

# MEMORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
PUBLIC HEALTH SERVICE  
HEALTH SERVICES ADMINISTRATION  
Bureau of Community Health Services

TO : The Surgeon General

DATE: December 18, 1981

FROM : Dr. Mary Lynn Fletcher

SUBJECT: Establishment of an Office for Disability Affairs

It has become obvious there is a need for policy coordination for health care services, research and regulation that affects disabled children, the aging disabled and the elderly disabled. One need only review the activities of the recent White House Conference on Aging as well as the International Year of the Disabled Person to realize a focal point within the Public Health Service is needed for these high risk populations. Indeed, just collecting information from the various agencies as to their responsibilities, activities and interest in these populations has become an exercise in futility.

This paper addresses the greatest concerns and suggest some administrative remedies which could improve the coordination of policy. Equally of concern is the lack of an inhouse advocate for these high risk populations. Advocacy in this instance in not being used to refer to the establishment of programs rather one office be designated spokesperson externally and the watchdog internally as to policies affecting these populations.

There are many examples where the lack of coordination has resulted in serious gaps both in services as well as research. The most recent example is that of the post-poliomyelitis victims who are experiencing unexplained disease manifestations. In 1950, there were 60,000 confirmed cases of paralytic poliomyelitis; in 1952, 42,000 cases. When immunization became widely distributed in 1956, the country took a sigh of relief and put polio out of mind. The most effective private organization in assisting polio victims also changed its focus to birth defects. This left post-polios with little or no access to information on long term care. The Neurological Institute of the National Institutes of Health (NIH) has become involved with more discreet laboratory problems such as amyotrophic lateral sclerosis. The most logical place for research into the long term effects of polio is the National Institute for Handicapped Research which is housed within the Department of Education. Unfortunately, the medical advisory committee of the Institute has not met for three years to set priorities.

Personal experience gained from tracking twenty-two patients (see attachment)

suggests a growing, if not absurd set of assumptions about the health problems of the post-polios largely due to mis-information, no information and no long term studies of the victims.

It is fair to say there is a lack of research into the aging disabled, which by all accounts costs the Medicaid program 13% of its total budget. Post-polios are but one example of the gaps in knowledge which exists because of a lack of coordination. Presently, there is only one small study being conducted on post-polios which is tragically under funded and the most revealing diagnostic tests are unavailable because of money. This illustrates the low priority chronic disease research has within the research community.

The following is suggested as a beginning point to remedy these concerns:

OBJECTIVE I: ESTABLISH WITHIN THE OFFICE OF THE SURGEON GENERAL AN OFFICE FOR DISABILITY AFFAIRS

Its functions would include:

- o Coordination of all special activities such as the White House Conference on Aging, the International Year of the Disabled Persons.
- o The establishment of an information/advocacy role to the States, private sector and private foundations for these high risk populations.
- o Continual assessment with outside and inside input as to the changing needs of these populations e.g. manpower needs, research information for the private sector.
- o Establishing a focal point for organizing volunteer self-help groups of parents and the disabled. The objective would be for the newly disabled to learn from both parents and the disabled without having to deal with several layers of social/medical workers.

OBJECTIVE II: ESTABLISH WITHIN THE OFFICE OF THE SURGEON GENERAL THE INSTITUTE FOR HANDICAPPED RESEARCH.

I do not mean to minimize the political battle this would entail. Currently, it is not certain where the Rehabilitation Services Administration nor the Research Institute will be placed after the Department of Education is broken up. Furthermore within the rehabilitation community there is real fear that if NIH controls the Handicapped Institute's functions rehabilitation will again be placed in a low priority as it was in the past. There is serious opposition to the Institute for Handicapped Research being placed at NIH. The alternative would be to place it in the Surgeon General's Office. Irrespective of where it is placed it needs to be in the Public Health Service.

OBJECTIVE III: THAT THE OFFICE OF SURGEON GENERAL NOT ONLY MONITOR EXTERNAL ACTIVITIES RELATED TO THE MISSION OF THE PHS FOR THESE HIGH RISK POPULATIONS BUT THE INTERNAL ACTIVITIES AS WELL.

The functions would include:

- o A concise statement of the responsibilities of the PHS has both in its training, hiring, promotion and access of the disabled.
- o An on-going evaluation of resources that are specifically ear-marked for these high risk populations.
- o Establishing interagency task forces which coordinates the problems in one agency with another agency. All DHHS program coordination should reside within the Secretary's Office and not the Office for Human Development (OHD) as is currently the case because of the lack of authority to force cooperation.
- o Review of all long term planning and budgets affecting these high risk populations.

The above three objectives cannot be implemented immediately but there is an opportunity to immediately establish an Office for external liasion. This function could serve as the focus to organize parent and disabled self-help groups.