



MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA

DEPARTMENT OF PUBLIC WELFARE

DATE OF ISSUE
JUNE 13, 2003

EFFECTIVE DATE
Immediately

NUMBER
00-03-05

SUBJECT:

Principles for the Mental Retardation System

BY:

Kevin T. Casey
Kevin T. Casey
Deputy Secretary for Mental Retardation

SCOPE:

- County Mental Health/Mental Retardation Administrators
- Base Service Unit Directors
- State Center Directors
- Non-State Operated Intermediate Care Facility (ICF/MR) Directors
- Community Home Directors
- Family Living Home Directors
- Adult Training Facility Directors
- Vocational Facility Directors
- Early Intervention Program Directors

BACKGROUND:

In 1991, the Office of Mental Retardation convened a planning retreat with members of the OMR Planning Advisory Committee (PAC) for the purpose of developing an overall vision for Pennsylvania's mental retardation service system. The PAC, which was the first advisory body to the Office of Mental Retardation to include people with disabilities and families as full participating members, focused its work on what people with disabilities and families said was important to them and what kind of supports they needed. The result of the PAC's efforts was *Everyday Lives*, published by the Department of Public Welfare in 1991.

Since its publication, the values and vision expressed in *Everyday Lives* have provided the framework for planning, policy development, service design and all related activities in the mental retardation service system. *Everyday Lives* has served as the foundation for both the Pennsylvania's Multi-Year Plan for the Mental Retardation Service System and the Plan to Address the Waiting List.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:
Appropriate Regional Mental Retardation Program Managers

In the fall of 2000, the PAC asked the Self-Determination Consumer/Family Group to review developments in the system since publication of *Everyday Lives* in 1991 and to create an updated edition, *Everyday Lives: Making It Happen*.

This 2001 publication of *Everyday Lives: Making It Happen*, adopted by the PAC in November 2001, reaffirmed the values of choice and control, individual freedom and safety, individuality and relationships, success, stability and the recognition that comes from making a contribution to the community. The new edition also introduced the values of collaboration, quality, mentoring and accountability. The document closes by spelling out the challenges of the future.

Principles of the Mental Retardation Service System:

The values, articulated as principles in *Everyday Lives: Making It Happen*, set the direction for the service system. They provide standards for policy development, service design and decision-making. They articulate the outcomes in person-centered terms that our system should achieve and they are a guide for personal action.

Principle #1: Choice – In all aspects of life including the services people receive, who provides supports, where to live and with whom, where to work, recreation and leisure activities, vacations, planning individualized day activities, and having support provided at home.

Principle #2: Control – over a person's life including relationships, budgets and how money is spent, supports and services they receive, medical issues and planning.

Principle #3: Quality – of life determined by people. People want quality supports and services to enable them to have the life that they want. When people pay for high quality supports, people expect to get high quality.

Principle #4: Stability – feeling secure that all changes in their lives are made only with their input and permission – "nothing about me without me."

Principle #5: Safety – to be safe at home, work, and school and in their neighborhood, as well as in all other aspects of their lives. People want services that ensure individual health and safety without being overprotective or restricting them.

Principle #6: Individuality – being known for their individuality and being called by their name. Being respected by having privacy of their mail, files, and history and being able to choose to be alone at times.

Principle #7: Relationships – with family, partners, neighbors, community people such as pharmacists, hairstylists and grocers, support staff and having friends they choose.

Principle #8: Freedom -- to have the life they want and to negotiate risk. People want others to use 'People First' language and to have freedom from labels. People with disabilities have the same rights afforded to all citizens. They want to exercise the freedom of choice, to associate with people they choose, to move from place to place, and to use complaint and appeal processes.

Principle #9: Success -- freedom from poverty and having a chance to be successful in the life they choose. Living independently with sufficient support to be successful and having expanded opportunities for employment with supports provided as needed.

Principle #10: Contributing to the Community -- being full citizens of the community, voting, working for pay or volunteering, participating in leisure and recreation activities, belonging to a religious community, owning or renting one's own home, living among family and friends and not being segregated. People want to be recognized for their abilities and gifts and to have dignity and status.

Principle #11: Accountability -- State and county government, together with support workers, provide the services and supports that people need when they need them and make sure that they don't lose needed supports that they already have.

Principle #12: Mentoring -- people and families trained as mentors to help other people and families by providing information and working with them until they can do things on their own; experienced Supports Coordinators mentoring new Supports Coordinators; senior support staff mentoring new support staff; and individuals and families mentoring support staff.

Principle #13: Collaboration -- between the Office of Mental Retardation and other offices within the Department of Public Welfare and other state and federal departments. People want collaborative planning during times of transition. They also want a seamless system that bridges from education to people/services/systems that are involved with them.

Principle #14: Community Integration -- in all aspects of the person's life. People want to be able to use community resources, like banks and food stores, just as other people in the community do, without feeling left out because of a disability. Integration means both being in the community and having the opportunity to participate in all that the community has to offer; including generic resources that don't label people as "special."

Obsolete Bulletins

Mental Retardation Bulletin 00-02-04, Principles for the Mental Retardation System, issued March 25, 2002.