

Eunice Kennedy Shriver
Remarks on Mental Health and Mental Retardation
NIH meeting on November 29, 2001

Let me begin by saying how honored I am to be addressing this historic meeting of leading researchers and educators, federal agency heads, advocates, and distinguished guests.

Your work over the next two days can set our nation on a course of action to ensure that people with mental retardation have access to mental health supports they need throughout their lives.

Seven million Americans have mental retardation. So many have suffered and continue to suffer unmentionable indignities. They are abandoned, institutionalized, denied appropriate education, denied medical care, taunted without mercy, and banished to lonely lives of sadness and hopelessness. Yet they have done nothing wrong, committed no crime, and perpetrated no injustice. They suffer only because they are different. We are here today to challenge our nation to give them freedom!

Over the last forty years our nation has struggled to understand the needs of people with mental retardation. We struggled to understand the difference between mental retardation and mental illness. Our new challenge is to understand the connections.

Let us review some facts:

First, 20-35% of people who have mental retardation also have a psychiatric disorder. And yet, our service system is constructed as if people have either mental retardation or mental illness – but not both.

Secondly, People with all levels of mental retardation experience a full range of mental health challenges. And yet, 39% of psychiatrists admit that they prefer not to treat people who have mental retardation.

Finally, Children with mental retardation who are depressed are not likely to get the help they need in schools. Unless their behavior is disruptive, they are more likely to be ignored or even removed from the class. Next year, when IDEA is reauthorized in Congress, we should pay special attention to teacher training and related services so that children with mental retardation who have mood disorders or behavior problems will be helped.

Our work at the Foundation and at Special Olympics teaches us that people with mental retardation have the same needs and problems as every other human being. Our work teaches us we must focus on the whole person – on their physical and mental health needs, their educational and vocational needs, and their social and spiritual needs.

We have learned that if we give people with mental retardation a chance, they can accomplish great things. With high expectations, freedom, and proper support, Special Olympics athletes have become extraordinary leaders. More than 900 American athletes travel throughout the country to speak to PTAs and professional organizations about the needs and capabilities of people with mental retardation. Their powerful speeches demand the inclusion of people with mental retardation in all aspects of American life.

We have also learned that if we give ordinary Americans a chance, they will accomplish much to help their special fellow citizens. For example, the Best Buddies college program matches young adults who have mental retardation with college student volunteers, strictly for the purposes of forming and maintaining friendships. After their experience with Best Buddies, 94% of the college volunteers say they would support people with mental retardation living in their neighborhood – and 75% said they have a more positive attitude about people with mental retardation. The work of the Buddy teams is intended to improve the civic image of people with mental retardation, and to build their self-esteem.

And it is working!

As proud as we are of these programs, that can reach thousands of citizens, our nation must reach millions. To improve mental health supports to every American who has mental retardation—and their families—we must focus on research and training. Today and tomorrow you will explore many examples of good ideas for special persons, but let me outline a few thoughts with you:

For example, here is a research problem:

Adults and children with mental retardation experience a rate of mental illness triple that of the general population. Yet, people with mental retardation are excluded from research studies and medication trials.

And here is a research solution:

Under the direction of self-advocate Tia Nelis, the University of Illinois at Chicago has published a handbook to help you include people with mental retardation in research projects. I commend this work to you. I know my friend David Braddock is here today and would love to talk to you.

Here is an example of a training problem:

Even now, school children with mental retardation suffer needlessly as a result of the lack of training afforded to school psychologists, school nurses, and educators on how to make appropriate referrals and interventions.

And here is a potential training solution:

The University Centers for Excellence in Developmental Disabilities were created to provide interdisciplinary training in every State. With targeted resources, these centers can train professionals in the mental health field to work with people who have mental

retardation. And they could train professionals who work with special people to recognize, screen and refer people for help.

And finally, our service system has problems, too:

The biggest problem is that our service system is fragmented—people are eligible for different supports depending on what their primary diagnosis is—not on what problems they have.

We will all need to work together to find solutions to service problems of our special friends.

For example, caring professionals will need to help ensure special persons have access to federal payment systems: Medicaid when they need it and, in the same visit, suggest S-CHIP for families with slightly higher incomes.

We all must do everything we can to stop States when they attempt to eliminate or minimize services available under federal plans, and to stop States from imposing restrictions on eligibility.

After forty years of exploration, we know what the problems look like: and people still need services! We know what the interesting research questions are: but people still need services! We know that our professionals don't have the training they need to be able to help: but people still need services! We must find the courage to demand the help that people with mental retardation need. Real help. Hands-on help. Yes, we need research; yes, we need training; but over the next few days, do not forget that people need services!

With your leadership, we can reaffirm the values that made our nation great—to seek equality for all men and women, to create hope and education for every child, to heal the illnesses of all who are sick, to carry the torch of freedom to a new time and place, to believe as my brother said, that “here on earth, God’s work must truly be our own.”

We now know that people with mental retardation and their families can live decent, fulfilling, happy lives—lives full of joy, hope, love and friendship.

That is God’s work.

Today we must make it our own.

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