Testimony of
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presented before the
Assembly Standing Committee on Aging
Dennis Butler, Chairman
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I am Frances G. Berko, State Advocate for the Disabled. My presentation this morning concerns a possible problem at which nobody is really looking and which may create major crises in two delivery systems within the next five to ten years.

The aging process results in disabilities. However, there is a segment of the population who had disabilities long before the onset of the aging process might be expected. Whether the aging process itself differs for any such disabled persons is a virtual unknown. Not only does the nature of this difference, if any, need definition. There also has to be clarification of predetermined factors associated with such deviances, i.e., type of disability, severity of disability, age of disability onset and other parameters.

With the improvements in medical science, the life span for the disabled citizens has increased markedly over the past two decades. Some estimates put it at or near that for the population at large. Yet there are no reliable statistics on which to estimate the extent of the need for attention to this population, either for the group as a whole or for specific disability groups. In the Children's Budget for New York State, it is estimated that there are 2.5 million persons with disabilities, or 14 percent of the state's population. Estimates based upon projections of incidence in specific disability groups based upon the 2.5 million find no agreement with other standard projections for the same group. For example, such a projection for the incidence of mental retardation and developmental disabilities is projecting an incidence of 100,000 and this figure includes persons with other disabilities. While such discrepancies may be explainable, at least in part, they illustrate the dearth of reliable information on a substantial segment of the population.

Another offshoot of the improvements in medical practices is the known decreases in early onset of disabilities. Not only have there been marked reductions in the incidence of congenital disabilities, but such causative agents as poliomyelitis and erythroblastosis have virtually disappeared. With the end results that the disabled population is aging. Many have already entered the delivery system for the aging.

One estimate projects that 20 percent of the disabled population is age 65 or over and 28.5 percent are between the ages of 45 and 64. This estimate of the total population cannot be verified even in respect to the partial data available from specific disability groups.

The problem therefore resolves itself into one of lack of information. Reason dictates that certain segments of the disabled population, particularly those whose disabilities originated in the formative years, may present differing problems in aging. Since the majority of these persons will enter the delivery system for the aging population as a whole and since there is strong probability that research and information gathering on the aging process in the pre-aging disabled will shed light on the unknowns in human aging, focus on this problem should be begun before the dearth of information has major impact on the already overburdened delivery system for the aged. The lack of attention to date is attributable to the emphasis of both governmental and voluntary agencies on obtaining adequate services for other age groups.

Although there have been seminars in other states, like Pennsylvania and Michigan, to begin to ascertain the nature of the problem with the aging and the aged disabled citizen, there has been no such undertaking in New York State. Nor, to my knowledge, is one scheduled. The providers of services to disabled citizens are preoccupied by the daily pressures of maintaining current services on a daily basis and are not thinking in terms of future needs. Nursing homes and other residential facilities for the aging and aged population are already serving some of the disabled citizens who are aging. However, no special programs and/or approaches are used or contemplated for this population. Nor do we know whether such special approaches are necessary. It is my belief that more information urgently is needed before both groups of providers are so glutted with calls for services from this population that the delivery systems will be unable to serve those for whom they're presently geared to serve.

It is difficult to make recommendations when you don't know whether there is a problem. It is also difficult to establish a role for the New York State Legislature in determining whether a problem exists, except to suggest that perhaps hearings such as this should be held on a regional basis throughout the state -- with due notice to all provider groups, advocacy agencies and organized groups of disabled and aging persons. In addition, the following strategies are suggested to determine whether there is a problem:

...The New York State Office for Aging, in conjunction with the Office of the Advocate, the Commission on Quality of Care for the Mentally Disabled and the Department of Health, should survey nursing homes to ascertain whether they are now serving individuals whose disabilities predate the aging

process, the diagnosis, severity, multiplicity and age of onset of such disabilities; what, if any, specific deviances are inherent in aging for this group as differentiated from others in the delivery system; and what impact that deviance has on the delivery system itself. This information combined with information now being gathered by OMR/DD through their developmental disabilities information service will provide sufficient information to determine whether a problem exists and, if so, to what extent.

...There has been some preliminary research done by the Institute of Basic Research in aging processes associated with Down's syndrome, the exact nature and extent of which is unknown. There also may be information in the professional literature and other research projects which is not generally known. It is recommended that the Office for Aging in conjunction with one or more branches of SUNY cause to be assembled a search of the literature and on-going research projects to determine the exact nature of present information.

...The decision made over three decades ago that large expenditures to measure the incidence and prevalence of disabilities are neither cost-effective or cost-efficient probably is still valid. However, a low-cost survey of service providers, voluntary and proprietory, will yield basic information for indicating the quantiative extent of the problem within the next decade. Such a project may be sponsored by anyone or all of the following agencies: State Office of the Advocate for the Disabled, Commission for the Blind and Visually Handicapped, Office for Aging, Office of Mental Health, Health Planning Commission, Department of Health and Department of Social Services.

...If the above information reveals enough data indicating the existence of a problem, a statewide conference representing governmental, voluntary and proprietary agencies concerned with the various disability groups and the aging be held to develop strategies for resolution.

...Similar strategies should be recommended to other states. It may be that the incidence within a given state is insufficient to justify the required basic research. But nationwide, the lack of information is cause for concern.

...Interagency support be given to a grant application to federal administration on aging, now in preparation by OMR/ DD and the Office for Aging, for data collection on one segment of the aging and aged disabled population.

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