News Letter

THE GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES & THE DEVELOPMENTAL DISABILITIES PLANNING OFFICE OF THE STATE PLANNING AGENCY

Vol. 5, No. 2 State of Minnesota Summer, 1980

Inside you will find these features on aging:

INTRODUCTION— Aging of Persons who Have Developmental Disabilities

The previous issue of the DD *Newsletter* featured Early Intervention articles. Now we embark upon a theme which examines problems faced during later stages of life's journey; namely, aging—aging of persons with developmental disabilities.

On April 28 and 29 of this year the Governor's Planning Council on Developmental Disabilities, in cooperation with The DD Planning Office, sponsored a Conference on Innovative Services for the Aging Developmentally Disabled Person. Well over two hundred people came to this conference which was deemed necessary because of apparent lack of services to meet the needs of this older population. The purpose of the conference was to stimulate thinking about ways to better meet presumed needs in this area.

We say presumed because there is not a surplus of data about the nature and scope of the problem nor is there general agreement as to just what the problem is.

The aging issue is an unusually broad one for many obvious reasons. First, our nation's and our state's population continues to grow out of proportion in the upper age brackets, and this includes persons with severe disabilities.

Secondly, there is a real scarcity of literature on the subject and what there is pertains to mental retardation—very little about other disability groups.

Thirdly, special problems arise for the developmentally disabled, who are living at home, when their parents or family start to get too elderly to continue their parental role and planning for the inevitable separation is forestalled.

Furthermore, our society tends to concentrate its services on youth—not the citizens who are aging.

Finally, we need a better understanding in our society about aging conditions. In 1976 a series of workshops called HELPING PARENTS OF RETARDED PERSONS AS THEY GROW OLDER was sponsored and conducted by the Metro ARC's, Mental

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Increased Numbers of Aging DD Show Need for Better Planning

Information for this article was provided by the Human Resources Section of the Minnesota State Planning Agency (SPA)

The Elderly: The 1980s will see the beginnings of a major change in Minnesota's elderly in terms of the size and characteristics of this population. While many of these changes will not be fully evidenced until the early 21st century (when the post World War II "baby boom" population reaches retirement age), the modifications that began taking place in the 1970s and will continue through the 1980s will have an impact upon the delivery of human services to the elderly population.

changes in the elderly population is the growth in both numbers and in relation to the rest of the population.

The Elderly of Minnesota, a publication of the Minnesota Department of Health, shows that between 1970 and 1990, the elderly population in Minnesota is expected to grow from 408,919 to 499,438. This is a 22.6 percent increase in the elderly population over 20 years, in comparison to an overall population increase of 16.2 percent. In addition, between 1970 and 1990 the proportion of elderly individuals in Minnesota will have increased from 10.7 percent to 11.3 percent.

It is possible, given currently low fertility rates, that the national proportion of elderly in the population could exceed 20 percent by 2030. Indeed, in some Minnesota counties the proportion of elderly is now approaching that percentage.

An increase in the number of elderly in relation to the remainder of the population means an increase in the average age of the population. In 1900 the average age of the United States population was 23 years. The average age is currently 29 years and is expected to be 38 years by 2035. This aging phenomenon is due to a number of factors, including a decline in the fertility (birth) rate, medical advances that have allowed individuals to live longer and immigration patterns.

While the elderly population generally is growing, the largest proportional increases are taking place in the oldest age groups, the groups of elderly with the highest service needs. Whereas the size of the 65-69 age group will increase by 21 percent between 1970 and 1990, the 85 + age group will increase by nearly 30 percent. In addition, the ratio of women to men is becoming even larger. This is due, in large part, to medical advances that have lengthened life expectancy for females even more than for males. This is also true for minority elderly. Whereas the average national life expectancy for white persons increased by nearly one-half between 1900 and 1975, it doubled for non-whites. This will result in the elderly population as a whole increasing by 115 percent between today and 2035 with the number of minority elderly nationally increasing by 300 percent.

In addition, there will be a new group of elderly (those now 55 to 65) to consider as the current population of those aged 65 to 75 moves into the 75 to 85 age group. This group of individuals is expected to have different characteristics than the previous elderly, due, in large part, to their differing backgrounds. In general, they will be better educated, they will have different employment experiences, they will have a higher average income, they will be healthier, more likely to be in the labor force, more mobile, and have had more children. Many of these trends will become even more pronounced as years progress.

WILL MINNESOTA'S ELDERLY POPULATION HAVE DIFFERENT PROBLEMS, SERVICE NEEDS AND DEMANDS IN THE 1980s?

Although these changes in the size and composition of the elderly will just begin to occur in the

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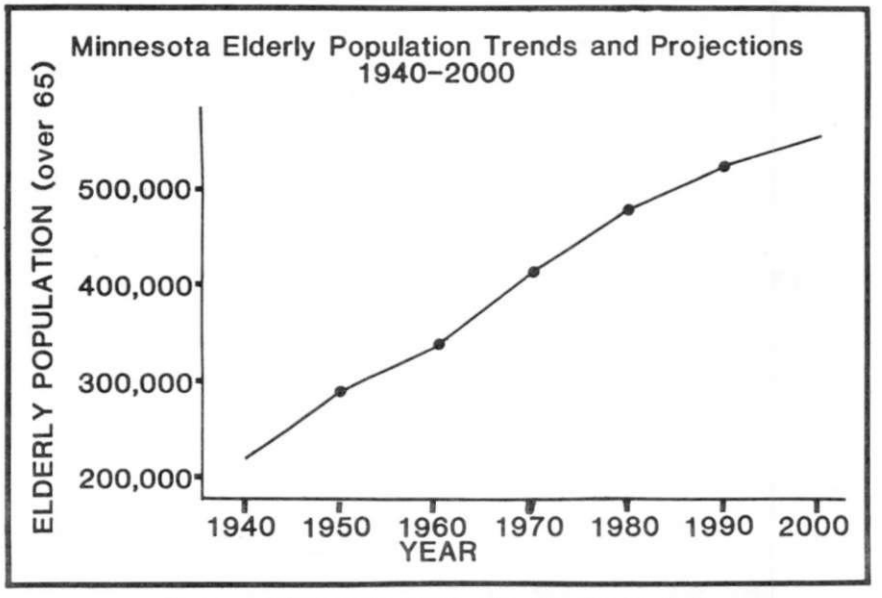


Source: Minnesota Center for Health Statistics

1980s, they represent a major shift in the population structure. Policies or programs for the elderly initiated in the early 1980s may have minimal implications at first, but their effect may change greatly as the elderly population changes. For example, how will this changing population affect the rate of admission into nursing homes? Will the use of nursing homes or the need for home-care services rise due to an increasing elderly population and an increasing number of very old citizens or decrease due to the changing characteristics of the general elderly population? Will there be a need for greater funding for cash assistance programs such as Supplemental Security Income or Minnesota Supplemental Aid? Or will the elderly of the future, who will probably have higher incomes, have less need for these programs? These questions can be asked for every type of program or service relating to the elderly.

MEDICAL COST CONTAINMENT

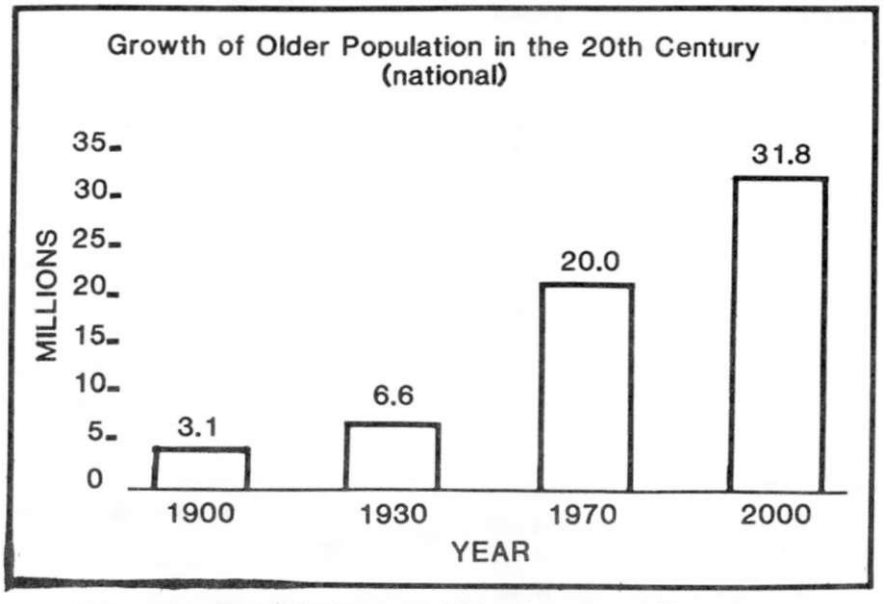
Tools for medical cost containment were developed in the past decade. Medical costs, particularly the Medicaid program, continue to be the driving force behind government expenditures for health and welfare. The growing elderly and handicapped population in need of medical services will keep attention on these costs and challenge the containment tools.

HOW WILL MINNESOTA'S COMMUNITIES BE INVOLVED IN SETTING POLICIES FOR THE ELDERLY?

In the past, few policies for the elderly have been made at the state level. The federal government has always assumed primary responsibility for elderly-related programs. Approximately 90 percent of all funding for the elderly comes directly from the federal government. If this continues, state policy will be determined, for the most part, by federal policy. On the other hand, it is possible that, in the future, some of the responsibility for elderly programs may fall on the state and local governments if federal funding remains at a relatively constant level but must be used to serve an increasing population.

While this shift would offer communities the opportunity of tailoring programs to meet local requirements, it raises other questions. How will human service resources be distributed among several groups—the elderly, the handicapped, the disadvantaged? Will there be budgetary constraints that require different allocation methods? If so, how will priorities be set? What should be the level and proportion of resources from the federal, state, and local governments? And, of particular importance, how will the private and non-profit sector participate in the delivery of services so that citizens have choices that meet the changing needs of the '80s?

The decade of the 1970s witnessed the development of significant networks of volunteers providing assistance and support for elderly persons. Can this voluntary effort from churches, community organizations and concerned individuals be sustained in the future?



Source: ''Facts about Older Americans,'' 1978

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Health Centers and DAC's. In the course of the workshops the following true-false items were given:

1. Physical stress is harder on a person than emotional stress.
2. Most people who are over sixty-five live in nursing homes.
3. Long term memory is highly resistant to the effects of aging.
4. People who have gratifying lives live longer than those who are unhappy.
5. Age is the most important factor in learning.
6. Men live longer than women.
7. All older people are pretty much alike.
8. Senility is nearly inevitable with aging.
9. Older people do not need very much money to live on.
10. Retirement at sixty-five was established during the 1960s.

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Here are answers to this brief quiz provided by Nancy McNeff, Ramsey County Welfare, Mental Health Center.

1. False, 2. False, 3. True, 4. True, 5. False, 6. False, 7. False, 8. False, 9. False, 10. False

How much do we know about our elderly citizens? There are places in a person's life where sweeping generalizations have dire effects. For example; many employers, public and private alike, interpret age 45 as the cut-off point for hiring despite the possibility of an age discrimination suit. Also, with major assistance from the provisions of Social Security legislation and public retirement programs, age 65 is viewed as the time when you retire and go on to drastically change your life style. For some this is a favorable change, but for many others this is unacceptable both financially and socially.

A review of literature on the subject of aging developmentally disabled and of the aging conference discussions shows some key questions coming forth over and over again:

1. *What is unique about the problems faced by this population of our aging citizens?* Some conference participants maintained that there is nothing truly unique. Others, spearheaded by conference key-noter Martha Ufford Dickerson, stressed the phenonemon of "double jeopardy" — the compounding of all problems for persons both aging and developmentally disabled.

Dickerson's contention points to some realities. For example, if a person who has been treated all of her/his life as mentally retarded, cerebral palsied or otherwise disabled is placed in a nursing home, they very readily become lost because the nursing home views them as a chronological person rather than one who has a developmental disability. Dickerson strongly asserts that because of such placements, the person with a developmental disability becomes invisible, lost amongst the rest of the aging population.

Another recurring question is— What is aging? Or when does it begin? Is it a chronological or a functional definition? There is subjective evidence that persons with Down's Syndrome demonstrate aging symptoms during their late thirties. Persons who have resided in institutions tend to appear older than those who have not.

The questions that have arisen on this topic go on and on: Should there be special service centers set apart for the younger persons who have developmental disabilities? Should aging DD persons be integrated with non-DD? Are nursing homes a desirable alternative to group homes and/or institutional settings? Who plans the details of funeral arrangements, wills, estate settlements and these kinds of practical concerns?

Persons who have developmental disabilities are definitely living longer due to medical technology and better programming. Innovative planning is warranted. Greater reliance upon the family may happen depending upon the economy and social attitudes.

This and many other issues are addressed in the articles which follow.

GLOSSARY

AGING: A birth to death process focusing upon the personal changes occurring after completion of the developing years.
AGED: Describes the segment of our population whose characteristics are: (1) significant losses related to physiological, psychological and social-personal changes, and (2) chronological age eligibility for certain public services, rights and restrictions.

ADULTIZING: The opposite of infantalizing; that is, giving the person the opportunity to be as self-sufficient as he or she is capable in terms of self-care skills, mobility, language, work, free will and decision-making.

GERIATRICS: The branch of medicine that deals with the diseases of hygiene of old age.

GERONTOLOGY: The scientific study of the process and problems of aging.

GUARDIANSHIP: A legal status providing protection, care and management of a person considered incapable of managing his own affairs.

INFANTALIZING: Applies especially to those with mental retardation and other severe learning limitations. The tendency of people to label a person, treat the label, close off receptivity, withhold opportunities for "growing up", to over-protect and thus establish a state of dependency. Low expectation of the person is maintained and any degree of self-sufficiency and adult behavior is postponed.

OLDER AMERICAN ACT: This 1965 Act, as amended in 1978, provides for services to the elderly through the U.S. Department of Health and Human Services.

RULE 34: A Minnesota Department of Public Welfare rule entitled "Standard for the Operation of Residential Facilities and Services for Persons Who Are Mentally Retarded."

SENILITY: The conditions or signs of old age which affect both mind and body.

Region V Study on Aging/Aged Developmentally Disabled

The keynote speaker for the April Conference on Innovative Services for the Aging Developmentally Disabled Person was Martha Ufford Dickerson, M.S.W. Dickerson is currently Director of an H.E.W. granted project to study Aging/Aged Developmentally Disabled in Region V.* This project is a cooperative effort between the Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD) and the Macomb-Oakland Regional Center housed at Ann Arbor and Mt. Clemens, Michigan, respectively.

The intent of the project is to develop a model of community based services for the Aging/ Aged Developmentally Disabled persons (AADD). Furthermore, it intends to use that model to demonstrate a training program between a university and a community-based facility; to develop and test new service and training methods and to disseminate tested materials on state, regional and national levels. The project runs three years, October 1, 1979, to September 30, 1982. Funds originate from Public Law 95-602 as a Project of National Significance in Developmental Disabilities. Further information about the project can be obtained by contacting Martha Ufford Dickerson at the ISMRRD, University of Michigan, 130 South First St., Ann Arbor, MI 48104, (313) 764-4115.

In her opening remarks at the conference, Dickerson explained the history of Region V Project activities on this subject, showed a video tape, which will be available from the ISMRRD, and referred to a major research monograph on project findings entitled *DOUBLE JEOPARDY: The Plight of the Aging Developmentally Disabled in Mid-America.*

Dickerson

During the early seventies, Dickerson had joined with others in Michigan who had backgrounds in mental retardation and gerontology to form a team who would seek answers to two basic questions: What happens to a person with a developmental disability when they get old and and where are the services? Original members of the team were Dickerson and Robert Segal of ISMRRD and from the gerontology field, Jane Hamilton (Cooper) and Robert Huber (now deceased).

In 1974 the Michigan team keyed in on data on institutionalized mentally retarded in Michigan and found that:

3,500 were age 21-44
1,200 were age 44-64
155 were age 65 and over

The team then interviewed 35 of these persons who were 65 and older and lived in a variety of settings such as residences for mentally retarded and nursing homes. Dickerson commented, "When people go into community placement they begin to lose a lot of the descriptors—all of a sudden they are just people on welfare who are old and nobody knows where they are historically."

On the basis of the collection of data and the interviews, a paper entitled "The Invisible Client" was written by and presented at the AAMD Conference in 1979 at Toronto, Canada. Dickerson observed many consciences being stirred because of the apparent scarcity of attention being given to this older population.

The Michigan team decided that a great deal more information was needed, more issues should be explored and questions raised about the AADD population and the presumed service gap. A start in this direction was the listing of eleven basic questions:

1. Do those with mental retardation age faster than non-mentally retarded and if so, why?
2. Are there similarities in the aging process of the mentally retarded and the mentally ill?
3. Are aging processes for the mentally retarded related more to the lack of sufficient self-care skill or to lack of education and training?
4. Do the mentally retarded who reside a long time in institutions live longer than those who do not?
5. Do house parents and other staff tend to infantalize the residents and, if so, why?
6. How can agencies keep a better count of mentally retarded who have left the institution to live in the community?
7. Why have there been no surveys to identify case findings for the mentally retarded living in the community?
8. Should there not be programs for institutions and group homes, etc., that prepare the adult retarded person for problems of aging?
9. Do the mentally retarded tend to bypass the middle years and, if so, why?
10. Would those with mental retardation be satisfied liv-

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*Michigan, Illinois, Indiana, Minnesota, Ohio and Wisconsin.

Report from the Conference on Services for the Aging

Panel presentations generated much of the discussion at the April 28-29 Conference on Aging. These presentations brought together the expertise and opinions of planners, social workers, administrators and service providers to address the relatively new problems of the aging developmentally disabled.

Comments from people who work with aging...

Patsy Costello from the Ebenezer Center for Aging in Minneapolis, Elyse Marcus from the Wilder Foundation in St. Paul and Chuck Wiesen from the Minneapolis Age and Opportunity Center (MAO) presented a profile of service models for the elderly. The panel, moderated by Jim Tift from the Minnesota Board of Aging, provided insight to services for the elderly that could be helpful in planning for the aging developmentally disabled person. A summary of a few of the concerns raised during a question and answer period follows.

FUNDING

Adult day care programs are funded through Title III grants. Some clients who can afford to pay for services do so. Donations are accepted, but organizations receiving federal money can't charge for services. Wilder Foundation also receives Title XX funding, and asks for a $15 donation per client, or whatever the client can afford to pay. Ebenezer depends heavily on volunteer time in its day care programs, and students are the biggest source of these volunteers. Ebenezer counts heavily on volunteer time in applications for Title III funding.

PROBLEMS

The biggest problem in providing services for the elderly is funding. There are more than enough clients to serve, but there are not enough staff and facilities. Part of the problem lies in the funding system. There is no network funding to cover network services, so funds must be obtained piecemeal and based on income criteria or location criteria.

HELPFUL AGENCIES OR ORGANIZATIONS

Adult day care centers throughout the state have formed an association called The Minnesota Adult Day Care Association. They are working together to obtain Title XIX funding. Their clients often need a variety of services, and they have helpful contacts in related service areas. This organization may be able to help in locating services and can be contacted through:

Dorthy Ohnsorg, President
Minnesota Adult Day Care Center
Wilder East, 696 Delaware Place
St. Paul, MN 55106

Also, area agencies on aging are located in regional development commissions in each of Minnesota's 13 planning regions. The Minnesota Board on Aging and the regional agencies can answer questions about aging programs, services, funding and resources.

ADULT DAY CARE CENTERS

There are approximately 22 adult day care centers throughout Minnesota. These centers are usually limited in the areas they serve because

of transportation problems and fun

Adult day care centers provide people during the day. Some of the tional events, meals, shopping modified therapy and social and other problems.

ACCEPTANCE OF DD CL

Group acceptance seems to be one developmental disabilities in prog serve people with a wide range of lems, and the people relate to one

Oftentimes, people with mental physical functioning than those w drome. They tend to want to help th much a part of the mainstream act

NO NEED TO LIMIT RATI

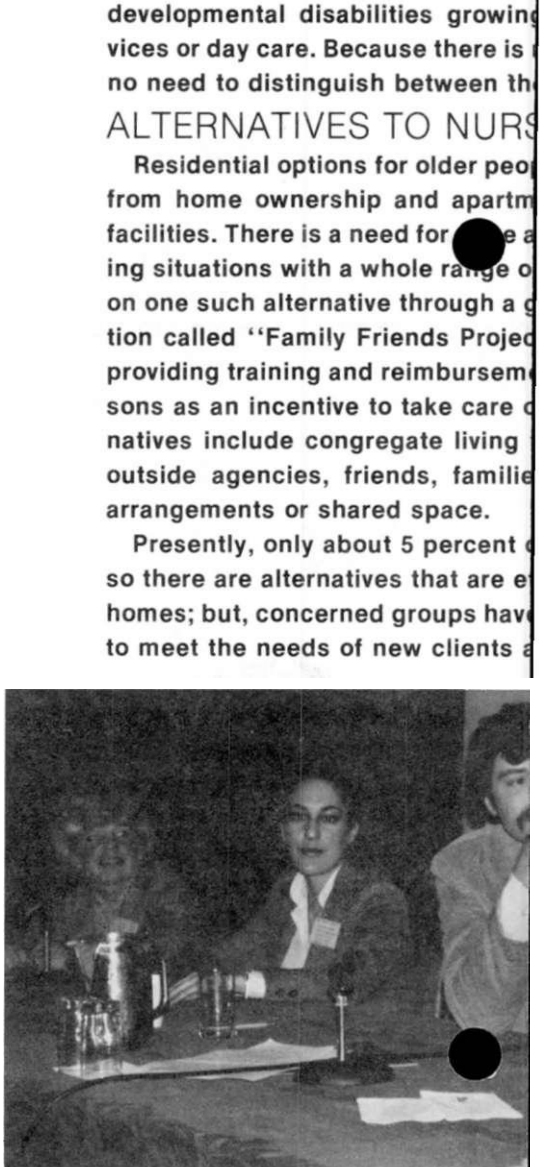
Although the number of older pe growing, members of the panel sav people in programs for the elderly.

As nutrition and health services i developmental disabilities growing vices or day care. Because there is no need to distinguish between th

ALTERNATIVES TO NURS

Residential options for older peo from home ownership and apartm facilities. There is a need for ing situations with a whole range o on one such alternative through a g tion called ''Family Friends Projec providing training and reimburseme sons as an incentive to take care natives include congregate living outside agencies, friends, familie arrangements or shared space.

Presently, only about 5 percent so there are alternatives that are e homes; but, concerned groups hav to meet the needs of new clients a



Left to right: Patsy Costello, Ebenezer; Elyse
Chuck Wiesen, Mpls. Age and Opportunity C

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supportive environment for elderly
e centers provide social and recrea-
pportunities, structured exercise,
to with financial, legal, housing

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separation in programming, there is
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are quite varied. Alternatives range
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' With this project, Ebenzer will be
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d new situations in the future.

rcus, Wilder Fdn.; Jim Tift, MN Board on Aging;
er.

Left to right: Phyllis Metzger, Dept. of Health; Ardo Wrobel, DPW; Neil Tift, Outreach Group Home; Jean Searles, RESA Inc. Hopkins

...and developmental disabilities

A panel representing state administrators of service providers offered the following comments about the problems of aging developmentally disabled persons. J. Neil Tift, director of Outreach Group Home in Minneapolis, moderated the discussion.

PHYLLIS METZGER, Supervisor Metro III District, Licensing and Certification Section, Minnesota Department of Health, Minneapolis:

-"Our general population is living longer, and therefore the MR population is getting older. I read in an annual report from a large church-connected nursing home in Minneapolis that the average age of admission has risen to 84 and is now requiring much heavier care than in the past."

-"The alternative resources and service providers in the community ought to be able to help our elderly DD people stay in a residential setting or in their own homes."

-"Who becomes an aged developmentally disabled person cannot be counted by birthdays, it's got to be a very individual thing."

-"When we first started to survey for the ICFMR regulations, we heard two ideas: 'normalization' and 'we are not a medical model.' But as your population becomes aged, I think you will be rethinking the medical model idea. You will probably be becoming more of a medical model than you were in the past. For instance, the typical Supervised Living Facility (SLF) Class A is full of barriers like stairs with no elevators. We are now realizing that some group homes will not be able to serve the aged as they become medical models with infirmities and disabilities."

-"As we get old, we face things that will be diagnosed as a medical problem. At the time that the primary diagnosis of a person with mental retardation becomes a medical diagnosis and their MR becomes a secondary diagnosis, we're all going to have to take another look at this person. It is at that time that the interdisiplinary team is going to become more important than it is now."

-"When an MR person gets old, there are going to be a whole new set of problems. I see the county social worker becoming an even more important person on that team. He is the advocate, he should be readily available to list what the alternative resources are for a person. He is the person who should be telling his county 'We don't have the alternative

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Literature review: *Findings on Elderly Persons with* MR

An article entitled "The Elderly Retarded: A Little Known Group" by Louis DiGiovanni appeared in the Gerontologist, Volume 18, 1978. DiGiovanni at the time of writing, was a graduate assistant with the University of Minnesota Program in Hospital and Health Care Administration. This article surveyed literature on the subject of elderly persons with mental retardation and identified patterns and problems affecting this population. Here is a summary of DiGiovanni's findings in the article.

ADVOCACY

Traditional concerns have focused on younger, not older, persons with retardation and the chief advocates for these persons have been parents and family members. What happens when they outlive their best political advocates? Or who picks up the advocacy slack when these people are institutionalized, thus separated from their families, especially as they grow older?

INCIDENCE:

Elderly retarded are an extremely small group in relation to the total United States population. Researchers estimate from 50,000 to 315,000 exist nationwide who are elderly and have mental retardation. Elderly was considered in these studies as over 65. The 50,000 estimate was based upon the 1970 census and upon a 2.4 percentage rate of mental retardation of the nation's elderly population.

The 315,000 estimate is based upon methods used by the Hennepin County Office of Planning and Development. This office said that 10% of the U.S. population is over 65 (that's about 21 million) and 1.5% of those have mental retardation. Of this 315,000, the percentages for mild, moderate, severe and profound retardation were 89, 6, 3.5, and 1.5, respectively. Applying this to the Minnesota 1980 population, 4,076,780, there would be 6,115 persons over 65 who have mental retardation.

Generally these estimates refer to those who are so-called "visibly mentally retarded" and does not account for unknown numbers of such people who have never been, or are not currently accounted for; for example, always stayed with the family -never entered a special program or service system.

INCIDENCE IN CERTAIN AGE BRACKETS:

One survey showed only 18.2% of persons who resided in facilities for mentally retarded were over forty years of age - this amounts to 382,000 nationally and is proportionally much less than the non-retarded over 40 population. A study in Ontario Province, Canada showed that in 1960 there were 199 institutionalized persons with mental retardation who were between 70 and 88 years of age while in 1930, there was only one such resident in that age group.

Even though the elderly persons with mental retardation are a relatively small group, many researchers have established a definite trend for them to live much longer.

FOUR ASPECTS OF AGING:

One approach to conceptualizing the aging process considers four aspects; physical, intellectual, emotional, and social.

Researchers have found a greater rate of deterioration in vision and hearing among those with mental retardation whereas the weakening of hand grip between them and the non-retarded was at a lesser rate.

PHYSICAL ASPECT:

In physical appearance, retarded persons who are 40-50 have appeared to researchers to be 60-70 years old, especially if they resided in institutions where there was a minimum of special programming in self-care, dental hygene, bathing, grooming, etc. The question arises, "Are physical changes related to the mental retardation or to the non-rehabilitation-minded setting of some institutions?"

INTELLECTUAL ASPECT:

That intellectual decline occurs with age may be the big myth for all elderly. In reality, there are specific areas where intellectual decline occurs, e.g. short term memory.

One study used the Wechsler/ Bellvue intelligence scale to test groups of institutionalized persons with mental retardation. The oldest group had the lowest score, yet all groups showed an increase in scores time and time over again, especially if the environment was one of stimulation and higher expectations. Intellectual decline depends upon the environment, age and length of institutionalization and have been better predictors of successful community placement than has the intelligence quotient. The rate of loss of intellect for those with mental retardation is no greater than for the rest of the population.

EMOTIONAL:

Individuals who have mental retardation experience emotional problems in aging just like anyone else due to medical trauma, grieving over loss of loved ones and other personal sadness. The prob-

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lem arises when professional personnel, residential staff, social workers et cetera, are unable to determine whether the person has an emotional problem or has mental retardation, because symptoms like slow thinking can show up in either case.

SOCIAL ASPECTS:

DiGiovanni said, "It is perhaps the social aspects of aging where the elderly retarded have been shown to be able to blend more effectively with the non-retarded population; particularly with those of the elderly in nursing homes." The point is, such people have already acquainted themselves with the duller environments of nursing home settings (as well managed and brightly decorated as they might be) and are thus able to make easier adaptions, and evidence shows they make "ideal" tenants, although they can be very sensitive to lack of attention on the unit.

The author of this article concludes with six major patterns found for persons who are elderly and have mental retardation:

(1) Their number is growing due to medical and eductional advances.

(2) There is much more training in independent living, and only 5% are institutionalized (as in state hospitals).

(3) Many go undetected in society as members of "regular" family settings, in widowhood, and as psuedomentally retarded.

(4) Many may instead be experiencing emotional problems and may not be retarded.

(5) Home health care is increasing for all elderly to keep them from nursing home placements, thus there is more space for nursing home placements.

(6) Community social acceptance is better.

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resources, we need different kinds of living arrangements.' "

-"The consultant RN and physician would be a very important part of the team. It would be up to them to decide at what point a person could no longer reside in a Class A facility and when a person would need additional services."

-"Everyone groans when you even think of a nursing home. Nursing homes aren't that much different from any other facility. If you look closely at the people there, you would see that they are where they need to be for the types of needs they have. They are there for a reason and their needs are being met."

JEAN SEARLES, Administrator/program director, RESA Inc., Hopkins:

-"One of the things that has really stood out at this conference is the need to develop a lot more of an interchange across the fields of aging and developmental disabilities."

-"In response to previous speakers at this conference, I'd like to highlight a few points—

-"I see the possibility for a shared housing program where a senior with an under-utilized house could have a person who has retardation living with them, helping out with the care of the home and perhaps having services like MAO coming in and helping. We could develop a lot of combinations of alternatives without getting into a lot of new funding.

"We need to anticipate as our clients get older, we just can't wait until they're 70, when everything falls apart for them.

"I think that resident councils are a concept that nursing homes have developed to larger extent than we have in DD. I think we should involve residents in the actual operation of a facility."

ARDO WROBEL, Director, Mental Retardation Division, Minnesota Department of Public Welfare, St. Paul:

-"Groups of people have a tendency to present a solution to a problem before they really know what the problem is. Solutions have to come from people in the field through experimentation and exploration of alternatives."

-"Aging in and of itself is not a problem, but aging presents some problems. I hope we're not segregating out aging as the problem."

-"In our planning, we're not making any special issue out of aging other than trying to include people who are aging into the ordinary principles of programming that we have already developed, that is the normalization principle. You don't take people out of principles of living and deny their rights because they're old. We have to talk about individual program planning.

-"We support the idea that sometime in the life of a person, his needs and capabilities change. But that doesn't mean that at 70 he will not need a DAC, employment, recreation or money."

-"Acceptance and physical disability problems are things that the aging experience, but these things are not unique to aging."

-"There is no such thing as a person, when he gets old, losing his rights: the rights continue. People have a right to live anywhere they want to. A person should be able to live and retire in his own home. An ICFMR or group home is his own home. He's been there a long time. Just like a state hospital; some like it in a state hospital, its their home. People have a right to go to a hospital when they get sick; they should have a right to a nursing home if they are disabled; they have a right to keep working if they are working; they have a right to handle their own money."

-"The developmentally disabled are just as sensitive as you or I. If

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ing in any of a number of settings as long as their basic needs are being met?

11. What are the unique needs of those with mental retardation compared with other members of their society?

In 1975, with Federal HEW support, a consultation conference was conducted made up of two experts from each state—one for aging and one from developmental disabilities. Few of the experts had expertise in both fields. Following this, five projects were funded nationwide in Oregon, Utah, Georgia, Nebraska and Michigan each taking three years to find out what was going on with the aging developmentally disabled and to develop constituencies. After three years, Dickerson reports, a constituency of more than 1500 persons was identified across the nation who were now aware of the problems and were beginning to think about what could be done. Different concepts emerged:

1. Indices of changes from aging were both primary and secondary. A primary index could be biological, social or psychological and affected one's ability to cope with stress—that's where wrinkles and gray hair come in. Secondary indices were those resulting from trauma such as loss of a loved one and thus grief and depression.

Whatever the biological change, primary or secondary, the ability to maintain stability under stress is altered. The older we become—the more difficult it is to cope with stress. Think about that for the developmentally disabled who have the complications of their life-long disability.

2. Social aging. Two dominant theories emerged: Disengagement, which holds that people mutually disengage from society and go on to the next state of being—death. Activity states that a person will remain active in later years in relation to the expectations put upon them by society and people close to them. No options—no activity.

In the United States we have arbitrarily picked age 65 as the older age cut-off. This stays in line with the Social Security legislation formulated in the 1930's. The Older Americans Act uses age 60 as a reference point for their services.

The issue is, should we be so rigid about the 60-65 limits? Wouldn't a better question be: What is one's life expectancy? Determine one's expectancy and then gear services to that, not chronological age.

3. Infantalizing versus adultizing. Particularly for the mentally retarded population, the Michigan team and other aging groups reasoned, society and program staff tend to label the person, treat the label, close off receptivity of the person, withhold opportunities, over-protect and thus infantalize the person. Adulthood is skipped over and before you know it, the person is considered at the age of senility.

Dickerson told about a 62 year old woman who had lived alone for two years, managed her own finances, self-care, shopping et cetera and then her guardian decided she should be in a group home. In that home the rules were posted everywhere—even on the refrigerator door. She had to go to bed at 10:00 p.m. "Ridiculous!" Dickerson concluded.

4. Double jeopardy. There are very few people who care to look at the unique needs of people who present the two conditions of age and developmental disability.

With the emergence of the above kind of thinking about persons both aging and developmentally disabled, the focus of the Michigan team and others around the nation settled on the double jeopardy theme and the hypothesis that special attention was absolutely necessary.

In order to test this hypothesis—that the aging/aged developmentally disabled had special service needs—a survey questionnaire was designed by Nola Thomas and Dwight Sweeney and tested in Region V states. It was mailed to 639 agencies with a 55% response rate. Of the agencies responding 56% reported services rendered to the aging DD population.

The questionnaire addressed four central questions:

1. How many AADD persons were receiving services?
2. What kinds of services were being provided?
3. What additional services were needed?
4. What were the obstacles to effective service delivery?

A major survey finding had been that neither agency employees nor their administrators understood clearly what developmental disabilities were, and only a few agencies were able to supply information about clients' ages. A state by state analysis of the data revealed no statistically significant variance in the frequency with which services were provided to the AADD population.

From these results it was projected that approximately 12.8% of the estimated AADD persons in the country are being served.

The best data about older persons was by agencies such as nursing homes because they looked closely at the age factor but they tended to group all residents under the medical label of aged or brain syndrome rather than developmentally disabled.

The types of services the agencies said they provided in order of greatest frequency were: information and referral; adult recreation, transportation, medical, and staff development. Greatest needs

Continued on page 12

Summary

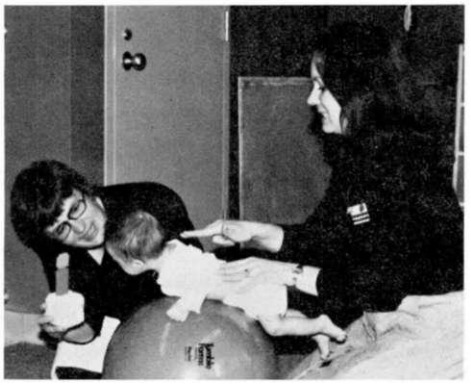
Some ideas that came out of the conference on services for the aging

Dr. Bruce Balow, Chairman of the Governor's Planning Council on Developmental Disabilities, moderated panel presentations on the issues of integration vs. segregation, family care vs. institutional care and funding of services at the conference on aging.

Dr. Balow also presented a conference summary in which he pointed out the following concerns and problems brought up by participants at the conference.

1. Whether persons with developmental disabilities who are old and growing older present particular problems or not is still an open question. Some people say that they do present special problems and others say that there are no problems other than those experienced by elderly persons without developmental disabilities or people with developmental disabilities who are not old.
2. It is clear that there are problems for some people with developmental disabilities who are aged. In some cases, a particular person and a particular set of environmental circumstances may present a problem. What may present a problem in outstate Minnesota may not be a problem in the Twin Cities and the converse may also be true.
3. There are at least minor to moderate additions to the usual problems of growing old in our society when a person is developmentally disabled. This is what has been termed "double jeopardy."
4. Integration and acceptance among the aging developmentally disabled and between these people and society does not just happen. Success depends on one-to-one kind of work and acceptance develops slowly.
5. Day activities in the community for aged people with developmental disabilities need some creative energy on the part of us all.*
6. Facility type does not always mean success. Moving from larger to smaller, a big state institution to a small group home, does not always mean an improvement for a given individual. The main concerns are care and suitability of placement.
7. Planning before a crisis is absolutely imperative. We need to look ahead for an eighty-year-old mother who is caring for a fifty-year-old developmentally disabled person. There should be planning before the mother has a heart attack and is placed in a nursing home or dies rather than hustle around for a solution after the crisis occurs.
8. Problems sometimes arise when a family that looks after a developmentally disabled member depends on and uses that person to survive as a unit, as was the case of a family that fell apart when the developmentally disabled person was moved out of the home.
9. There was a need expressed by participants for some centralized system of information, referral and central placement system at the county level.
10. Integration, interaction and communication among service delivery agencies is an age-old problem that has yet to be solved. "Good persons of good intent can agree on the general goal, but it is enormously more difficult to agree on the details of how the goal can be accomplished."
11. The Governor's Planning Council on Developmental Disabilities does not have the resources, energies, or answers at its command to respond to the range of issues that have been raised by the conference. The Council will maintain a sustained interest and pay attention to the issues at the planning level. As an advisory council with much responsibility and little authority, the council can only attempt to persuade and encourage in this area, and perhaps the participants in the aging conference can keep the issues alive and raise them among constituents in appropriate places.

**On-site visits to residences and/or Development Achievement Centers will reveal the creative type energy which Balow points up. Examples can be found statewide. In St. Paul, the editor visited with Mr. Harold Kerner of the Merriam Park DAC where several persons with developmental disabilities between the ages 60-69 participate daily. Kevin Martineau of the Merriam Park DAC in St. Paul provides special programming for 16 individuals ages 45 and over. In Washington County, the Park Adult DLC under Director Dawn Barger has been providing special programming to older MR since 1974. Barger says the seniors themselves came up with the program ideas including integration with existing community senior citizen groups.*



In our last issue on early intervention, we inadvertently left out the caption to this picture. For those of you who were left wondering, this is JoAnn Theis and her son John with therapist Nancy Koering at Riverview Hospital in Crookston.

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you're a case manager and you're making decisions or restricting the lives of developmentally disabled people, then you're in an extremely sensitive spot. One of the most important principles is that the individual who is being affected must be involved in the decision. I would expect that plans for people who get old would essentially come from, and as a result of, participation of people who are getting old."

J. NEIL TIFT

"I talked to a couple of people who currently operate facilities serving people who are over 65, and I found a general trend of five relatively distinct differences between elderly DD people as opposed to younger developmentally disabled people.

1) Day programming: people over 65, or whenever, no longer require vocational training.

2) Psycho-social interests are changing. Older people don't have the same interests as they did when they were 20 or 30. That's not saying that their interests will be completely different, but changes are apparent in their relationships with other people and what they do in their free time.

3) Family contacts are different. There tend to be fewer family members involved with the person and fewer contacts among those members. It's hard to have your folks come and visit you on your 70th birthday, there might not be a lot a family members left.

4) Physical changes: not only health related, but in ways in which people react to their environment are different.

5) Energy level is very different in older people. The change isn't automatic at a certain age, but people do slow down.

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were transportation, housing and adult activities with greatest obstacles being lack of adequate funding and staff training and unfavorable community attitudes.

The data from the questionaire was analyzed and is presented on a state by state basis in the Monograph. For further information contact:

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Four New Members on DD Council

Governor Al Quie has appointed four new members to the Governor's Planning Council on Developmental Disabilities. The appointments were effective April 1st and all four terms expire on the first Monday in January, 1983.

The new members of the Council are Ernie Silbernagel, an editor and publisher from Eagle Bend; Ben Bryant, coordinator of the Adult and Adult Basic and Continuing Education for St. Paul Schools; Mick Joyce of Marshall and Janice den Hartog of St. Paul.

The four new members replace Lois Fort, Eugene Frey, Ron Leif and Steven Chough, respectively.

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