his values. He knows what they'll cost; he's willing to pay the price. As the jargon might put it, he seems to have got it "all together".

"He's a quiet guy who really listens," said Marilyn Dale, whose 5 month old daughter, Cassidy, died at DMU. "He treated my husband and me as if were persons, not just another case. Even though Cassidy was profoundly mentally retarded and physically handicapped, he never made us feel as some doctors did that she was just nothing. He was al¬ways honest with us, but we felt he cared. He referred to Cassidy as our daughter; he called her by name."

"Do you ever get discouraged and wonder if it's all worthwhile?" I asked.

Dr. Rice visits Eric Sutherland at DMU who is not feeling well, but he's in good hands.
"Of course," he nodded. "We all have our ups and downs, but there's always something we can do to make them more comfortable."

You get the idea he's not just talking about the same very sick little children you saw at DMU, but human beings who have distinct personalities and need love and affection as we all do.

"It's really something," Pat Henry, GOARC-Youth Advisor told me, "to watch him playing kitchy-coo with a baby. You forget the child is a sick baby—the scene is so natural."

The "man of distinction" likes to be where the action is. Reports have it on Awards Night, he shed his jacket and joined forces with Project II and GOARC-Youth workers who were setting up tables and chairs.

During a blizzard last winter, he walked five blocks from his home to the hospital and DMU. "He thought we might be short-handed," said Gail Morrissey, a line nurse. "He hung around all day, dressing, playing, and helping us with meals and caring for the kids."

When I asked him during our conversation "how come?", he alleged it was easier than staying home and doing chores.

"How do you deal with stress?" I asked. "My family helps me," he replied, explaining that his four young children and wife are very important to him. "Professionals historically let their jobs overshadow their family obligations," he added. "I decided long ago my main goal was not to make money. I'm willing to settle for less income in order to have time to spend with my family."

The Rice family, according to him, aren't much for getting involved in highly organized activities; they just enjoy being together. Since both he and she wife, Mary Jo, come from large families, extended family situations with lots of uncles, aunts, and cousins provide lots of good times.

Beside his office listing in the Yellow Pages, a notation reads: "Telephone answered 24 hours." On a Sunday afternoon, less than 15 minutes after I placed a non-urgent call, his partner, Dr. Paul Nelson, was on the phone answering my questions—a clue to their joint family practice philosophy, Larry and Paul met as residents at the University Hospital. Working together, they discovered they shared many of the same ideas about the kind of doctoring they would like to do. Teaming up has provided each of the doctors with support and re-inforcement that makes it easier for them to stick to their goals.

"Larry always gives me good advice when I need it," said Dr. Nelson. "When I'm not on call I can depend on him to take good care of my patients. He has a kind of quite, wry humor that takes the pressure off when things get hectic."

"We try never to schedule patient's appointments too close," said Gail Harrison, an office assistant. "Neither of the doctors want patients to feel they're being rushed in and out."

Describing the office atmosphere, she called it friendly and unpressured. Many of the patients call the doctors by their first names. "Always, when I'm ready to leave for the day," she said, "the doctors tell me 'thanks.'"

By this time, you begin to feel you've met the real Dr. Welby, not just the shadow of a man on a television screen who makes viewers long for the old-time doctor.

You've decided Larry Rice is more than a man with a medical degree and a license to practice; he's a 'committed person who puts his skills and energy into values he perceives as lasting and real. In that sense, you might even call him a religious man, for in his own unique way both the man and the doctor have taken to hear that well-known Biblical admonition. "Lay not up for yourselves treasures upon earth, where moth and rust doth corrupt, and where thieves break through and steal. Lay up for yourselves treasures in heaven, for where your treasure is, there will your heart be also."
HOWARD MARCUS not only believes mentally retarded people should have a better image in society, he's doing something about it. Along with other members in Scout Troop No. 597, he's helping give a mentally retarded member a feeling of belonging. Proceeds from a recent garage sale sponsored by the troupe, were given to GOARC.

THE GAME'S THE THING - Chris Beem, President of GOYARC & Pat Henry, sponsor, attended a conference called "New Games" on June 24-25 at the University of Nebraska at Omaha. "The focus," said Chris, "is not so much on new games but on a new philosophy for playing games. It's more important to have fun than to win; fancy equipment is played down; and it's important to involve as many people as possible. You don't have to be a top grade athlete to participate and have fun."

TWO TOM'S BREAK INTO PRINT - Tom Heeren, son of Larry & Pat Heeren was recently pictured and his many accomplishments featured in a story in the (Omaha World Herald. As a result, many not congratulations poured in, one of them from Rosemary Skrupa who suggested he must make it hard on others who just want to slide along the easy way.

WALLPAPERING WITHOUT WALLS - showed Tom Blackstone, son of Alice & Glen Blackstone, with a collage of a cat he had created mainly out of wallpaper. "Tom was especially thrilled when a visitor from Texas not only liked but bought two of his original art works, an owl & a cat. He's busy getting ready for a show in mid-November at the Antiquarian Book Store in the Old Market."

FUN AND FITNESS for the Handicapped began July 3rd and runs daily from 12:30 to 3:30 PM (except holidays). For eight weeks at the YMCA West Branch at 75th & Maple, Directed by Dianne Dummar, participants enjoy swimming, exercises, games, and crafts. A similar program runs during the school year from 3:15 to 5:15 PM.

DAVIS GANG SPREADING OUT - After 11 years of an increasingly "cramped" lifestyle, Glenda & Larry and the 6 Davis sons have burst out of their home and are spreading themselves out over 3600 square feet of floor space on three levels at 5116 Burt Street.

JOGGING ALONG - Tom Miller, Bonnie Shoutz, and Mike Curoe recently made a 9 mile run from Dodge Park to 16th & N Rd, with one casualty-Mike sprained his knee.

NEW PILOT PARENT - Kathryn Schowpke hosted a morning coffee at her home at 2212 South 103rd Circle. "TYPICAL LADY'S LAMENT - "The only place I didn't bother to clean," said Pat Heeren, describing the light of Pilot Parents to hide out in her basement during a tornado scare. About 40 parents spent the fearfully seating at their annual picnic in her backyard.

ANDREA ADAMS - arrived on June 7th to join big brother Aarik and his mother Willy. Aarik, 3, is visually impaired. Pat Heeren who pilots the family, says Aarik has made super progress.

CITY PARKS AND RECREATION DEPARTMENT prepares COMMUNITY CENTERS TO HANDICAPPED Benson Community Center, Christie Heights, Florence and Sorenson Community Center are offering arts and crafts, physical fitness programs, and social hours for mentally retarded and physically handicapped people. Schedules for Fall will soon be out. For detailed information call Glenda Davis at the GOARC Office.

IKE NUSCHY - Professor of Special Education at the University of Nebraska at Omaha is busy working on a curriculum for Omaha Public School teachers of profoundly retarded students.
Aloha Hawaii

Karen Knudsen, Gazette editor, and her husband Greg will be leaving this month for Hawaii. Greg has been awarded a two year federally funded grant to study "the effects of mass communication on developing countries" for his masters degree in communications at the East-West Research Institute. The institute is located at the University of Hawaii campus in Honolulu, Hawaii.

Besides being the Gazette editor, Karen has held the position of Communications Specialist at the Eastern Nebraska Community Office of Retardation. She, too, plans on working towards her masters degree in Teaching English as a Second Language.

After Karen and Greg's two year stay in Hawaii, they are hoping to live in Asia or the Pacific Islands. The GOARC staff and volunteers appreciate all the time and effort Karen has put into the Gazette and wish the couple well.

Outreach Specialist Returns Home

Sherry Noley has been working as one of the Outreach Specialists in the Pilot Parent Program since April 10. She is the parent of three daughters. Lisa is 14 and will be a sophomore at Burke High School this fall. She is very interested in marine biology and has a dream of some day living in Australia. Kimberly is 10 years old and enjoys playing cards, drawing pictures and guitar music. Miki will be five in August and likes to eat chocolate ice cream and green apples at the same time. The entire family spends a lot of time camping and swimming.

Sherry is originally from Omaha but for the past seven years she has lived in Teaneck, New Jersey. In Teaneck, Sherry was active in voluntary parent support groups. She is the former executive director of the Commission on Voluntary Service and Action of New York City and has worked with many voluntary service organizations throughout the United States and the world. All of the Noleys are glad to be back home.
On Monday night, July 17, that fun bunch of people called Pilot Parents, and their families got together at Cooper Farm for their annual picnic. The crowd was great, (over 200), the food was delicious, the weather was perfect and friendships were blossoming. All of the necessary ingredients combined for a fun picnic.

A good time was had by all, thanks to Pat Henry and a bunch of GOARC Youth who led the group in "NEW GAMES". Jaws was there, lurking under a parachute, and a mysterious killer roamed through the crowd, inflicting his deadly poison on many.

The only showers were from a group of crazy adults throwing eggs at each other, goodies pouring from the pinata, and water balloons "bursting in air".

About 10 PM a lot of tired parents packed up the remains, and a lot of full, dirty, tired and happy kids then headed for home with many pleasant memories.

A SPECIAL THANKS TO: Peggie and Chris Christiansen (without them, it wouldn't have happened), Mary Lou and Carl Christenson, Darlene and Mike Hawley, Pat Henry, GOARC-Youth, McDonald's, WOW Radio, Cooper Farm, and all the Pilot Parents who pitched in and made a successful evening.
The above is the inscription on a plaque given to our Ombudsman in recognition for outstanding advancement and program development. I say "our" because Carl worked for all of us, not just the developmentally disabled, but for an understanding of all our rights as human beings to respect ourselves and others even through differences.

Carl stands behind his beliefs with action as well as words. He has developed an Ombudsman program that began serving only the clients of the Eastern Nebraska Community Office of Retardation to a program now serving the persons who are developmentally disabled in all of Region VI. He has been through several funding sources from ENCOR & GOARC to the Comprehensive Employment and Training Agency (CETA) and now through the Nebraska Developmental Disabilities Council. Carl has helped to establish many on-going policies to protect and promote the rights of developmentally disabled persons.

Carl will now be employed by the Illinois Protection and Advocacy Agency as Resident Advocate in Illinois' largest institution, Dixon State Hospital in Dixon, Illinois.

Good luck Carl! We miss you already.
Randi Growing Up

There's not much you can say about Randi Christiansen that hasn't already been said by others - that she's cute, didn't faze her, and even from the end of the dance line, she seemed to know that nearly everyone there had their eyes on her.

She has learned to read and do arithmetic in Mrs. Monik's class at Madonna School, and all year she has written her own invitations. The bright lights and the big crowd didn't faze her, and even from the end of the dance line, she seemed to know where she was going.

Someone said about Randi, "She knows where she's going." True. Like her parents, Peggie and Chris, she makes it all very simple. Not to worry. Just do it, whatever it is, with charm, with style.

One could see her growth and confidence at her June 2nd dance recital, for which she grew up.
Randi is happy dancing and likes just having a good time with her mom and dad.
ENCOR Policies Given

Questions often arise regarding ENCOR policies and procedures. The following information should help to clarify and answer questions regarding appeals and grievances; alternative communication systems, and consumer participation and representation.

ENCOR POLICY ON APPEALS AND GRIEVANCES — The Eastern Nebraska Community Office of Retardation hereby declares and affirms the right of any mentally retarded individual or person acting on his behalf (parent, relative, legal guardian, citizen advocate, agency representative) to appeal any decision made or action taken by ENCOR regarding the mentally retarded individual.

It shall be the responsibility of all ENCOR employees to explain and to model ways of resolving problems, including discussion, compromise, and the right to appeal, whenever they are contacted about complaints, and, if necessary, to help the complaining person to start the appeal process.

There shall be two processes for appeals of ENCOR decisions, designated as formal and informal. If a decision which involves a substantive issue is made in regard to a mentally retarded person, the mentally retarded person or his guardian or other representative shall receive written and oral notice of the decision and of the reasons for the decision, in addition to notice of the effective date of the decision and notice that an appeal for a review of the decision may be filed. In these cases, if an appeal is filed, a formal appeal process will go into effect. For the formal process, a hearing examiner will be appointed by the ENHSA Governing Board.

The formal process consists of the following elements:

a. a hearing by an impartial hearing examiner within a reasonable amount of time.

b. the keeping of a permanent record of the hearing.

c. provision of opportunity for the mentally retarded person and/or his or her representative to be present.

d. and, if desired by the person making the appeal, a review of the findings to the hearing examiner by the governing board of the Eastern Nebraska Human Services Agency. The ENHSA governing board has the authority to affirm, amend, modify or over-rule any decision made by the Agency hearing examiner. The written decision of the governing board will be given to the appellant and kept in the record.

The hearing examiner shall automatically be called to hold a hearing on any decision to terminate direct services to a client on an involuntary basis. The hearing examiner may review other decisions, upon the request of the mentally retarded person and/or his or her representative.

For all other complaints, grievances, or disagreements, and informal appeal procedure, designed to provide for resolution of the problem within the agency, will be provided.

Any employee who is contacted about, or becomes aware of, a consumer complaint about or objection to an ENCOR decision or action must contact the consumer’s advisor. The advisor will investigate the complaint by contacting the complaining party, and will put his or her findings in writing. Depending on the results of the investigation and the wishes of the consumer, the advisor...
will help the consumer to file an appeal.

During the time an appeal is in process, the service status or decision is in effect at the time the appeal was filed will be continued. If, for example, a decision was made that an individual would be involuntarily terminated from services, services would continue at the same level during the appeal process. If, on the other hand, an individual appealed a decision after it had been implemented, the decision would stand during the appeal process.

Nothing in this policy shall be construed to mean that the individual cannot seek redress for his grievance in court at any time.

For any consumer who cannot readily understand or communicate the English language in meetings where decisions will be made concerning him/her, a person agreed upon by the consumer and the Individual Program Plan team must be available to interpret all information discussed with the consumer and should interpret to other members of the team anything which the consumer indicates that he/she wants.

A person or persons will be designated by ENCOR as liaison with public/private schools or other agencies for consumers started on alternative communication systems in ENCOR. The person(s) will coordinate training for staff persons in the other agencies and monitor progress by consumers.

Each person must be present at his/her Individual Program Plan team meeting. On any occasion when a person receiving services from the agency does not attend an IPP meeting concerning him/her, specific reasons must be clearly stated in the written record of the meeting as to why he/she was not present.

If the person is under the age of majority or has a court-appointed guardian, parents, or legal guardian must be invited.

The agency supports, as a right, the participation of consumers in matters affecting them and/or representation by a legal guardian in such matters.

Who To Turn To For Help

The Action Committee on Poverty and Mental Retardation has now made available to interested parents a Pocket Directory of Services. Billie Cook, Coordinator of the program, said the purpose of the directory is to "inform parents of services in an emergency situation".

The quantity of directorys are limited. For more information or to obtain a copy of the directory contact Billie Cook at the GOARC office (348-9220).
Recently, while in Minnesota for a two-day conference, I took advantage of the opportunity to visit the Minnesota Diversified Industries. This is a non-profit corporation which employs handicapped and non-handicapped people side-by-side in a unique approach to hiring handicapped individuals. While I was there, I was able to visit two plants. One is the Maplewood plant and the other is the original plant on Pelham Blvd.

Minnesota Diversified Industries has a staff of 380 with a total budget of $2.5 million. Currently their plants operate at an 82% self-sufficiency rate and the other at a 79% self-sufficiency rate. The rest of their monies are in a subsidiary. These subsidies come from local industries and from their state division of vocational rehabilitation. The goals of the Minnesota Diversified Industries are: 1) maintain the current level of agency self-sufficiency, 2) have available the resources need to further improve the self-sufficiency of the corporation, 3) to provide the resources needed to expand the current 200 employment positions for persons who are handicapped to a total of 400 positions by September, 1980.

Minnesota Diversified Industries is a business model on the idea that one worker can learn from another. By use of the "model worker", a great deal of their training takes place. Minnesota Diversified Industries is run totally as a business.

In their capital fund drive booklet it says "this is not kindness this is a business. They're good workers and they're a good investment." The attitude is that this is a business; this is not a social service department. People are treated as valued workers and are given the same kind of incentives. I was extremely impressed with the diversification of the contracts, the people doing them, and what I saw happened while I was there. Currently, they are working for Sperry Univac doing micro assembly jobs. In this job they have a record of producing 2 million parts without a reject. Another job they have involves counting, sorting, and packaging electrical terminals and other items from local and national marketing firms. Each product contains over 11,000 parts. Another contract was assembling muffler clamps that employ 25 individuals and would continue as long as the muffler manufacturer is in business.

It seemed to me that the hallmark of this entire operation was that a great deal of people have worked to allow handicapped persons to attain a greater self-sufficiency in working. A quote that I saw there was "Work is important to each of us ... yet for some it is critical..." I think that pretty well spells out what type of operation they had going.
Convention Drawing Closer
by Bonnie Shoulztz

The first annual convention of "People First of Nebraska" will be held on August 26th - 27th at the Nebraska Center for Continuing Education, 33rd and Holdredge, in Lincoln. "People First of Nebraska" is a yet-to-be-formed organization which is a major goal of the members of Project II.

Registration for the convention, which will cost about $21.00 per person, should be completed as soon as possible. For registration forms, contact Ray Loomis or Lynne MacDonald at GOARC.

The convention's agenda is as follows:

CONVENTION AGENDA

August 26
11:00 A.M. - 1:00 P.M. Registration (provide your own lunch)
1:00 P.M. - 5:00 P.M. Who and What We Are, and Why We Are Here
   Film - 'People First'
   Floor Discussion - Introducing yourself &
   telling what you believe
   Workshop - How to Start Your Own Group
6:00 P.M. - 7:30 P.M. DINNER
8:00 P.M. - 11:00 P.M. Dance

August 27
7:30 A.M. - 8:30 A.M. BREAKFAST
9:00 A.M. - 12:00 noon Resolutions
   Election for Statewide officers
   Future Plans for 'People First'
12:00 P.M. - 1:00 P.M. LUNCH

Publicity Efforts

Project II members Ray and Nancy Loomis, Ollie and Lowell Rector, and Robert Fox have spoken about the convention to groups in Lincoln, Fremont, Blair, Omaha, Valentine, South Sioux City, Norfolk, Wayne, and four other Nebraska towns. In addition, Ray and Nancy Loomis were featured on Community Connection, a KETV (Channel 7) show moderated by Betty Shapiro.

The newsletter of the President's Committee on Employment of the Handicapped will soon include a feature article on Project II, thanks to Tom Houlihan, Project II Vice President. Tom has sent brochures and other information on Project II to many of the national and local agencies, to the media, and to many elected officials.
No one expected a victory in the softball challenge by the Douglas County Young Republicans. But GOARC-Youth were jubilant in their 7-4 win.

During the camp-out to Lewis & Clark, 25 Youth would have gladly headed home to their warm, dry beds. But after 5 inches of rain came a full day of sun. Sleeping bags dried. Spirits lifted.

Jim Toms has a premonition that this tent may not hold out the coming rain.
John Glynn will begin as the new Executive Director of the Greater Omaha Association for Retarded Citizens on August 16, 1978. He is currently the Project Coordinator for the Children's Rehabilitation Unit at Kansas University Medical Center in Kansas City, Kansas. Prior to that, Mr. Glynn was Planning Director for the Kansas Planning Council on Developmental Disabilities in Topeka, Kansas.

Mr. Glynn offers GOARC a unique balance of administrative skills and a strong belief in people and their potential.

Dear GOARC:

I would like to take this opportunity to express my thanks for receiving your Special Teacher of the Year Award. This honor would not have been possible without the dedicated help of so many of your GOARC members, especially members of the Pilot Parent Program. It has been a privilege to be associated with such a dedicated group of people. I sincerely hope that their interest and their support in helping me to develop a curriculum for severely handicapped will continue.

Once again, thank you for selecting me for this special award. I am looking forward to your continued support.

Sincerely,

Michael Nuschy
Nearly 20 GOARC volunteers have worked hard at developing our issue of the Gazette. Some took pictures. Some wrote articles. Some stapled it all together.

GOARC’s members are actively involved in their GOARC Gazette and loads of other projects—large and small.

Others cannot be as active. But they join to lend support to the GOARC cause and the work its people do.

COUNT ME IN AS A GOARC MEMBER:

Name: ___________________________ PHONE: ___________________________

Address: ___________________________ Zip Code: ___________________________

City & State: ___________________________ Count on my help: ___________________________

Enclosed: ___________________________

O ACTIVE - call me for volunteer projects
O SUPPORTIVE - I believe in the cause

$9.50 Adult or Family Membership
$5.00 Youth Membership

_MRGJJ979...Art-Design Contest_

All mentally retarded citizens are encouraged to enter in the NARC Art Contests by drawing or painting as many pictures as they wish. The winning entries in the contest will be produced as designs for the NARC Christmas cards and the 1980 calendar.

Entries should be traditional Christmas scenes or designs, or general holiday scenes adaptable to a "Season’s Greeting" message.

All entries are to be in by November 1, 1978.

For details on entering call: GOARC 348-9220

The printing of the GOARC Gazette is financed, in part, by a donation from SWING FOR THE RETARDED.
At home at ENCOR's Chicago Street Residence...story page 10.

Greater Omaha Association

For Retarded Citizens
A Message From The Director

Dear GOARC Member:

This will be the first of what I hope are many messages to you. I am thrilled, and more than a little awed, by being here as a member of the GOARC team. GOARC and Omaha have a rich tradition of being responsible and responsive to the needs of people as they struggle with the dependencies that pose barriers to human rights and human dignity. I am impressed by the maintenance of the value of the family, which in so many places has been misplaced if not lost. I am encouraged by the young people of GOYARC, knowing that the effect of this particular group of young people is growing, gaining strength, and is challenging to us older people as we see the exhuberance of life they so freely exhibit. I am deeply moved by the strength of conviction the parents show as they work, and it is very hard work, to achieve all the independence their child is capable of sustaining. I have encountered a staff that lives its commitment to the cause of human dignity as they work to find resolution to the suffering caused more by social stigma than physical discomfort. And I find strength in those who have struggled beyond what could have been life without purpose to lives of independence and who now organize to help themselves with Project II and People First.

We have all the elements of a good organization that is destined to get better. We have tradition rich in progressive spirit. We have youthful exhuberance and monitoring. We have belief in our convictions by people willing to work hard in the struggle to remove inequity and inequality. We have examples of the dignity of self-help.

The tasks before me are tremendous: providing leadership and motivation for the staff; being responsive to the Board of Directors; and being responsible to the parents and citizens we serve. Because of your progress and the quality of the persons who have gone before me my best may be just adequate. I do not mind this. I think I will thrive here, grow from your experience and support. I will contribute the bits of information and knowledge I have, a willingness to work, a commitment to your goals, and the strength of my principles. I hope you will accept that as sufficient reward for what I shall take from you.

As a starting point for our journey together I would like each of you to keep in mind that a disability is a diagnostic categorization of a human being, placing a label on a person to either indicate eligibility for services or to identify that person as being different, deviant, unacceptable. Too often the latter is the cause of the label. I do not intend to waste the time of the staff, the Board of Directors, or the Membership trying to resolve disabilities. We will direct our energy to the resolution of handicaps, those barriers to normative living. If a person can perform a task but needs a place to perform it, we'll find a job — remove the handicap of economic dependence, provide the dignity of self-sufficiency. If a child needs a piece of special equipment to communicate, we'll find, procure, or invent a way for that child to communicate — remove the handicap of silence, provide the dignity of social interaction. If a couple can't marry because of community attitudes — we'll work on attitudinal change providing dignity of social acceptance.

And when our own weaknesses become barriers to the fulfillment of human rights and dignity we'll reach out for the support of our brothers and sisters realizing that our task transcends us as individuals and builds within us the dignity of being human.
Bits 'N Pieces

by Ed Skarnulis

Usually the President's message is a lengthy discussion of one subject but for a change of pace, I thought it might be worthwhile to just share a variety of thoughts, opinions, and issues which are not burning with you.

Welcome aboard to our new Executive Director, John Glynn. If you haven't met John, please feel free to stop by the GOARC office and say hello. I'm sure you'll find him an engaging person. Your Governing Board certainly felt that way when they interviewed him and selected him for the job. He certainly can't be accused of being a slow starter in the job. He's been going full blast since the day he opened the office doors (see the rest of the Gazette for examples).

The National Education Association passed a motion at its annual convention this summer which recommends that all of its teachers and member chapters become involved in the work of local associations for retarded citizens. Members are encouraged to assist ARC's in fund raising, monitoring and advocacy, and support for parents. Since most of the teachers in our schools are members of the National Education Association it gives all of us a beautiful opportunity to invite them to join our organization and participate in our programs. Next time you're at school with your son or daughter, why not take a few minutes to talk with their teachers about this? GOARC and the local chapter of the National Education Association could be very powerful allies.

One of the best bumperstickers I've seen around is the one that says, "Have you hugged your child today?"

Your new Board and Executive Committee have been meeting since July 1 to plan for the coming year. The meetings of the Executive Committee are held the first Tuesday of every month at your GOARC office, 7:30 P.M., and the Board meets at the same place and same time on the third Tuesday of each month. Why not do a little personal monitoring to see if you're getting your money's worth from the people you elected? The meetings are open to all members.

Honey Sunday is coming up soon! Something many members may not realize is that this is one of the few sources of uncommitted funds GOARC has. The money we get from United Way and from federal grants always has strings attached to it which forces us to use it in a certain way for a certain program. The Honey Sunday money gives us freedom to sponsor special activities that are not otherwise possible.

Speaking of funding - we are now approaching funeral home directors for permission to place Memorial envelopes in their mortuaries. Many people prefer to donate to a charitable organization rather than buy flowers and we're hoping that friends of GOARC will see this as an opportunity to establish a living memorial. Also, Don Grimm is looking into the possibility of setting up a foundation for GOARC which will allow friends of mentally retarded persons to leave bequests designed to help GOARC continue its work. He'd appreciate any suggestions from members who are familiar with this sort of arrangement.

NARC has its national convention in Boston this year November 15-18. Any body interested in attending, please contact Amy Humphries at the GOARC.
office for further information. Start saving your pennies now — the 1981 convention is in Hawaii.

I THINK ALICE BLACKSTONE HAS DONE A TERRIFIC JOB in her feature on families and their children. And, least he be forgotten, ROBERT COLEMAN and his photography work is equally outstanding.

CONGRATULATIONS TO DON GRIMM on his new job at Touche-Ross, TO GENE AND JUDY NICHOLSEN on their new addition to their family, TO CRAIG FECKER on his new job at Northern Natural, TO RAY LOOMIS AND PROJECT II for their "super" first convention, AND A SINCERE THANKS TO ALL OF THE VOLUNTEERS WHO WORK ON COMMITTEES AND SUB-COMMITTEES OF THE MENTAL RETARDATION PANEL.

I'LL BE HOSTING THREE VISITORS FROM ENGLAND during the months of September, October, and November. Doug Wantling is an architect with Barnardo's (an organization like Boys Town only for both sexes and their houses are small group homes). He'll be here from September 28 to October 2. Vince Gorman, a friend of Derek Thomas who visited us in the early part of the 70's, works in an institution that's trying to put itself out of business. Vince will be here from October 1 through the 6th. Alan Tyne works for Campaign for the Mentally Handicapped, the advocacy organization in England that has fallen in love with GOARC and ENCOR. Alan edited a book about ENCOR that is better than anything we've written here. If anyone would like to meet these gentlemen or help me host them, please give me a call.

Anyone who would like to help put together a display of these awards and memorabilia, please contact Amy Humphries. We need people to help frame pictures and newspaper articles, as well as design an attractive arrangement on one of the walls in the office. If you're handy with hammer and nails or want to exercise some artistic talent, let her know.

CONGRATULATIONS TO DON GRIMM on his new job at Touche-Ross, TO GENE AND JUDY NICHOLSEN on their new addition to their family, TO CRAIG FECKER on his new job at Northern Natural, TO RAY LOOMIS AND PROJECT II for their "super" first convention, AND A SINCERE THANKS TO ALL OF THE VOLUNTEERS WHO WORK ON COMMITTEES AND SUB-COMMITTEES OF THE MENTAL RETARDATION PANEL.

FINALLY, when this Gazette goes to press the outcome of JIM WOOD'S EFFORTS to halt the opening of yet another nursing home for mentally retarded adults will not be known, but Jim should be recognized nevertheless for the time and energy he has put into this human and legal rights activity.

Do You HAVE SPARE TIME?

The secretarial staff needs help with light office duties such as: stuffing envelopes, collating, stapling the Gazette, etc. If you can type, that's a big help.

To volunteer call: Lynne or Donna at the GOARC Office (348-9220).
ELAINE VAN WE RIDES THE BIG BIRD - Elaine left for a week's vacation on October 1st to visit her mother in Washington State. She wasn't really scared, just excited about her first plane trip. Elaine works at the Holiday Inn.

RECENT CATARACT SURGERY - on both eyes didn’t keep HAROLD EDWARDS AND WIFE INEZ participating in the “People First" Conference recently held in Lincoln, Nebraska. Although Inez didn’t win a prize for dancing this time, she had a lot of fun.

TOM HOULIHAN DOESN'T WASTE A MINUTE - another enthusiastic member of Project II, he not only enjoyed his week of vacation at the Easter Seal Camp but used it to recruit people for the “People First" Conference. Tom often chairs Project II meetings. He works for the St. Vincent de Paul Society.

MOVING DAY IS COMING FOR LOWELL AND OLLIE RECTOR. Excavators will soon begin moving dirt for their new three bedroom home on 72nd Street near Crossroads Shopping Center. Ollie has worked for the past two years as a sandwich and salad maker for the Omaha Field Club; Lowell works for the Methodist Hospital Laundry Department.

OLD FRIENDS TURN UP - JACK CONRAD says he met many old friends from Beatrice at the recent “People First" Conference. "Many of them wanted us to help them get organized," Jack said. "We told them not to be afraid to speak out. We wouldn’t let them down."

RADIO PUT OUT THE WORD THAT RAY LOOMIS was coming to the sioux city workshop to talk to people about "People First". Who showed up and surprised him? A brother he had lost track of. "We had a nice little reunion." Ray said.

ED ROBECK VISITS BEATRICE - "... surface everything seemed so nice," Ed said, describing the trip he took with GOARC Director, John Glynn. "But pictures were bolted to the walls - not a good example of a normal home setting. None of the staff seemed to interact with the clients as they do at ENCOR, where every body feels like part of the group. The staff are all just medical and therapy models." Ed is a senior at Burke High and an enthusiastic member of GOARC. Asked how he happened to get involved, he said a friend asked him to a meeting and he got "hooked".

SUE HALVORSON, a 1973 winner of a Volunteer of the Year Award, has become a "big sister" to Bobby Schellhard, 9, who is a student at ENHSA's Children's Center (for children whose disability is mainly emotional). Sue got to know Bobby this summer while working on an excursion at least once a week - swimming, to a football game, on a hike through Fontenelle Forest. Sue said that the special attention is having a positive effect on Bobby who she describes as "a really neat kid...He's come a long way."

INSPIRATION FROM JOHN GLYNN - "... cloud does not know why it moves in just such a direction and at such a speed. "It feels an impulsion... this is the place to go now but the sky knows the reason and the patterns behind all clouds and you will know, too, when you lift yourself high enough to see beyond horizons." FROM ILLUSIONS by Richard Bach.
CONGRATULATIONS TO DAN SAKATA on his recent promotion. Dan has been selected to head the Health, Education and Welfare Region VII Office of Developmental Disabilities.

HELP WANTED FROM YOUR ROVING EDITOR - ODARCia is growing rapidly. I have only two eyes and ears to catch what's going on. Call me (553-6381) when you have a bit of news. Your cooperation will be a boost to better coverage. Remember: ODARCia wants to know what you're up to!

MICHAEL NUSCH is developing a curriculum for student teachers at UNO for teaching severely/profoundly handicapped children rather than for OPS teachers as printed in the August issue of the Gazette.

LEAD POISONING REPORT: OVER 4,000 CHILDREN TESTED

The Omaha-Douglas County Health Department Childhood Lead Poisoning Program has tested 4,025 children as of August 31, 1978.

The program which received a federal grant February 1, 1977, is doing blood testing of children from six months through five years of age by means of a simple finger stick for lead poisoning and iron deficiency anemia. It also does necessary medical and environmental follow-up on children found with a problem.

Thus far, the program has identified 191 children with some degree of elevated blood lead ranging from minimal to extremely high. This is 4.7% of the children tested. In addition, 108 children have been referred for nutritional counselling because of iron deficiency anemia.

The program pediatrician has chelated 24 children since the program began to remove dangerously high amounts of lead from their bodies.

The first year target area in Northeast Omaha, from Dodge Street north to Redick and from 48th Street East to the river, was expanded in April of this year to Southeast Omaha, from Dodge Street South to Harrison and from 42nd Street East to the river. Door-to-door screening by Lead Program personnel continues in both the North and South areas. The target areas were selected because they contain a high percentage of housing units built prior to 1950 when paint containing large amounts of lead were commonly used.

High levels of lead in small children if left undetected can result in mental retardation, blindness, and death. The Health Department urges all parents of children between six months and five years to take advantage of this free program, particularly if they live in or frequently visit homes built before 1950. Call 444-7825 Monday through Friday between 8:00 A.M. and 4:30 P.M. for an appointment to have your children tested in your home.

Wayne Downie
Registration begins

Dave Menousek
Delegate

Co-Chairperson, Ollie Rector talks to
U.P.I. Reporter

Elaine Van Wle
Delegate

Roger Gunn with fellow delegate
discusses issues.
"PEOPLE FIRST"

People First of Nebraska was a first for Nebraska in many ways: handicapped people organizing themselves as a powerful and effective group; proving that they are ready to wield political power; defying stereotypes; and preparing to systematically attack what one young man called "the barriers that have been set up in front of us." Behind the political scenes, however, the People First experience touched and changed many people in a very personal way:

One middle aged man who had never spent a night away from home and his parents had his first exposure to his own social peer group. Though quiet and soft spoken, he left saying softly, "stand up for my own rights".

A woman spoke of anger she feels when she wants to go somewhere in her community, her staff has to know where she's going so it can be charted as part of a socialization program. She learned how to ask some questions about it.

Another man, a resident of a nursing home, spoke also in anger of the complete lack of privacy in his life. He asked for, and received, the assurance of the group that he is right to be angry.

The issues of freedom, of resenting that other people are in the position of telling them what to do; of the strong drive and the need for autonomy that many agencies and programs cannot tolerate, much less encourage; the lack of privacy, and most of all the anger—these were heard over and over again in the course of the two day conference. And gradually we began to hear other kinds of statements interwoven:

"We can help each other by talking to each other, about the problem we have".

"I don't need anybody to push me around any more. I go shopping, go out places, meet people, have a good time; help other people, too."

"You have to be persistent to get through to politicians. You have to band together as a group."

"You can help yourself. You can do anything."

"You believe in yourself. The idea of People First is helping others."

Gradually, people began to realize that they could help themselves and help each other. The focus of the conference widened from a discussion of individual problems, to the level of organizing and identifying with other handicapped individuals in one's hometown; to finally, the level of establishing the framework for a statewide "People First" organization, and drafting a list of resolutions reflecting their beliefs.

As a professional, I was an "outsider" at the conference and found it a very different perspective from which to view handicapped adults. Sometimes, it was hard not to speak up, or to intervene to help somebody who seemed to need it. But what is unique about the "People First" movement is that it provides something that no professional or service agency or parents' organization can give to a handicapped individual: the pride of self-determination; of having made a decision or voiced an opinion or expressed a feeling as an autonomous, respected, and dignified adult. I realized how often I had interfered too soon, offered too much help, or used my professional status or title to put some distance between myself and the handicapped people I know. Professionals can too easily perpetuate the state of inequality between normal and handicapped persons, even when they work for community based agencies or are members of an advocacy
oriented group who believe in the principle of normalization. Wolf Wolvensberger has warned that the "self advocacy'' movement could easily become a scapegoat, allowing other citizens, professionals, or parents to conclude that there is no need for "other advocacy" groups, and I think it is a legitimate worry. The role of non-handicapped advocates must grow stronger, not weaker, as the self advocacy movement grows. And People First needs some very sensitive support from parents, professionals, and other citizens in order to continue to flourish as it has. As one of the participants in the professionals' workshop at the People First of Nebraska Conference stated to the delegates:

"Our job is not to give you ideas. You are the only ones that can provide the ideas and the initiative. It's your group, and our job is to only help you find ways to carry out the ideas and do the things you want to do."

Another professional pointed out that sometimes the main thing that self advocacy groups will need from their non-handicapped advisors or consultants is to be protected from well meaning but inept interference; from being controlled or directed by forces from outside their own group. Otherwise the group cannot evolve according to its own unique dimensions.

We have good reason to be proud of Project II and the People First movement which its membership has started in Nebraska.

STATEWIDE CONFERENCE SUCCESSFUL

In August, GOARCs own Project II sponsored a tremendously successful first - a statewide convention of mentally and physically disabled people. About 170 delegates from 24 Nebraska cities and towns attended the convention, which was held at the Nebraska Center in Lincoln. (One group of 5 people came from Valentine, which is over 350 miles from Lincoln.) Convention leaders were Ollie Hector and Ray Loomis; they encouraged (and received) lots of give and take between speakers and audience.

One major accomplishment of the convention was the development and adoption of a set of resolutions. Another was the election of a statewide "People First" Committee. The Committee will coordinate the fledgling statewide organization and will meet bi-monthly to plan future moves. Its members are Ray Loomis and Jack Conrad, Omaha; Roger Gunn, Bellevue; Pat Miller, Blair; Rick Kocil, Columbus; and Jim Beeson, Norfolk.

The mood of the convention was activist; the delegates were very aware of the need to advocate for themselves and to make their voices heard. Their resolutions have already been submitted to the Nebraska Mental Retardation Panel, to the Developmental Disabilities Council, and to the Nebraska Advocacy Services. Group members will offer to consult with those who are planning for future services.

The convention was a time for fun as well as work. A dance, with music by singer-guitarist John Adams, was held on Saturday evening. Many people got together with old friends whom they had known in the Beatrice State Developmental Center.

None of this would have been possible without the faith and commitment of Project II members, who had to learn how to plan, how to speak in public, how to get publicity, how to organize, how to stuff envelopes, and many other things in order to put the convention together.

CONGRATULATIONS, PROJECT II.

Bonnie Shoultz
DELEGATES ADOPT RESOLUTIONS

Editors Note: What follows are some of the Resolutions, Goals, and Statements adopted by "People First of Nebraska" during their convention. A complete list may be obtained by writing or calling the GUARC Office (342-9110).

I. Philosophical Statements:
1. We believe that we are people first, and our handicaps are second. We wish people would recognize this and not give us a tag like "handicapped" or "retarded".
2. We believe that we have to fight for our own rights,- and that unless we do we won't get them.

II. Realization of Our Rights:
1. We have the right to stand up for what we believe in.
2. We have the right to live where we choose.
3. We have the right to equal pay for equal work.

III. Statements Relating to Services:
1. There should be better contracts in the workshops.
2. The workshops need to be improved.
3. More money is needed for the programs, so that we can have new, better ones instead of the old ones. The world is changing and the programs must change right along with it.
4. The workshops are too crowded; something must be done about this.

IV. Action Goals:
1. That a group like Project II be started in every city and town.
2. That we form a committee which would represent all of us, that would get the communities behind us and get a statute that would guarantee all our rights.
3. That we have another convention next year.
4. That we show the federal, state, and local governments that we can destroy any barriers that are put up in front of us; that we show them how we feel about being shut out.
5. That we work to pass a law prohibiting any business, church, or other organization from discriminating against us.
Sometimes it's difficult to put your finger on what's happening. At least that's the way I reacted when I first visited 4910 Chicago, a residence that is part of the ENCOR cluster managed by Robin Mahoney.

I'm not sure what I expected to find. Perhaps I thought the five clients would be lined up in their best bibs and tuckers, waiting like well-rehearsed children, to show off.

But no, it wasn't like that. They were relaxing, catching up on chores, and planning activities for the weekend. It could have been Saturday morning anywhere.

When I drove up, Carmen was sitting on the front steps enjoying a cool breeze; Becky (staff) greeted me at the door; Jack got me a cup of coffee and sat down beside me on the sofa; Delores, on her way with a load of laundry, paused briefly to tell us Donna had gone to Lincoln to participate in the "People First" conference. John, the newest client, was in the hospital. Except for Jack, who had previously lived in a nursing home, all of them had formerly been institutionalized at the Beatrice State Developmental Center.

Nothing about the outside of the two-story frame house sets it apart from others on the shady, tree-lined street in Dundee. As it has in a number of nearby yards, creeping Charlie (my name for it) has supplanted blue grass. Orange marigolds camouflage the brick foundation and lend a cheerful note. A broom, someone forgot to put away, leans idly against a wall of the porch and gives the house a "lived-in" look.

Earlier in the week, I had met with Robin Mahoney, manager of the residence. Mid-morning, except for the two of us, the house was quiet. Earlier, clients had dressed, breakfasted and taken off for their jobs by van or public transportation. Late afternoon, staff and clients would return to begin the evening meal.

"We don't have many specific rules," Robin told me. "When there are too many, clients tend to use them for manipulation. Breaking a rule is often the only means they have to attract attention."

Petite, young, low-key, nothing about Robin seems "managerial." Not only does she supervise the staff at the residence, she's in charge of several ALU's (alternate living units) where clients live in a less restricted fashion. She appears easy-going, but serious. You get the feeling she likes what she is doing and is good at it. She apologizes for being late for our appointment. She and the staff were up late the evening before working on PASS (Program Analysis of Service Systems), a tool for helping analyze normalization of clients.

We talked about the importance of human dignity, the important part equality between client and staff plays in morale, and normalization — a term that frightens people who think it means pushing clients into situations they can't handle. The business of the staff she said was "to help people develop power — to help them know and get what they want."

Sounds good. I thought. BUT — textbook philosophies don't mean much unless they can be translated into action that produces results: Talking is one thing; watching it happen is another.

Hoping to watch people preparing dinner, I returned on a Friday. Carmen and Becky were in the living room talking about "going out." Most of
the time Carmen loves to cook, but ton-
ight, the end of the work week, she was
ready for a change of pace.
Pizza? Footlongs? Hamburgers? They
were trying to decide.
Normalization, Becky pointed out when
Carmen was out of earshot, means having
the right to make choices. It also
means not always going with the same
people or in one big group. In smaller
units, clients have more opportunity to
be individuals. And there’s less chance
the public will stare than when the
group goes out en masse.
Determined to spend an evening when
everyone was home, I returned on Wed-
nesday. Dinner was in progress. Joining
them at the table, I met John, now home
from the hospital and Wilma.
Wilma? Staff or client, I wondered.
Funny how important it is to put people
in categories.
"How does it feel to be home?" I
asked John.
Words tumbled out. He was anxious
to tell it like it is.
"Good," he said, smiling. "I like
it here. It’s not like Beatrice. Becky
got me out of Beatrice."
You got yourself out, John," Becky
interrupted, putting a hand on his
shoulder. "Remember?"
"It’s not like Beatrice," he repeated.
"At Beatrice, they have guards."
"What do we have here, John?" Becky
asked.
"Friends," he replied, taking her
hand. "Becky and Wilma are friends.
Not mom, friends. We have freedom. No
guards. I like my job. I earn money.
At Beatrice, no money."
John, I learned later, likes to take
pictures and thinks of himself as a
photographer. This fall he will attend
a class in photography, sponsored by the
public schools.
Constant interaction goes on between
the people at the table. It’s not a
process you can isolate and examine. It’s
subtle, but real. As a psychologist
might explain it, individuals are con-
stantly giving one another "strokes",
like a tree about to burst out into bloom
because the sun, wind, and mother earth
sign it’s time, you feel people are
stirring internally-that growth, even
if you can’t put your finger on it, is
going on all the time. Adults are
learning to be adults in a live-in ex-
périence, one that maximizes exposure
to normal, everyday life.
Results show in Delores, a shy,
quiet woman who has learned to write
her name, address, and telephone number.
She points with pride to a large, plastic
"D" above her bed — a reward for kicking
an anti-social habit she brought from
Beatrice. Her face lights up with anti-
cipation as she tells me she and Becky
are going shopping after dinner for new
clothes.
After years in a nursing home, Jack
didn’t want to get out of bed. His
vocabulary was close to zero. Tonight
he set the table — a perfectionist,
Wilma calls him. He not only goes to
work every day but sometimes brings
home the biggest paycheck.
Carmen has learned there’s a better
way to get new clothes than by cutting
up her old ones. She not only selected
and paid for the new bright red sweat-
shirt she is wearing but loves to go
alone to the beauty shop to get her
attractive, curly black hair styled.
Soon Donna will be able to point
to symbols in a sign language she’s
learning. Until now, because of cere-
bral palsy, she has had to depend on
body language for communication.
Visiting with staff members, I re-
alized the wisdom of Robin’s statement:
"I’d rather operate short-staffed than
hire someone who wasn’t right for the
job."
I’m intrigued as Wilma brags about
the progress Jack has made.
"Sounds like Jack’s your baby," I
.....
"Oh, he is, he is," she tells me.
"The whole staff is crazy about him."
I watch while she tactfully moves
a sandwich Donna is trying to cut to
a place where it won’t slip. A lesson
in human dignity, I think, as I watch
Donna’s crippled hand triumphantly
push the knife through the bread.
The staff, it seems, worried when
John went to the hospital for an evaluation soon after he arrived at 4910. They didn't want him to think he was going to be sent back to Beatrice. Staff and clients alike visited him during his two-week stay.

I believed Wilma when she told me: "I wouldn't work for just salary. There's got to be more."

It's easy to put your finger on the "more". In Robin's words: "It's the satisfaction of not only helping people touch their environment but helping them get the power to change it."

At right: Two friendly Chicago Street neighbors pose for John and his Kodachrome camera.

AMONG FRIENDS by Pat Henry

A feature story in the last GOARC Gazette was accompanied by a picture of Dr. Larry Rice holding Eric Sutherland. Dr. Rice saw Eric often during the youngster's stay at ENCOR's Developmental Maximation Unit (DMU). Eric has been a seriously sick little boy.

These past months have been a hard time for his family, too. They were constantly caring for their youngest. Even his brother, John, made sure that Darth Vader and other galaxy figures were pictured on his crib.

This family fortunately did not stand alone. Dr. Rice and the DMU staff backed them up with the skills and pooled energy beyond what any family could do alone. They believed in Eric - truly a sign of hope to him and his folks through the long Summer months.

The Sutherlands were still gathered around him, even on that last day. Eric's mother had been at his bedside since the night before. His father held him throughout the afternoon as each breath became so belabored, and so uncertain.

It's hard to understand death, particularly the death of a child. But there were things that were graphically clear about Eric's 20 month life. Despite his illness, his eyes always gleamed. Maybe he took that trait from the eyes of his older sister who so often showed she loved him. Maybe it was from his parents that he found the endurance and strength to carry him through crisis after crisis.

Many GOARC members know the Sutherlands. They share in the family's sorrow, and truly admire the life they gave their son.
Old GOARC Executive Directors don't fade away, they just seem to write and write. Tom Miller is now traveling and he plans to write articles for the GOARC Gazette as he trots around the globe. Whatever happened to that director before Tom ... that funny Bob Perske?

Bob and Martha Perske have settled in Darien, Connecticut, near enough to New York City to commute as needed. Bob's writing accompanied by Martha's illustrations have appeared in several books authored in the past two years. Their latest book has led to outstanding recognition. Mealtimes for Severely and Profoundly Handicapped Persons has been named an award winner by the American Medical Writers Association. Bob was cited as editing the National Book Award winner in the category of allied health fields. He didn't do it alone. As editor, he involved 79 contributors in his search for the best from across the nation.

Obviously, a book targeted at the needs of severely handicapped people, and limited to mealtimes is a very specific interest. But it appears to be a pioneering work in a much neglected area. Despite the slim market, sales have been brisk. All royalties have been pledged to the American Association for the Education of the Severely and Profoundly Handicapped.

Bob believes that the pen can be a potent weapon in social change. Only fifteen years ago, 10 out of every 100 residents of institutions died each year. Many of these victims choked on food. Others accidentally inhaled what was carelessly forced on them during a hurried "feeding". These victims of such dehumanization were often victims, again, of aspiration pneumonia. The word is out now, and in print, that this can all be different.

Well done, Bob.
On August 16, 1978, John Glynn reported for duty as Executive Director of the Greater Omaha Association for Retarded Citizens. Thirteen years earlier, he was reporting for duty in Vietnam as a Marine Corps enlisted man. It was there that he decided he wanted to get into some kind of social work with young people.

A few years later, a softball game gave him his chance. He injured his leg, ending his twelve year career as a Marine with a medical disability discharge.

He was accepted by Washburn University in Topeka, Kansas. Despite working full time and carrying a full load, John made the Dean's List twice. He received his master's degree from Kansas University.

Their move to Omaha was fairly smooth. Kathleen said they usually do things on the "spur of the moment", but not this fast. In three weeks, they had found an apartment in Omaha, packed up their belongings, unloaded the U-Haul, and were settling in at Washington Heights Apartments.

Erin, their 4-year-old daughter, has already made friends at St. Luke's Pre-school. Two-year-old John Jr. rounds out the family.

The Gazette may have found some new talent in John's wife. Kathleen wrote articles for "Women Aware", a Topeka women's magazine, and John said she has stacks of material ranging from poetry to satire that she has written over the years. In Topeka, Kathleen read to the blind under the Adjustment to Life program at the Kansas Institute for the Blind. When asked what hobbies he enjoyed in his spare time, John replied: "Spare time? Don't have much. My kids are my hobby right now. But I do enjoy racquet ball and any physical sport."

Before accepting the position of Executive Director of GOARC, John was a planning director for the Kansas Planning Council on Developmental Disabilities. While attending college, John worked with mentally and emotionally disturbed young people at the Menninger Foundation.

John would like to re-identify all of our projects with GOARC so the name becomes associated with advocacy as we originally intended. Then, when people talk about projects they will be talking about GOARC. A long range goal, and an on-going task, would be to put GOARC in the development of community resources. The two most pressing needs are: 1) immediate resources for people to come out of the Beatrice State Developmental Center; and 2) to get our membership up. He would like to see membership over 1,000 by July, 1979. Present membership is 400.

John commented "everyone has made me feel so comfortable. There has been an excellent response from the staff, and members that I have met have been open and willing to cooperate and move things forward."

"In its 15 or so years, John said, "GOARC has built a rich and prestigious tradition that we can grow from. We aren't anywhere near our potential or have we realized our power in securing rights for the retarded. The membership now will be the nucleus for reaching this goal, and with more new members, GOARC will be even more powerful."
COMING SOON ...

HONEY

SUNDAY

November 12
- TO VOLUNTEER CALL
348-9220

GENERAL MEMBERSHIP MEETING

November 2

ATTENTION: PARENT-PROFESSIONAL FORUM, FALL 1978
WATCH FOR DATE & TIME  COORDINATED BY DICK GALUSHA
What's a Moby? It might be one of the grey vans with white bubble-tops you see around town during the week. Or it could refer to the portal-to-portal transportation system being offered by Metro Area Transit. But to many handicapped and elderly persons in the City of Omaha, Moby means something they've had to do without for too long — mobility.

Begun in February of 1978, and billed as "A Whale of a Service", Moby is providing simple, inexpensive transportation to a variety of people who cannot drive or use regular MAT buses. While there are problems and the system is not all it might be, Moby is providing a needed service where none existed before.

In order to use Moby, a client must first be certified for use and the trip must fit Moby's need priorities. Just which clients qualify for what trips, and the rather stringent limits on both, is one of the main sources of dissatisfaction among potential users and some human service agencies. One of the first things Moby asks is how a person is "getting there now." If they cannot drive, cannot use regular buses and cannot get someone else to take them, potential users are then asked to submit an application and Moby personnel pass on their qualifications.

WHO QUALIFIES?

Moby certifies potential users in one of three categories. Category One is persons in wheelchairs. Category Two is for those using other types of personal assistance devices, such as walkers, braces, crutches, etc. The Third Category covers all other persons who have a disabilities which restrict them from using regular buses. This group must provide documentation of their need from their doctor.

Persons who would qualify under Category Three must have a disabilities which are expected to last at least a year and who fit at least one of these criteria: aged; using walker, wheelchair, etc; one or more missing limbs or using prosthetic devices; significant visual or hearing impairment; cardiovascular or respiratory condition; neurological condition that affects strength or coordination (polio, cerebral palsy, etc.); muscular-skeletal condition that impairs motor skills (muscular dystrophy, severe arthritis, etc.); learning disability; mental retardation or mental or psychosocial impairment resulting in reduced capacity; requiring dialysis treatment; having epilepsy. Also, persons with one of the above conditions of a temporary nature (three to twelve months) may qualify for that time period.

Once certified, Moby users must schedule their trips 24 hours in advance. The charge is 50 cents per one way trip. If an escort is required, the escort rides without charge. The Moby van comes to the client's home and meets the rider at the curb, in the driveway or at some other outside point. Users must live within the City of Omaha but may be delivered to points outside the city limits (Bellevue, Papillion, etc.) and be returned from these points.

EDUCATION

The lack of service to persons living outside the city limits is one of the areas of dissatisfaction many potential Moby users have. Under current guidelines, areas outside the City of Omaha must contract with Metro Area Transit before these clients can be served.

Another requirement which many persons and agencies feel is an added complication is the stipulation that applicants come to the MAT office to be photographed and to apply. MAT contends that this is not a particular difficulty since Moby transportation is provided to and from MAT headquarters and that the photo cards are useful for identification and check cashing purposes. Opponents point out that a mail in registration system is much easier and less expensive and is being
used successfully in many other cities. They add that with the new state policy of providing photo "non-drivers" licenses, MAT is duplicating a state service.

The limits currently placed on Moby usage in terms of days of the week and types of trips allowed is also giving dissatisfaction to many potential users. MAT guidelines currently limit the types of medical needs and transportation to work and school or training sites. The vans operate from 6:00 AM to 11:00 PM weekdays. There has recently been some limited usage on Saturdays for grocery store trips for some persons.

While it is obvious that unlimited day and night usage would be both unreasonable and impractical, many persons feel that the guidelines are too tight. They say that a person who cannot go out to the grocery store for food or to the drug store for needed medication has as important a need as the person going to the doctor's office for a shot; and that the person needing transportation to an informal group therapy session should be given as much priority as the one going to a training session. It is, of course, a matter of judgement and priorities and some persons are concerned with just who makes these decisions.

Although, currently somewhat limited in scope, the Moby program is making a great improvement in the lives of those who can take advantage of the service. For those who qualify it has the potential to open up a larger world of services and recreation. It is hoped that within a reasonable time the guidelines will become less stringent and that this expanded world can be made available to an even larger number of persons who are transportation disadvantaged because of disability or age.

A JOB TO ENJOY

Kevin Casey, EMOR's Director, has been on the road. To Sandy Rogers, his visit at the Developmental Vocational Unit (DVU) was a welcome event in her day... and likely in Kevin's, too. Carol McCabe is one of a staff working hard to see that Sandy and her peers look great.

Patrick Henry
MCRI Expands Training Sites

by Cindy Meier

Until 1970 there was no formal training for direct care personnel to work with developmentally disabled persons. Today, Meyer Children's Rehabilitation Institute (MCRI) offers a two year program training Human Services Technicians at three Nebraska sites.

Karen Faison, MCRI's Director of Human Service Technician Training said that MCRI hopes to expand its reach throughout the State of Nebraska so that graduates will be available statewide in this much needed field.

FIRST PROGRAM ESTABLISHED AT METRO TECH

The first program was established in 1970 at Metro Technical Community College in Omaha. (The official name for the program at Metro Tech is "child care technician"). Other programs in this area are available beginning this Fall at Iowa Western Community College and McCook Community College, as well.

Administration and associated academic instruction for the program is the responsibility of the host institution, while courses relating specifically to philosophy and ideology, especially normalization, assessment and programming, handling, direct care, the interdisciplinary process, data collection and the developmental model - all for developmentally disabled persons - as well as practicum experiences are provided through MCRI. Practicum sites include the Nebraska Psychiatric Institute, University of Nebraska Hospital Pediatrics, the public schools, Eastern Nebraska Community Office of Retardation, Woodson Center, Head Start, other pre-schools, and the state facilities for the deaf and visually impaired.

Mildred Nisley, Community College Program Head for the training said, "Our graduates have been well received ... There is a growing recognition of the importance of having personnel specifically trained in the daily care aspect of service to developmentally disabled persons."

STUDENTS EXPERIENCE ON THE JOB TRAINING

Much of the students' time is spent in on the job training or practicums. Students in their first year do practicum work with recreational therapists. Second year students are in integrated pre-schools, ENCOR Industrial Training Centers and the Nebraska School for the Deaf. Nisley said that "very often graduates are employed as a result of their practicum experience."

Fifty students have now graduated from the technician program at Metro Tech. Training takes two years if undertaken on a full-time basis. The course load is both demanding and time consuming but the resulting knowledge and ability has been lauded by those who employ graduates.
Bill Montooth, Director of ENCOR's Bellevue Industrial Training Center said that Metro Tech's technician graduates are the most prepared of all the people he interviews for jobs at his facility "because they are more specialized to this line of work."

Bob Brinker, Residential Manager for ENCOR's North/Northwest Children's Residence said that the technician graduates that he has hired at his residence are "excellent staff members...They are really well equipped for their work in the residence and display superior job skills."

PILOT PARENT NEWS

GREAT EXPECTATIONS! That was the theme of the Pilot Parent Regional Advisory Committee workshop held in Omaha on Saturday, September 16, 1978. Twelve parents representing the four states of Iowa, Kansas, Nebraska, and Missouri met at the Ramada Inn Central.

Over sweet rolls and coffee, participants shared information about their involvement in the Pilot Parent Program. The outreach sites represented are in various stages of development and a sizeable portion of the morning was spent in problem solving.

During the day, participants were asked to evaluate two films for possible use this year. Another block of time was spent sharing information about the technical assistance offered by outreach staff. Suggestions were made as to how this might be improved and expanded.

A key element of the workshop was Patty Smith's summary of the Pilot Parent grants. Her update of the progress of this year and the projections for the next two years were very exciting.

As Don Beamgard stated, we need to "lead, follow, or get out of the way."

Sherry Noley
Outreach Specialist

VISITOR FROM NORWAY

Pilot Parents and GOARC entertained a visitor from Norway from September 10th through the 13th. Mr. Olaf Hegland, the President of the Norwegian Association for the Mentally Retarded, is the father of a 17-year-old mentally retarded son, Eric. He and his wife, Ruth, have been leaders in the Norwegian national movement since its inception.

The progress on behalf of mentally retarded citizens has been pushed forward by the parents of Norway during the past 11 years. The commitment to the rights of the mentally retarded being protected and the commitment to normalization for all retarded is outstanding.

During Mr. Hegland's stay he toured ENCOR services and met with GOARC staff persons regarding their programs.

He was hosted by Mr. and Mrs. Thomas Upton, Mr. and Mrs. John Glynn, and Mr. and Mrs. Lenis Schoepke.

Patty Smith
Coordinator
IN SUPPORT of Aaron Dean  
by John Glynn

Cheri Dean came to my office in September with what I'd call a real problem. ENCOR's In-The-Home Support Services Worker was terminating employment. This means that Cheri is going to lose the support she needs to keep her son Aaron in the home, with the family. ENCOR offered out-of-home services. In effect this would move Aaron away from his mother and his sister, away from the love, compassion, and care that he has come to depend on for his security in what must be a confusing and often alien world. Cheri says that ENCOR would pay for an In-The-Home worker on the condition that she recruit and select such a worker.

There is a very dangerous and devastating ripple going through our direct service system. There are very large, complex issues involved in the ability of an agency to provide service. These issues, regardless of how large or complex they are, without exception equate to the life of a single human being. I am told that ENCOR has surplus funds, a cushion. Certainly, it can be argued that "cushion" is a legitimate business practice in a free enterprise system. ENCOR, however.

WANTED

In-The-Home Support Services Worker - to assist mother in providing for her child who has multiple handicaps. Duties include those activities necessary to the care and growth of a child. Requires 30 hours per week. Schedule is worked out with the family. $3.07 per hour. Will consider two persons at 15 hours per week. Live in may be possible.

Contact Cheri Dean at 445-7227, or the GOARC office at 348-9220.

Satak and Aaron Vzan

is not a free enterprise activity. It is a publicly supported agency created for the purpose of providing services, without discrimination, to mentally retarded handicapped persons in a five county area of Nebraska. The federal government does not allocate funds (Title XX) to provide a "cushion". The allocation is for services. The state government does not allocate funds to provide a cushion. The allocation is for services. The taxpayer does not provide dollars to create public agency surpluses. The taxpayer provides the dollars necessary to meet the specific needs of specific people at specific times. The taxpayer has a right to have all those dollars expended for the provision of services to resolve the needs of the people at the time they occur. The taxpayer also has the right to have all unexpended funds returned. To maintain a surplus in a public agency is to tell the taxpayer that all the needs of all the people have been met.

Aaron Dean is a five year old with needs not being met. His right to live with his mother and sister is at risk. The cultural value of family integrity is at risk. Yet we sit on our "cushion", we protect the system. I cannot accept this. Every penny of that cushion has to be turned to service and if there is still need we must find more pennies. We cannot, in the name of a business principle, ever
deny an infant, child, adolescent, or adult access to the resolution of need. As an Association we must mobilize as an advocate for Aaron Dean's right to services. We must insure that as long as there are dollars in the service system Aaron Dean will receive services in the most appropriate setting. We must do this for Aaron Dean and we must do this for every person who comes to us in need.

NEW WORLD BOOKS

Have you "seen" the current issue of Popular Mechanics, Ebony, or Newsweek? A blind person has a chance to keep up with a free service of the United States Library of Congress. But what may not be known is that this service is also available to people with physical or mental disabilities as well.

Children's periodicals, like Ranger Rick, and the Fun Journal, are in the Library catalogue. National Geographic and Playboy may well lose something in translation to braille, cassette, or disk. But these are among 300 periodicals also available in large type or open reel. Books are chosen for their wide appeal. Bestsellers, biographies, and how-to publications dominate the 1700 produced each year.

Since 1931, the free national library service has selected and produced thousands of full length books and magazines in braille or on recorded disks and cassettes. Reading material is sent to readers and returned by postage-free mail. This program was expanded in 1952 to include children, and again by Congressional action in 1966 to include people with physical impairments that prevent them from easily using a book.

Even playback equipment is loaned free for use with books or magazines recorded on discs or cassettes. Earphones, pillowphones, and remote switches can be requested.

Melissa Trevvitt of the Library of Congress replied to a letter by GOARC's Sherry Noley, "Mentally retarded persons are eligible for our program..." Inquiries can be directed to the Library of Congress, 1294 Taylor Street, N.W., Washington, D.C., 20542, phone 202-882-5500. The GOARC office (348-9220) is just a call away, too. Catalogues and further information can be found there.

by Pat Henry
A Vote of Confidence by Pat Henry

"No taxation without representation!" The battle cry of colonial days is reflected by today's citizen. The taxpayer is concerned about how his or her public dollars are spent. This is a time when people seem to be taking their "representation" seriously. But that same thing seems to be happening on the opposite end of public services, too. It's not just the taxpayer who pays for human services who wants to be heard. But it also is the handicapped person who receives them.

At least that is what Tim Butz heard at the "People First" Conference last month. GOARC's "self-advocacy" group, Project II, are leaders of this movement asking for a say in these services which profoundly affect their adult lives. Tim is an ENCOR Advisor and GOARC member working with several small groups of handicapped adults, emphasizing their right to vote and the responsibility to do this wisely.

Handicapped citizens are asked if they are interested. Many have registered to vote as Tim accompanies them to the Election Commissioner's Office. Voter registration continues until October 27, 1978. It requires simply that an adult be a current resident of Douglas (Sarpy) County. Mental handicap is clearly not relevant unless a court has formally ruled that a person is incompetent.

"It's a bit touchy", admits Tim. But the small group discussions are working to where people are encouraged to explore political issues. Newspaper articles and campaign information are used to start up discussion. Each group plans to attend "meet the candidates" rally.

Decisions made in the political process will influence the lives of handicapped adults. Thanks, in part to Tim Butz, these adults realize that they too have important decisions to make.

A Year Gone By by Patty Smith

As the first year of the Pilot Parent Program's Regional Grant comes to a close, I would like to share information on the progress made thus far.

The major goals of the 1977-1978 grant year were: to establish a Regional Advisory Committee and to conduct a regional advisory workshop; to establish ten new Pilot Parent Programs in a 4-state area; to expand the Omaha program as the model site; and to write a training manual to teach how to set up a pilot program. All the major goals have been accomplished. Along with these major goals were other supportive goals of publicity, media development, speaking engagements, and regular program administration.

The Advisory Committee, comprised of eight parents of handicapped children from the 4-state area (Nebraska, Kansas, Missouri, and Iowa) representing various disabilities (mental retardation, epilepsy, cerebral palsy, and autism) is an active-functioning group. They recently spent a working day in Omaha preparing for the next year's grant activities. The regional workshop was held during February, 1978 in Omaha for 125 participants from the 4-state area.

Currently, six new sites have completed Pilot Parent training and six other sites are conducting training. The Outreach Specialists have had requests from 13 other communities to begin Pilot Parent operations.

The Omaha program is still growing and expending its collective energies in many ways to benefit the Greater Omaha area. Currently, 13 new families are represented in training sessions each Monday evening. Fran Porter has recently finished the Pilot Parent Training Manual. This was edited by Robert Coleman and is currently being printed. Over 100 talks have been given on the Pilot Parent Program in and out of Omaha by volunteers and staff. The last major media item, a new slide presentation is being developed.

It is with joy that I share this information with you, the Gazette readership.
HELP MENTAL PROFESSIONAL

Interested parent for representation on the Special Education Advisory Committee. GOARCs delegate to this important post to be named promptly. Would you consider this leadership role? Call Liz Lankford (451-3361) who leads the "Comm. ity Arc aires v.committee."

TECHNICAL SUPPORT ENGINEER

The Magnetic Media Division of Control Data Corp. has an opening for a technical support specialist whose responsibilities would be:

To provide customer interface relating to disk pack and disk drive functions, resolve field problems with disk pack, provide technical sales training and interface with manufacturing, marketing and sales personnel.

Qualifications: 2 to 3 years experience with disk pack, disk drives or digital computer systems and a technical engineering degree.

A candidate with previous customer engineering experience within the above related field would be considered.

If you are interested in a career position with Control Data Corp., contact:

Contact: George Vogel
11615 S. 24th
Omaha, NE 68137
402-393-0240

/ C CONTROL DATA
VS EJ CORPORATION

ARCTIC EXPLORERS TRAINEE

GOARCs will be traveling to Ponca State Park to camp out for what may be a cool, brisk weekend. Need volunteers who would be willing to drive Youth and withstand the elements of far northeastern Nebraska on October 28-29. Prizes include warm campfire and hearty meals. Fun guaranteed, as well as the appreciation of Youth who could not go without your help.

Call C-GOARCS President, Chris Bean (333-8169) or Pat Henry (349-9220 or 397-3315).

NEEDED: People to translate ideas into print. Current GOARC Gazette involves about 12 volunteers to nurture thoughts into the finished copy and pictures. GOARCs column by Alice Blackstone (553-6381) always ready for fresh ideas, anecdotes, kids..."even interesting rumors." Call C. Heier, Editor, 556-9273.
On these cold Fall mornings, we become more aware of what it takes to get started on the way to work, school, or errands. What does it take, though, to spark into an action consumer group like GOARC?

...it takes some dreaming. Parents rallied with interested citizens and professionals to bring services for their handicapped children to the community which these families called home.

...it takes some strength. Handicapped adults from across Nebraska met to advocate for their own needs. All of this was led by GOARC's reject It.

...it: takes some i smc. The youngest members - those in GOARC-Youth - realize that handicapped adolescents need a group of honest peers. Earlier volunteer "helper" never really allowed handicapped youth to be equals. Now ITsy Gts friends.

...it takes some humility. The ideals of an advocacy group of volunteers are hard for them to live up to. How is it that people with handicaps are best served? What's now the most important-priority? Tough decisions, but once made they spark effective action.

...it takes members. People move GOARC. Volunteers are its motor, its vast fund of personal experience, its set of values.

... it takes you. It takes you. It takes you.

ENCLOSED:

COUNT ME IN AS A GOARC MEMBER:

Name: ________________________

Address: ______________________

City & State: __________________

Zip Code: ______________________

Phone: ________________________

Count on my help: Q ACTIVE: call me for volunteer projects

Q SUPPORTIVE: I believe in the cause

ENCLOSED: $9.50 Adult or Family Membership

Q $5.00 Youth Membership

Mail to: Greater Omaha Association for Retarded Citizens (GOARC)
c/o Membership Development Coordinator
3212 Dodge Street
Omaha, NE., 68131

Pilot Parent Program has been reviewed and favorably considered by the "Special Education Services Administration Task Force for the International Year of the Child 1979. This means that Pilot Parents will receive national and international recognition.

CONGRATULATIONS, PILOT PARENTS!
GAZETTE

December 1978

Seasons Greetings
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Message from the Director</td>
<td>1</td>
</tr>
<tr>
<td>Parents Are The Lifeblood Of GOARC</td>
<td>2-3</td>
</tr>
<tr>
<td>LB 889</td>
<td>4</td>
</tr>
<tr>
<td>Alice in GOARCia</td>
<td>5</td>
</tr>
<tr>
<td>Coming Soon</td>
<td>6</td>
</tr>
<tr>
<td>A New Home For The Rectors</td>
<td>7</td>
</tr>
<tr>
<td>ENCOR Residential Reorganization - Why?</td>
<td>8-9</td>
</tr>
<tr>
<td>Honey Sunday Wrap-up</td>
<td>10-11</td>
</tr>
<tr>
<td>With Faces All Aglow</td>
<td>12-13</td>
</tr>
<tr>
<td>Spotlight on Gene Tully</td>
<td>14-15</td>
</tr>
<tr>
<td>Facing The Wind</td>
<td>16</td>
</tr>
<tr>
<td>Reflections On NARC Convention/Survey Underway</td>
<td>17</td>
</tr>
<tr>
<td>M.R. Panel Challenging</td>
<td>18</td>
</tr>
<tr>
<td>In Focus</td>
<td>19</td>
</tr>
<tr>
<td>A Beneficial Service/Bucks for GOARC</td>
<td>20</td>
</tr>
<tr>
<td>New Staff Profile</td>
<td>21</td>
</tr>
<tr>
<td>In Memoriam</td>
<td></td>
</tr>
<tr>
<td>A Christmas Wish</td>
<td></td>
</tr>
</tbody>
</table>

---

**CREDITS**

Steve Chaffin, Cover Design  
Pat Henry, Cover Picture  
Cindy Neier, Editor  
Donna Reh, Layout Design  

SPECIAL THANKS: to all the contributors of this *Gazette*. Without you it would not have been possible.

Greater Omaha Association for Retarded Citizens (GOARC)  
3212 Dodge St.  
Omaha, NE  
(402)348-9220
Fred was a man some of you know, a man some of you have heard of, a man most of you have not heard of. Some will remember him for his efforts on behalf of the Nebraska ARC and the investigations of Beatrice. Fred was a man who was just stepping onto the threshold of greatness. Fred was a man who helped others step up, to see their potential, and to continue the struggle for the rights of humanity.

Fred was a psychologist, a professional who devoted his life to the retarded citizen and that citizen's right to humane treatment and cultural acceptance. Fred created programs to serve the retarded child, worked to gain acceptance of the handicapped child in Head Start, worked as an ARC member, and was an "all the time" advocate. Fred investigated and testified to institutional abuse. Fred challenged state government and the welfare bureaucracy of Kansas at a time when it would have been easier to "back off."

I met Fred when I was involved in a conflict situation with the Secretary of Social and Rehabilitation Services of Kansas about services to the developmentally disabled. While I was making sacrifices on one front, Fred was preparing a new position to operate from. Fred did so at great professional and personal risk. Fred's position at the University of Kansas was threatened. Funds for the University Affiliated Facility (UAF) were in jeopardy and a state official began to use the power of his office, in state government to control and intimidate. Fred stood fast in the face of intimidation and gave me a sanctuary, a place to regroup and to work from. He guided me through some rough days and weeks as we tried to keep moving forward.

Fred and I kept in touch by phone when I came to Omaha. We shared information and laughed that the Secretary of the Kansas Department of Social and Rehabilitation Services had commented that Nebraska was not far enough when he heard I was leaving Kansas.

Fred was a man whose compassion for others transcended self. Fred was a man whose quest for equality for the retarded caused much loneliness. Fred was a man whose sense of right has saved many from destruction. Fred was a leader. Fred was a friend.

"Let not the sun go down upon your anger."

"He that tarryeth in the way of the good, shall inherit it; he shall dwell in safety."

John R. Glynn, Executive Vicepresident
PARENTS ARE THE LIFEBLOOD OF GOARC

Over the past few years parent-members of GOARC have become increasingly concerned that their organization is experiencing a shift in "the balance of power" between parents and others (interested citizens, professionals, etc.). There is some legitimacy to that concern, especially when one looks at the history of ARC's in this country. During the 50's and 60's, parents often stood alone in the public policy arena, pleading for special attention to the needs of their children. Most doctors still saw mental retardation as a medical problem, not an educational one. Psychologists' main thought was that I.Q. scores were biblical prophecies of a child's potential. Educators believed the psychologists and doctors "education" was often little more than babysitting. Social workers were still playing Sigmund Freud, preferring to use labels like "guilt complex" and "shopping around behavior" to explain parents' desperate search for services.

GOARCs parents account for less than half of the total membership. Our bi-monthly General Membership meetings are certainly not well attended by parents. Although, our Board of Directors is more than two-thirds parents (22:30), they are having difficulty recruiting members to help them in their committees.

WHERE HAVE ALL THE PARENTS GONE?

In the late 60's, when we ran our own residential, educational, and vocational programs, and there was no ENCOR, a requirement for parents to get services was that they be a member of GOARC. Talk about a captive audience! Even after we stopped providing services and began monitoring them, many of the ENCOR professionals continued to support the parent movement; a bond of trust had been created between them and parents. Gradually, however, some parents began to drift away, preferring to involve themselves in their son's or daughter's industrial training center group home, or developmental center. Some veteran members were "burned-out", and with all of these new services available felt they deserved a rest. Later, as the schools began assuming responsibility for more and more children, parents saw their child's school as the center of the universe. Then too, the school administrators and teachers: (a) never worked for the parents and therefore felt no particular loyalty to their organization; (b) had a history of non-alliance to other community groups, partially based on a need for confidentiality; and (c) were trained by college/university professors who were either unaware of the parents role in creating this new demand for special education teachers, or were unwilling to admit their own failure to advocate for such a change.

We aren't alone. I attended the National Association for Retarded Citizens' Convention in Boston in November. At every level (national, state, and local) others are experiencing similar problems. Mandatory public education is a well-deserved victory for parents but it makes recruitment of new members difficult. A new family in town may enroll their children in school without our ever hearing about it. Similarly, many of today's ENCOR staff have no roots in the parent movement and may admit new clients without ever explaining the role GOARC played, and in playing, in the lives of mentally retarded persons.
NOW, FOR THE GOOD NEWS!

Children don’t stay in school forever. They now need adult vocational training and are finding more available. By joining with others, parents are determined to fill this gap.

Older parents whose sons and daughters are adequately placed today are turning to the ARC as an organization that will be around to ensure that nothing bad happens tomorrow.

Many of the “burned-out” parents are getting involved again. Their reasoning goes like this: (a) the difference between us and professionals in the schools and ENCOR is that professionals can bail out whenever they please. As parents, we have a lifelong commitment; (b) some scholars have said that parents go from a concern for themselves, to a concern for their handicapped child, to a concern for all handicapped children and adults. Many parents are growing to this highest level.

GOARC is fortunate to have an active Membership Committee that is made up of “veterans”. They’re scouring old membership lists for prospects, and renewed memberships are coming in.

Parents who have had trouble with their child’s program are quick to learn that a bureaucracy doesn’t respond very well to one voice. “In unity there is strength”.

GOARC IS GETTING BACK TO BASICS

Parents who call us need immediate and personal help. The Board is cautious about starting any new programs unless they can be tied directly to parents.

Staff are sensitive to the fact that GOARC parents are the lifeblood of the agency and deserve top priority in our work.

This is not to say that we won’t help parents who aren’t members (how do we build membership otherwise?) Nor are we ignoring our professionals, interested citizens, and others. We have room for everybody. But we are shifting our emphasis from pure advocacy to hard services. Unless some agencies get more responsive fast, we may even get back into providing services ourselves. We did it once, we can do it again.

* PARENT POWER * IS NOT LOST

One thing we have learned from this experience that should be engraved on the walls of all parent associations is that parent power is not lost by a “take over” of other groups. It’s lost by default, by parents themselves abdicating their responsibilities.

May I take this opportunity to wish all of you a joyous Holiday Season!

---

LB 889 by Loraine Jensen

LB 889 is a bill enacted by the Nebraska Legislature providing comprehensive special education services to preschool handicapped children.

Local educational agencies are responsible for service provisions, and must participate in developing a plan of services on a regional basis for handicapped children from birth or date of diagnosis.

If you have a preschooler who is in need of these services, the following people in your school district can assist you:

Bellevue  Richard Schoonover  291-3431
District #6  Nels Wodder  391-0646
Millard  Maurine Lee  895-8300
OPS  Dale Samuelson  978-7310
Ralston  Ed Tillard  331-4700
Papillion  George Spilker  339-3262
Educational Service Unit #3  330-2880
ALICE IN GOARC ia

by Alice Blackstone

SAY CH-B-E-S, PLEEEZE Darin and Rob Stevens, GOYARC members, have taken 32 slides of GOYARC activities. What's more, the brothers and GOYARC have made the nation's scene by now. Patty Smith just happened to take their slides along to show at the recent NARC Convention in Boston. The slides were shown locally at a recent GOYARC retreat at St. Timothy's Church. Anybody else wanna watch a good show? Call Pat Henry at GOAP (348-9220).

LATEST ON... ITCHY FEET MILLER
We hear that Tom, our former Executive Director, recently spent two weeks at the Vanier residence in L'Arche, France. His next leap will be to Africa. Yours truly recently received a postcard from Spain. Good to hear from you, Tom.

WORD GETS AROUND especially if you let the Loomis' carry it. Ray, Nancy, and little Billy Joe recently took the bus to Lyons, Nebraska, where they spent the night. Why? To help the people there organize a Project II group. What else?

WE'RE GONNA GROW that is if Judy Mercier, new Membership Development Coordinator, and L'Armand DeVore, GOARC Membership Chairman have their way. BUT, they need helpers. Volunteer by calling Judy at the GOARC office (348-9220). You'll not only be doing good work, with these two, you'll have a lot of fun. So call now!

TELL IT TO DEAR ARF3Y Recently, a lady in another state did. She poured out all the loneliness and frustration that centered around being tied down with a severely handicapped son. She had no friends, little hope of getting out to enjoy life. Abby had done her homework. She knew enough to suggest the woman write Pilot Parents in Omaha — that unique bunch who stated something no one else thought of. We ought to be very proud.

ON THE HOME FRONT Living with a celebrity and not gaining weight gets to be a problem. I refer, of course, to our son Tom's recent one-man art show and the hundreds of cookies I felt obliged to bake. Would you believe I didn't swallow a crumb? Why, I'm still fat is the subject of another story, too long to tell.

DO IT YOURSELF PLAN SHAPING UP Randy Kitch of Region VII has announced that Kansas University Affiliated Faculty at Lawrence, Kansas, has received a grant of national significance for technical assistance for self-advocacy for the developmentally disabled. The fund will be used to train and assist groups of developmentally disabled consumers to form their own statewide organizations and will promote the expansion of organized efforts of developmentally disabled persons to advocate for their own behalf. Last August, Randy attended the People First Conference, a brain-child of our own Project II, held in Lincoln, Nebraska.

WHERE IT'S AT If you think we're slipping grammatically we're only trying to tell you the new Pilot Parent Manual is not only out but made its debut in November at the NARC Convention in Boston. Fran Porter, writer, and Robert Coleman, editor, worked for more than a year preparing this 100 page manual to assist groups, particularly in our four-state area, launch Pilot Parent programs. "Orders are already coming in," says Fran.

NO POINT GOING HOME WHEN YOU'RE IN THE TERRITORY At least that's what Fran Porter decided when she left the NARC convention in Boston and travelled to Toronto to visit with relatives for two weeks. Torn between two loves (family and Pilot Parents), Fran sagely suggested to the latter she would be happy to return and give them her undivided attention if they would pay her travel expenses. You can't get a much better offer than that!
You have recently, or will soon, receive a questionnaire from the GOARC COMMUNITY NEEDS COMMITTEE. Unlike some other questionnaires, you will have an opportunity to learn the results and to discuss them at a PARENT FORUM. If you would like to see GOARC more involved in advocating or providing any of these needs or services, mark your calendar now and plan to attend.

PARENT FORUM

GOARC GENERAL MEMBERSHIP MEETING

JANUARY 25, 1979

FIRST FEDERAL LINCOLN
2101 SOUTH 42ND STREET
OMAHA, NEBRASKA

After a brief summary of the results of the questionnaire, several informal activities will follow. You may want to join one of the groups discussing the topics of the questionnaire or you can have coffee and visit with old friends.

SEE YOU THERE.  (WATCH FOR MORE INFORMATION)
Can you imagine what grand feeling filled Ollie and Lowell Rector as they stood at the site of their new home? Ground had been broken that morning but the Rector's conversation reflected that they saw beyond the excavated cavity to the day when their new house would stand on that place.

What a dream ... to build a home. How incredible this must be for Ollie who lived a part of her life in the Beatrice State Home. Lowell also lived in a state institution. But these are not people to let their dreams be confined by their past.

Ollie met Lowell when they were transferred to the same nursing home. As was common then, institution residents were sent to serve as, what might be called, indentured servants. Often for twelve hours a day, they were engaged in direct care of residents of the facility. For this they were paid a little more than a dollar a day. Even their monthly Supplemental Security Income (SSI) checks were collected by the nursing home administration.

It was a young Tom Miller, employed as a social worker, who told Ollie that she didn't have to live like that. Eventually, she became free of this exploiting environment. Lowell was helped by ENCOR and moved through the residential program to the point where he too could live independently. For two years, they had lost track of one another. But Ollie remembers a chance meeting on the street when she recognized a cherished friend who would in time become her husband.

Both have worked, Ollie at Field Club and Lowell at Shared Services. Months ago, they decided it was time to have a home of their own. Ollie and Lowell turned to GOARCs past president, John Clark for help with this major purchase. But they just couldn't find the house that matched their budget and their hopes. As discouragement began to wear them down, John asked them to consider building a house. It was John, says Ollie, that led them through the obstacles they faced, "in the book work and at the bank". A federal program to help new home buyers helped the Rectors develop the resources to swing the deal.

"...and the washer and dryer will go here". Ollie and Lowell Rector, let their imagination fill in the newly excavated basement of the home they have dreamed of.

The Rectors celebrated their 4th wedding anniversary this month. Now they look forward to a "house-warming" in late this Spring. That day will be a tribute to the Rectors and everyone who remembers how to dream and to make it come true.

By Vat Henry
ENCOR RESIDENTIAL REORGANIZATION—WHY?

Many of you have probably heard rumors regarding a change in Residential Services at ENCOR. Although no changes have occurred yet, research and planning directed towards improving the current service system is in process. I would like to explain why the staff at ENCOR has decided that a reorganization of Residential Services is necessary.

A PROBLEM WITH RECRUITING STAFF

You may be aware of the extreme difficulty ENCOR has had in recruiting and retaining Residential staff over the past year and a half. This continuous problem has required many hours of overtime and makeshift planning. Most disturbing to staff is the service quality has slipped since our last major restructuring in 1974. With this concern in mind, we began to research our present and past service systems for information to use in correcting the current system problems. Our review of the data resulted in some startling facts that I would like to share with you.

ALTERNATIVES STUDIED

As a result of our research, we made trips to study different patterns of residential services in such areas as New Jersey, Kansas City, Lawrence, Kansas, and Michigan. Additionally, we have interviewed countless visitors to ENCOR Residential Services attempting to gain insights into other residential programs that are successful. The development of this research has been a slow and deliberate process tinged with the excitement of finding new systems of service delivery.

Armed with this information, we have started a planning process within the ENCOR Residential Division that is aimed at incorporating what we have learned from our system and others. At present, we are approximately midway through our planning processes.

In future articles, I will review what our planning process has involved and what new directions in service delivery we will be taking.

By BahJty Lamont

A MAJOR CHANGE IN 1974

One of our major changes in direct service delivery in 1974 was to change from a live-in houseparent model of staff scheduling to a scheduling model that utilized 8 hour shifts. As a result, the number of staff working in facilities increased as much as 200-400%. It was planned that this increase in staffing levels would reduce the staff turnover rate and improve the service delivery as a result of less hours of responsibility and the ability to maintain personal lives outside of work for staff.

Our research now indicates that improvements in service delivery did not occur as a result of this change. In fact, data indicates that client growth and appearance, facility care and maintenance and staff turnover, have all suffered along with cost effectiveness and quality control.

Obviously, this was alarming data that none of us could live with.

HAVE YOU MOVED RECENTLY?

If you have changed addresses, recently married or divorced please notify the GDARO office at 348-9220.
HONEY SUNDAY WRAP-UP

Tom Welborn, Honey Sunday Chairman, worried as a cold rain diminished into a mist on Honey Sunday this year, but the rain failed to dampen the spirits of the 1500 volunteers who canvassed the neighborhoods of Douglas and Sarpy Counties. The weather wasn’t the best, but the sales were. GOARC and Madonna School will share record proceeds from the $38,000 gained from the hard work that "jars" into honey sales.

Thanks... 1500 times!

Honey Haleh led to a record fund-raiser. Help was provided by the Omaha Jayceeh.

PHOTOS BY PAT HENRY

Dave Gepford, Lt.; a Holeh, Mike Davit, , and Donna Keh label jars for sale

"Herkimer" travels in the arm of Amy Humphries
At left: Christy Forbes and Margaret Olson rest after selling honey.

Sue Sutherland rehearses her sales pitch.

Chris Davis finds honey "finger lickin' good".

"Oh, no! How am I going to drink the M juj!" nxzXucwed Robbie. 5-euena.
...WITH FACES ALL AGLOW

In spite of ice, snow, and cold winds the annual Pilot Parent Program Christmas Party was held December 3rd at St. Paul United Methodist Church in Benson.

Our warm thanks and appreciation to all who braved the elements to be there. We'd like to say a very special thank you to those who so generously contributed their time, talents, and resources.

It was a warm and happy group of parents, children, GDARC staff, and friends that thoroughly enjoyed the music, puppet show, refreshments, and last (but not least) the appearance of Santa Claus; who had a gift and special word for each child.
The goodies were all donated by Pilot Parents; the orange drink from McDonald's - and enjoyed by all of us.

A warm note of thanks goes to: the American Toy Company, Frank McGill Painting, the decorations and space made available to us by St. Paul Methodist Church is deeply appreciated.

And Bless you Santa for taking time out of your busy holiday schedule to drop in.

It was a great start of the Christmas season and really put us in the spirit. May you all continue to have a happy and blessed holiday!

The music and singing led by Jay and Linda Banta was something new this year, they were simply fantastic and a wonderful addition to the party. We hope they make it a habit.

What can we say about the Old Market Puppeteers? Try FUN...we loved the show!
March 20, 1978, was a Red Letter Day for Gene Tully — one neither he nor his family are likely to forget. It was the day the curtain lifted on a new scene — the day Gene took on a role more challenging than the one he had played for the past 17 years.

On that day, a star was born.

After Gene's graduation from eighth grade at Holy Name School in Omaha, the Tully family settled down to make the best life possible for themselves and their mentally retarded son. Gene had gone as far as he could academically; the outside world had no place for an illiterate with no special skill. The Tully's accepted what they thought couldn't be changed. What other choice did they have?

At that time nobody anticipated the breakthrough that would eventually come.

The seed that was to grow and change things for the Tully family was planted the day Patty Smith, Pilot Parent Coordinator, talked to a group of nurses at the University of Nebraska College of Nursing. Marlene Tully, Gene's sister, a nurse and teacher in the college, happened to have free time so she sat in on the session. From then on, it was a matter of time.

The Tully's were interested and excited about the news their daughter brought to them. But, as Alice Tully explained, Gene didn't want any part of it. Things were going well at home. Why rock the boat?

Fortunately, the story didn't end there. Margaret DeVore and I (both Pilot Parents of handicapped adults) visited the Tully's to share experiences. Result — the Tully's decided to take a change. It took a year for a place to open up for Gene. Now he not only loves going to the Benson workshop, he wishes he had a key so he could go on Saturdays.

Gene was born in Alliance, Nebraska, and spent his early years there in an extended family that included a grandmother, uncle and aunt. His father's work took him out of town a lot, but someone was always around to give the good-natured little boy love and special attention. Like other small town children, he played and rode his bicycle around the neighborhood.

Since the Alliance School System provided no special education classes, he attended St. Agnes Academy and later the public school. He was physically strong and always well behaved, so there was no objection. When he was about 10, his family enrolled him as a boarding student at the University of Denver Children's Speech Clinic. The Tully's had tried special tutors at home; they hoped the clinic would give him more help.

"After two years, the Director told us we were wasting our money — that Gene might do well on a chicken farm or some other rural setting," Alice explained, while "Tully," as she affectionately calls her husband, nodded his head in a way that told better than words how he felt about the Director's suggestion.

In the 50's when Tully was transferred to Omaha, Gene was enrolled at Holy Name. Academically, he made little progress, but it was better than staying at home. He was happy being with other young people.

Today, Gene looks and acts like a different person than the one Margaret and I met two years ago. He stands taller; he's more self-confident; he likes to share his experiences. He wasted no time when I asked what he liked about the Benson Workshop.

"Friends," he said enthusiastically. "I have friends there."

Gene had friends before he became
an ENCOR client. True, most of them were the characters in the soap operas he used to like to watch. Some people would have considered them shadows, but for Gene they were real. He worried about them, laughed with them and shared their secrets. They brought the outside world closer.

"HE'S MADE TREMENDOUS GROWTH..."

"Gene likes people and people like Gene," Tim Butz, his ENCOR advisor told me. "He's made tremendous growth in the area of interpersonal relations."

His current programmer at the Workshop, Suzanne Edgerton, called him a steady, hard worker. Together they work daily helping Gene master the difficult tasks of writing his name and address and recognizing the survival word cards each client is expected to learn. Occasionally "rest-room" comes out "restaurant". When that happens Gene smiles and patiently studies until he gets it right.

Suzanne predicts Gene will move on within a year, probably to Northeast Workshop where the work is more challenging. Within five years, she believes he will be working in a commercial situation.

"... A HIGH SENSE OF PERSONAL WORTH"

"He has a high sense of personal worth," Suzanne says, "something his family must have given him."

Many exciting things have happened in Gene's life since March. He has double-dated and taken a girl (there is a special one) to the movies and pizza parlor. He attended a party of about 100 people at Tim Butz's home and seemed, in Tim's words, "to make himself at home." He deposits his earnings in the bank; he rides the bus to work and manages his bus and "break" money. He's thinking about Christmas shopping. He stayed overnight in Lincoln where he attended the People First Convention.

By now it's getting to be an old story, one Tully gets a particular kick out of telling. It seems that Gene didn't want to go to Lincoln, but after he got there he had so much fun dancing, socializing and speaking out for his rights, he didn't want to come home.

GENE TULLY HAS COME OUT OF THE SHADOW

At age 41, Gene Tully has come out of the shadows. He no longer depends on the television screen for friends; he finds them at the Benson Workshop. As Molly Chamberlin, his former programmer puts it, "Gene is going nowhere but up."

Announcing

THE PUBLICATION OF THE PILOT PARENTS PROGRAM'S TRAINING MANUAL

The manual is a parents handbook for developing new pilot parent programs. It is written by co-founder of the Omaha Pilot Parent Program, Fran Porter and edited by Robert Coleman.

Copies of the manual are on sale through the GOARC office for $8.00 (including postage).
FACING THE WIND

If the nites are already cold, traveling even further north for a late Fall campout has its drawbacks.

Most of the 36 GOARC-Youth members would likely tell you that their camp site at Ponca State Park was just short of the Artie Circle. Pitching tents on top of a bluff overlooking the Missouri didn't provide much of a windbreak. But it had to be the prettiest place in Nebraska on that October weekend.

STORY & PHOTOS by PAT HENRY

GREATER OMAHA YOUTH ASSOCIATION FOR RETARDED CITIZENS
GOARC-Youth is a group of adolescents some having problems with retardation and some who don't. They come together almost every week out of a belief that being part of a peer group with handicapped teens will prompt all sorts of growth in every member. There are things to be learned, particularly in the area of social skills. Many of these can be taught only by the expectations and modeling of other peers.

"TO BRING PEOPLE CLOSER"
"You Can Make The Difference" was the title of an historical overview of NARC to formally open this years national convention in Boston, Massachusetts. The mood of the convention was one of optimism as stated in the new ARC slogan, "When You Give Help, You Give Hope."

The State of Nebraska was well represented with a total of nine people from Omaha and GOARC attending. Specifically from GOARC were: Billie Cook, Ed Skarnulis, John Glynn, Fran Porter, Sherry Bauer, and myself. Others attending were: John Delorenzo, ENCOR; Dr. Frank Mansiaco, NPI; Jack Stark, MCRI.

Many of the sessions throughout the week were most interesting and informative. A residential session chaired by Bob Perske (GOARC's former Executive Director); "The Changing Role of the ARC" presented by John O'Brien and chaired by Gil Johnson; and some find presentations on Citizen Advocacy-working with minorities in low-income outreach programs to name only a few. The Pilot Parent Program was presented during a session chaired by Gil Johnson.

As well, the Pilot Parents contributed to the exhibition area their new display which received numerous favorable comments.

Awards were given this year to people well deserving of recognition. Dr. B.F. Skinner, the noted behaviorist received the first NARC Distinguished Research Award. This includes a $1,000 prize. Dr. Gunnar Dybvik and his wife, Dr. Rosary Dybik were presented a special NARC award during this years banquet. Also, at the banquet, the ARC of excellence wards were presented. Robert Meyers, author of the book, Like Normal People was awarded for his story of one family's struggle to overcome the effects of mental retardation. It is a story written by a member of that family. This book was purchased by John Glynn and is available to GOARC members from the GOARC library.

A highlight of the convention week for many of us was the "Tony Orlando Benefit" held at the Boston Music Hall. Starting the show was a group called the People Players. They are a group of twelve Canadians, nine of whom are mentally retarded. As Tony presented his portion of the evenings entertainment the People Players joined him for a very moving performance.

I hope we have the strong representation from GOARC and Omaha at next years convention which will be held in Atlanta, Georgia.

By Patty Smith

SURVEY UNDERWAY

The Action Committee on Poverty and Mental Retardation requested that a questionnaire on respite care be sent to families living North of Dodge Street and East of 42nd Street.

The purpose of the questionnaire is to determine if families living in this geographical area need respite care and would use it if it were readily available.

Agencies serving the developmentally disabled population were identified. Those agencies who agreed to send out the questionnaire are: Head Start, Direction Services, ENCOR, Omaha Public Schools, Nebraska Vocational Rehabilitation, Madonna School, and GOARC.

The information returned by the parents will be compiled and presented to the business community to seek their financial support in the establishment of respite care services.

In the next Gazette, we will give you a statistical report on the information we will receive on the two hundred and forty questionnaires mailed.
M.R. PANEL CHALLENGING

I have had the most interesting opportunity (as a GOARC staff member) to give input on the Manpower and Development Task Force for the Governor's Mental Retardation Panel.

The Committee is charged with the task of constructing a plan to develop enough personnel to provide the needed staff over the next 3 years.

During the next 3 years the population of the Beatrice State Developmental Center will be reduced to 250 people. At the same time, the needs of the retarded citizen living in the community need to be addressed. Altogether, there is an awesome task to plan for this needed number of people to serve the mentally retarded citizens in local communities.

Sanford Smith, Director of the Office of Educational Services at MCRI, is the Chairman of this Committee. The members are Ernie Rutledge, Regional Director of Mental Retardation Services in Region II; Beth Macy, Director of Developmental Disabilities Council for the State of Nebraska; Mary Ann Shere, State Office of Mental Retardation, and myself.

The Committee has had the benefit of many of the experts in different related fields. Ken Keith, a Research Consultant presented, Dave Bohling discussing Title XX funds, Harlan Height talking about funding for programs, John Clark reporting on LB 889 and special education programs, John McGee covering the panel's plans, Jim Woods reporting on nursing homes, and Frank Menolascino discussing staff turnovers and burnout. A great deal of information has been gathered to help the committee to make constructive plans.

The plans for manpower will cover all aspects of the needs of mentally retarded citizens. My special "push" has been in the area of family support and training. I've encouraged the planners to be especially sensitive to the needs of family members of those returning from the institution. Also, special emphasis needs to be placed on family supports to prevent institutional need.

In the financial planning I've asked for a decline if not elimination of disincentives which plague the families of the handicapped. Parents should not be discriminated against financially for keeping their child at home.

This has been a most challenging task force to be part of.

By Patty Smith

IN FOCUS

Heather Hardin, host of Focus, invited Chris Bean, GOARC-Youth President, to be her guest to tell of his experiences and those of the youth he leads.

GOARC-Youth has been written into the sociology curriculum at Westside High School. Two years ago, Chris and Jill Nagel made their point that the section on mental retardation should not end with a visit to the institution at Glenwood. Students could be left to think that handicapped persons can only be served in dead-end programs away from their families. Twice this month, the seniors will hear from their peers in GOARC-Youth about the type of services that help handicapped people to grow and enable them to live at (or near) home.
A BENEFICIAL SERVICE

GOARC is pleased to announce that it is sponsoring a new and very beneficial service, for persons of Nebraska. Medical Data Bank, an Emergency Medical Information Service, can supply emergency personnel with information necessary to begin immediate treatment of an accident or emergency victim.

Medical Data Bank not only can save the life of a person, with a hidden or special medical problem such as epilepsy, diabetes, heart conditions, or drug allergies, but also provide information for the average healthy person who may need admittance to a hospital or medical facility.

This is done by providing subscribers with a laminated identification and medical information card, which is designed to do a number of very important things: identify the individual, provide emergency room personnel with a complete medical history, optional authorization of emergency first aid and surgical treatment, as well as optional donor authorization. A chip of negative microfilm in the upper right hand corner supplies all the above information. The information stored on this chip is completely confidential and can only be read with the aid of a microfilm viewer. This information is obtained from a form filled out by you and your doctor. It can be updated any time you feel an update is necessary through the life of the subscription. When an updated form is sent to Medical Data Bank, they make a new card and forward it to you.

Since a viewer may not be ready for needed situations, another part of service is the emergency answering service which is available to all emergency and medical personnel 24 hours a day via a collect phone call from anywhere in the world. Within seconds operators can relay information from the Data Center in Kansas City, where backup files are kept on computer. Also, available are the medical alert bracelets and necklaces. Emergency units, rescue squads, and ambulance services throughout the state have been notified of this service through the Nebraska Division of Emergency Health/Medical Services. In addition, all hospitals and nursing homes have received information concerning Medical Data Bank as well as personal contacts made by the Medical Data Bank Representatives to further train the emergency personnel.

As mentioned earlier, this service is being sponsored by GOARC because we realize the persons to whom the service would be most needed are those who can least afford it. Through the cooperation of Medical Data Bank, GOARC is able to offer this service not only to members, but to anyone who feels the need for such a service, by the disabled, diabetic, elderly, or a healthy person.

BUCKS FOR GOARC

GOARC's contract with Medical Data Bank also provides an unrestricted source of funds for the agency. GOARC receives one third of each membership fee that is paid - $6.00 on an individual fee and $12.00 on a family membership. Estimating three hundred and seventy five families in GOARC, that would produce 4,500 dollars in unrestricted funds. If each of these families got ten other families to participate that would produce 45,000 dollars in unrestricted funds for a total of 49,500 dollars in unrestricted funds.

I would like the families of GOARC to set aside the next four months to promote and sell this service. I would also like to establish a goal of 50,000 dollars to be raised by GOARC families by March 31, 1979.

To get us started an application for your family is attached to this Gazette. When you mail this in, Medical Data Bank will send you medical history forms for completion - then you get your individual family member cards.

by John R. Glynn
NEW STAFF PROFILE

LORRAINE JENSEN - STAFF ASSISTANT

Lorraine is a former 1974 SWEAT student and was an assistant coordinator for SWEAT in 1977. For ten months she worked and studied in institutions and community based services in Umeå, Sweden. She speaks fluent Swedish. Lorraine is now a citizen advocate for a 14 year old boy living in LOMR services.

Her talents, interests, and accomplishments are too numerous to mention. You can visit Lorraine at the GOARC office or at her and her husband’s artist coop, Cathedral Art Gallery, at 815 N. 40th Street.

DENA LAUNDEEVILLE - SECRETARY

Dena is our new Secretary/Receptionist. She recently moved to the Omaha area from Holdrege, Nebraska. Dena attended Hastings Technical Community College where she received her diploma in Secretarial Science.

Dena enjoys reading, softball, and horses. Her future goal is to travel. Next time you call the GOARC office, say hello to Dena.

HELEN SCHEFER - OMAHA PILOT PARENT COORDINATOR

Helen is a former GOARC Board member and is a Pilot Parent. She has been a member of GOARC and around ENCOR "forever". She has three children. She enjoys theatre, art, writing, and people...not necessarily in that order.

JUDY MERCIER - MEMBERSHIP DEVELOPMENT COORDINATOR

Prior to coming to work at GOARC, she worked four years at the World Herald in management. Judy has one daughter, Stacey. She plays softball and enjoys backpacking, fishing, and camping. She also plays and teaches tennis.

PATTY GROSS - DEVELOPMENTAL DISABILITIES OMBUDSPERSON

Patty began working as the Ombudsperson in November. Before coming to GOARC she worked at ENCOR, LOMR, and provided in-home services by private contract. She presently attends Creighton University and plans a masters in dance therapy.
IN MEMORIAM

MARY BETH CHRISTOPHERSON

Born September 15, 1964
Died November 3, 1978

"One of our Angels has returned to God. She will be missed by many for a short while."

Mary Beth Christopherson passed away on November 3, 1978 at age 14.

"Mary B," as her friends affectionately called her, had been a student at Madonna School for five years.

Those of us at Madonna watched her grow from a shy, head down, quiet little girl to a poised, young, well-mannered little lady.

Her family, from the beginning, jumped right into Madonna School - doing their share and much more - always in our endeavors - Style Shows, Hot Lunch, "Y" program, Special Olympics - always first to help with transportation and field trips.

Mary B had excelled in Special Olympics participating in swimming and bowling.

She was the youngest child in a family of four older brothers. She went on camping trips and fished with her Mom and Dad.

She will be missed by us all - her family, of course, first and most, and in a very special way by her classmates, teachers and friends at Madonna School.

There is no better way to close our story than to quote Mary B's mother. "Once again, what Mary Beth has taught us."

By Sister Mary Evangeline

---

MADALINE CHRISTENSEN

Died November 14, 1978

Madeline Christensen died November 14th and we extend our sympathy to her family and numerous friends.

Madeline was a long time member of GOARC and a significant force in our development. In the mid 1950's, Madeline enrolled her daughter, Kathy, in the Opportunity Center, which at that time was the only program available to retarded citizens in Omaha. The parents transported their children and acted as the custodians, teachers, and administrators for as many as 70 children. Those parents realized the need for a comprehensive program and worked diligently toward that goal.

In 1968, the Opportunity Center at 5016 California was closed and transferred to GOARC and in the Fall of that year, the Benson Vocational Center was opened with 17 of their sons and daughters in attendance.

Madeline had served two terms as Vice President of the Opportunity Center, always giving generously of her time and efforts. The opening of the Benson Center found her tiling floors and painting walls in preparation for the day they had all planned and worked for.

The past 10 years has seen great change and growth in community based programs. Madeline Christensen made a tremendous contribution in making it all possible. She was a true parent advocate for her daughter and for all retarded citizens. Madeline set an example for all of us and we have a commitment to carry forward for her.

By Helen Schaefier
MERRY CHRISTMAS
FROM THE
GOARC STAFF