STATE OF CONNECTICUT

DEVELOPMENTAL DISABILITIES COUNCIL

December 4, 1992

TO: Colleagues

FROM: Ed Preneta
Director

RE: Opposition To Changing From "Developmental Disabilities" To "Disabilities'[1]

It is in the national interest to maintain and strengthen a focus on people with the most severe and multiple disabilities, i.e. developmental disabilities, to assure America's most vulnerable citizens are at the forefront of an inclusive society and not in the backwaters of segregated facilities.

The current federal difinintion of developmental disabilities needs to be simplified and clarified to emphasize children and adults with the most severe and multiple disabilities as the focus of Congressional intent.

Expansion of Developmental Disabilities Act concepts to apply to some other broader definition of disabilties will be at the expense of, and detrimental to, people with the most severe and multiple disabiltiies, even if the broader definition includes people with developmental disabilities. DD Councils, and all other elements of the DD program (P&As, UAPs, National Significance Grants), are all guilty of neglecting people with the most severe and multiple disabilties in the services and supports they create and in the public policy they promote. The DD program has succumbed to the "creaming" phenomena, in which people with mild and moderate disabilities rose to the top, because they were easier to work with, and received extraordinary amounts of DD attention and resources in the name of "developmental disabilities".

The supported employment movement is, perhaps, the latest example of "creaming". The supported employment movement was given birth out of the concern that the existing "rehabilitation" system was not addressing people with servere and multiple disabilities. The DD program became a leader in promoting supported employment. Supported employment has proven to be an alternative to the traditional rehabilitation system but most of the people who have benefitted from supported employment are people with mild and moderate disabiltiies. People with developmental disabilities remain in sheltered unemployment

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centers and other segregated facilities.

The answer to "creaming" is not to expand the DD program concepts to a broader definition of disabilities but to focus the DD program on people with the most severe and multiple disabilities. Broadening the definition of disabilities, even if it includes people with developmental disabilities, will contribute to more "creaming" by making it easier, and legitimate, to work with people who rise to the top.

The Americans with Disabilities Act is creating unprecedented opportunities for people with disabilities to be included in society, especially people with mild and moderate disabilities. Reauthorization of the DD Act presents Congress with an opportunity to focus elements of the DD program on people with the most severe and multiple disabilities.

The United States, and the world, are undergoing significant economic change that could return people with the. most severe and multiple disabilities to pre-1970 conditions, including institutions, intentional segregation and euthanasia. We need only look to the rise of neo-nationalism in Germany today to be reminded that the more "different" people are the more vulnerable they become to unequal and violent treatment. Afterall. people with disabilities were amongst the first to die in the Nazi Germany Holocaust.

Here in the United States, it is unlikely people with developmental disabilities will ever experience an Holocaust, but it is possible they will be re-incarcerated in institutions and segregated facilities. While all reports say were are slowly closing institutions, there are still a significant number of people incarcerated in institutions. There is also backlash against the "community-based" movement and for good reason: group homes are often nothing more than institutions in the community. People with the most severe and multiple disabilities still tend to be "residents" of such institutions and there are signs of institutional growth: the conversion of skilled nursing facilities into "rehabilitation centers" and intermediate care - facilities for people with traumatic brain injuries; the backfilling with older adults with developmental disabilities into vacancies in segregated senior citizens housing and programs: the development of group homes for children: the prospect of rebuilding orphanages to house thousands of children left orphan by moms who have died from AIDS. Public policy continues to support such places. The proposed Oregon Medicaid Plan is a sign of the movement toward permitting the destruction of "Unworthy" life. In an economy where the competition for jobs

and resources is raised, a different kind of "creaming" will occur. People with developmental disabilities will rise to the top as the easiest to incarcerate because where places for incarceration still exist, and where places for incarceration are growing, and where public policy and public resources support incarceration, there are jobs. The logic will be that if incarcerating people with developmental disabilities was right then, it is the right thing to do now, especially for the economy. People with developmental disabilities will also be the easiest to destroy.

The DD progam is needed to promote alternative thinking, to change public policy and to demonstrate new programs and supports.

Expanding the concepts in the DD program to some broader definition of disabilities will be a public policy disaster. Working with people with the most severe and multiple disabilities is somewhat akin to experiences that people have had working in Third World countries (e.g. Oxfam), and experiences religious institutions have had working with "the poorest of the poor" (e.g. Mother Theresa), Out of these experiences have come lessons applicable to other situations. Out of the DD program's work with vulnerable people have come many public policy lessons about values, deinstitutionalization, supported employment, inclusive education, natural, neighborhood associations, and other lessons applicable to other population groups. These lessons grew into progressive public policy movements benefitting many. Expanding the concepts in the DD program to some broader definition of disabilities will result in public policy mediocrity as energy and resources are spent trying to come to consensus between existing services and supports, which tend to be based on old, traditional concepts that have benefitted people with mild and moderate disabilities, and new concepts born out of working with people with the most severe and multiple disabilities.

Expanding the concepts in the DD program to some broader definition of disabilities will hurt people with the most severe and multiple disabilities.