Kentucky's Plan

From Dreams to Realities for Quality
and Choice for All Individuals
with Mental Retardation
and Other Developmental Disabilities

A Recommended Plan From:

The Commission on Services and Supports for
Individuals with Mental Retardation and Other
Developmental Disabilities

Submitted in Accordance with House Bill 144 to:

Governor Paul E. Patton
and the General Assembly
April 17, 2001

The Commonwealth of Kentucky

Cabinet for Health Services

on Behalf of

The Commission

on Services and Supports for Individuals with Mental Retardation
and other Developmental Disabilities

Presents

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EDUCATION
PAYS

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Prospect

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THE VISION FOR KENTUCKY

Our vision is that all persons with mental retardation or developmental disabilities and their families are valued and respected as contributing members of their community, and have the same opportunities to be educated, to live, work, worship, play, socialize, and receive quality services and supports in accordance with their individual needs and interests as every other Kentuckian.

MISSION STATEMENT

The Commonwealth of Kentucky will provide the most flexible, effective, and integrated system of quality supports and services to meet the educational, residential, vocational, and social needs of all persons with mental retardation and developmental disabilities and their families.

INTRODUCTION

***"Kentucky ranked 50th** in the nation in funding of community based services for persons with mental retardation/ developmental disabilities."* The 2000 State of the States Summary Report. This is based on 1998 data and does not reflect any changes that may have occurred because of House Bill 144 funding.

"This is one of the most significant pieces of legislation with which I have been associated during my time in the legislature." Representative Jimmie Lee.

Kentucky citizens with mental retardation and other developmental disabilities and their families are in a state of crisis. Waiting lists for services and supports are lengthy and continue to grow. Young adults are exiting school with few or no options available that would support their active participation in community life. Parents who have continued to raise and care for their child into adulthood are aging and are realizing a decline in their health and ability to maintain the support the family members need. Both of these groups look to the service system for help in planning for their child's future.

As a result of this recognized need for additional funding and flexibility in delivering services, the 2000 General Assembly passed House Bill 144, which established the Commission on Services and Supports for Persons with Mental Retardation and Other Developmental Disabilities. The Commission was charged with the responsibility of evaluating the current service system and making recommendations to move that system toward a person-driven, outcome based model. This charge has resulted in the involvement of hundreds of people, representing a broad range of stakeholders, discussing issues and developing recommendations for the Commission's consideration. In accordance with Governor Patton's Strategic Planning Initiative, this plan reflects the principles and processes of a dynamic and moving document. Through the work of the

Commission and the Subcommittees, the values, vision, and mission have been identified. Commission members have examined the current situation of services and supports and debated what services and system would best respond to the needs of people with mental retardation and other developmental disabilities, their families and the community at large. The following document outlines both philosophical outcomes and specific strategies in meeting these outcomes. This plan will serve as the structure for guiding activities, for developing action plans, and for implementing and monitoring these activities. At future Commission meetings these efforts will be reviewed and where appropriate, goals, strategies, or actions may be modified and strengthened.

1700 people are waiting *for Supports for Community Living services.*

Destiny *is not chance, it is choice.* Disraeli.

THE COMMISSION

In September 1999, at the direction of the Governor and Secretary of the Cabinet for Health Services, a group of Kentuckians concerned about individuals with mental retardation went to Washington to participate in an Academy of the President's Committee on Mental Retardation (PCMR). Group representatives included state legislators, family members of individuals with mental retardation, advocates, business leaders and state government officials. The purpose of the PCMR Academy was to draft a state plan for inclusion of citizens with mental retardation in the community. Their difficult task, along with other advocacy movements such as the Arc of Kentucky's A Key of Our Own, and the Coalition for Quality and Choice would spur a movement within the state that resulted in the drafting of the most significant legislation of the decade affecting individuals with mental retardation and other developmental disabilities, House Bill 144.

House Bill 144 established the Commission on Services and Supports for Persons with Mental Retardation and Other Developmental Disabilities to serve in an advisory capacity to the Governor and General Assembly and to develop a ten year plan for serving persons in the most appropriate setting, submitting their final recommendations by October, 2000. Secretary Jimmy Helton, The Commission's Chairperson, convened the initial meeting in June, 2000.

Because of the enormity of their task, the Commission sought permission to extend their planning time by six months and submitted a "Plan to Plan" to the Governor and General Assembly in October, 2000. The "Plan to Plan" provided the framework under which the Commission would function during the next six months.

MANDATES

- *Develop a statewide strategy to increase access to community-based services and supports for persons with mental retardation and other developmental disabilities. The strategy shall include: a) Identification of funding needs and related fiscal impact; and b) Criteria that establishes priority for services for individuals approved for slots that consider timelines and service needs.*

- *Assess the need and potential utilization of specialized outpatient clinics for medical, dental and special therapeutic services for persons with mental retardation and other developmental disabilities.*

- *Evaluate the effectiveness of state agencies and public and private service providers including nonprofit service providers in:*
  a) Dissemination of information and education;

In an effort to accomplish the tasks set before them, the following seven subcommittees were established: Prevention and Education; Services, Supports and Systems Issues for Children and their Families; Services, Supports and Systems Issues for Adults and Adults and their Families; Specialized Outpatient Clinics; Quality Assurance and Consumer Satisfaction; Priority Criteria for Service Access ("Waiting List"); and Finance.

Each subcommittee, whose members included many involved Kentuckians, was asked to review state and national trends, outline gaps in services affecting individuals, and develop recommendations for the Commission's consideration. Over 300 citizens devoted countless hours over a period of ten months to develop the recommendations contained in this plan.

b) Providing outcome oriented services; and
c) Efficiently utilizing available slots and resources, including blended funding streams.

- *Develop a recommended comprehensive ten-year plan for placement of qualified persons in the most integrated setting appropriate to their needs.*

- *Recommend an effective quality assurance and consumer satisfaction monitoring program that includes recommendations as to the appropriate role of family members, persons with mental retardation and other developmental disabilities, and advocates in quality assurance efforts.*

- *Advise the Governor and the General Assembly on whether the recommendations should be implemented by administrative regulations or proposed legislation for the 2002 General Assembly.*

RECOMMENDATIONS

PREVENTION

Every year in the United States, we prevent:

- *1000 cases of mental retardation due to congenital hypothyroidism, thanks to newborn screening and thyroid replacement therapy; and*
- *4000 cases of mental retardation due to measles encephalitis by the use of a measles vaccine.* (The ARC Homepage).

Forty-four percent (44%) of individuals reported that they received their brain injury prior to age 22. This meets the definition of a developmental disability. Source: Brain Injury Services Unit survey of individuals who had received services for a brain injury within the last two years.

Mental retardation and other developmental disabilities can be caused by any condition, which impairs development of the brain before birth, during birth, or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains unknown. For those known causes, significant advances in research over the past thirty years have resulted in the prevention of many cases of mental retardation and other developmental disabilities. These prevention activities have had a significant impact on the lives of people, their families and society. The following strategies provide for other activities, which can have a major impact in preventing mental retardation and other developmental disabilities.

OUTCOME: THROUGH PUBLIC EDUCATION AND PREVENTION EFFORTS, MORE CHILDREN WILL BE BORN HEALTHY AND THE INSTANCES OF DISABILITIES WILL BE REDUCED.

STRATEGIES:

♦ ***Support existing prevention efforts regarding acquired brain injuries and with additional funds increase public awareness of acquired brain injuries.***

Citizens must have access to information regarding acquired brain injuries and steps which can be taken to prevent their occurrence. Current efforts include those provided through the Brain Injury Association of Kentucky (e.g., helmet give-away); Mothers Against Drunken Driving; Safe Kids Coalition (e.g., fall prevention, water safety); and Council on Child Abuse. Each of these agencies also conducts public awareness efforts, which require continued support and expansion.

- ***Improve data collection within publicly funded programs to allow for greater determination of the number of individuals with an acquired brain injury.***

There are currently no requirements that health care or human service agencies report the number of people who receive their services as a result of acquired brain injuries. The requirement for an annual report indicating numbers served would give the state a more accurate estimate of the number of people who need their services and assist in planning efforts.

- ***Promote current programs and funding on folic acid awareness.***

Current efforts through the Department of Public Health (DPH) provide public awareness regarding the effects of insufficient folic acid, which can result in spinal cord exposure, mental retardation and motor deficiency. The continued support of these efforts is essential in the prevention of life long disabilities.

Folate's potential to reduce the risk of neural tube defects is so important that ***the FDA requires food manufacturers to fortify enriched grain products with folic acid****.* USFDA FDA Consumer February 1999.

- ***Establish an Adult Phenylketonuria (PKU) Clinic at the University of Louisville for the western part of the state and maintain the adult PKU clinic at the University of Kentucky for the eastern part of the state.***

PKU is a hidden hereditary metabolic disorder, present at birth that leads to severe mental retardation, seizures, and other chronic disabilities. It is detected through the state newborn screening program, which began in 1966.

In the 2000 General Assembly, legislation was passed that affected individuals born after 1966 have been treated beginning at birth; however, only one-fifth who are beyond age ten have been able to maintain dietary compliance. Until recently, it was thought that skills never developed in the untreated patient or those who did not maintain dietary compliance. It has now been determined that individuals returning to or starting the diet as adults are able to recover some lost skills. In the fall of 2000, the Division of Mental Retardation, through the Department for Public Health, provided funding to establish an Adult PKU Clinic at the University of Kentucky to serve the eastern part of the state. The next step in this prevention effort will be to establish an adult clinic for the western part of the state.

*Every year in the United States, **250 individuals are prevented** from having mental retardation as a result of PKU due to newborn screening and dietary treatment.* (The ARC Homepage).

The importance of newborn screening tests was reaffirmed in the 2001 legislative session with the passage of Senate Bill 31, sponsored by Senators Long, Boswell, and Herron Jr. Senate Bill 31 expanded the types of screens and required the Cabinet for Health Services to apply for additional federal funds.

- ***Develop an initiative with First Steps providers to increase their ability to identify mothers who may have a substance abuse problem requiring treatment.***

Current efforts to increase identification of pregnant women by health care providers to determine their need for substance abuse prevention or treatment services is underway. For example, Health Access Nurturing Development Services (HANDS) works with first time parents to assure their ongoing connection with pre-natal care and other support services. However, there is no initiative with First Steps providers to increase their ability to identify if a mother of an infant receiving supports may have a substance abuse problem requiring treatment. This initiative could prevent the next infant from being exposed to alcohol or drugs inutero.

- ***Increase the capacity to provide substance abuse treatment for women of childbearing age.***

While there are sufficient funds related to substance abuse services for pregnant women, there is not sufficient capacity for other women of childbearing age who need gender sensitive substance abuse treatment, particularly at the residential treatment, intensive outpatient treatment and transitional living points in the continuum of care.

Alcohol use or abuse *by the pregnant woman poses extreme and unique risks to the fetus and is associated with fetal alcohol syndrome.*

Fetal Alcohol Syndrome *is the number one known preventable cause of mental retardation.*

PROMOTING CHOICE

***Self-determination** is the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve the goals to which they aspire, and to acquire the skills and resources necessary to participate fully and meaningfully in society.*

***Choice** is the experience of one's own autonomy, both in everyday matters (such as what to wear and what to eat), as well as in large, life defining matters (such as what sort of work to do, where to work, or where to live and with whom to live).* From John O'Brien's Five Accomplishments.

Kentucky must empower and support all citizens with mental retardation and other developmental disabilities to realize their own vision and goals for their lives. To accomplish this, families, friends, individuals, provider agencies, advocates, the community, and government must work together to move the service delivery system into one that is responsive to individual needs and desires based on the basic principles of self-determination.

Historically, people with mental retardation and other developmental disabilities and their families have been given few choices in the way they live their lives. Services and supports have generally been prescriptive, with professionals or systems determining which service the individual receives and how it will be delivered. The result of this prescriptive planning has put people into programs that have vacancies instead of developing supports that meet the individual's needs. While freedom of expression and choice are considered fundamental human rights, this has been less true for people with mental retardation and other developmental disabilities.

OUTCOME: THROUGH THE PRINCIPLES OF SELF-DETERMINATION AND INFORMED CHOICES, PEOPLE WITH MENTAL RETARDAITON AND OTHER DEVELOPMENTAL DISABILITIES WILL HAVE ACCESS TO SERVICES AND SUPPORTS THROUGHOUT THEIR LIFESPAN.

STRATEGIES:

- ***Create new supports and services for individuals that are driven by person-centered planning.***

Person-centered planning refers to a group of approaches to developing supports and services in coordination with the individual/family. Each person has the authority to define and pursue his or her own vision. Supports start with listening to the person and honoring, respecting and supporting each person's vision. The goal is to promote each person's empowerment, dignity and positive self-image. Systems have traditionally functioned with the expectation that the person must change to fit the program. For the plan to be effective, services and funding streams must change to create new supports to fit the person.

- ***Provide support coordination through both independent agencies and agencies that provide other services.***

The support coordination system in Kentucky should be directed by the individual/family/circle of support, and flexible in meeting their needs. The system should consider all community resources when assisting the individual to secure services. Assistance should be culturally attentive and responsive, accessible to the individual/family/circle of support and have the appropriate technology to respond to the individual's needs. The number of persons to be served by a support coordinator will be based on individually determined levels of support needs.

Support coordination *provides an interface or connection between individuals and the system of publicly funded and other services and supports, and assures that these services meet reasonable standards of quality and lead to important outcomes for individuals.*

Principles of Self-Determination include:

1. ***Freedom*** *to choose a meaningful life in the community;*
2. ***Authority*** *over a targeted amount of dollars;*
3. ***Support*** *to organize resources in ways that are life enhancing and meaningful to the individual with a disability;*
4. ***Responsibility*** *for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities; and*
5. ***Confirmation*** *of the important leadership role that self advocates must play in a newly designed system of services and supports for the self- advocacy movement.*

♦ ***Implement self-directed funding such that individuals and families control the money available for their supports****.*

Self-directed funding holds the promise of providing only those services and supports that individuals want, need and by whom, rather than limiting them to the service constellations we now have.

♦ ***Hire support coordination staff who meet core competencies.***

Support coordination staff should have a bachelor's degree in human services, and pass criminal records checks. They should also demonstrate the following core competencies:

- Effective communication skills;
- Effective crisis intervention skills;
- Understanding of mental retardation and developmental disabilities;
- Effective conflict resolution skills;
- Good time management/organizational skills;
- Negotiation and budget development skills; and
- Knowledge about alternative funding methods.

♦ ***Develop a support coordination system which supports the principles of self-determination.***

The Support Coordination system in Kentucky should:

- Be individual/family directed;
- Be flexible in meeting the individual/family needs;
- Respond to all issues in a timely fashion as directed by the individual/family;

- Utilize the natural resources of the community;
- Be accessible to the individual/family;
- Be culturally attentive and responsive;
- Have appropriate technology to respond to the individual's/family's needs and requests;
- Produce accurate and timely reports; and
- Have a caseload system that is based on individually determined levels of support needs.

- ***Conduct further study to examine the advantages and disadvantages of independent support coordination.***

While several subcommittees discussed the merits of independent support coordination, consensus was not reached. Time limitations for the submission of this plan prevented additional research of the issue. Therefore, further research regarding support coordination will be conducted during the upcoming year. Particular focus will be upon the effectiveness of agencies and providers in disseminating information and education directed at empowering the individual/family/circle of support.

OUTCOME: AN ARRAY OF SERVICES AND SUPPORTS DESIGNED TO MEET THE UNIQUE NEEDS OF INDIVIDUALS WILL BE AVAILABLE IN LOCAL COMMUNITIES.

- ***Develop an alternative low cost waiver to serve individuals with less costly needs.***

"Only when individuals and families have control of both the services they receive and the funding to pay for those services will they have control of their lives."
Beverly Lynch,
Paducah.

♦ ***Develop a model of reimbursement that is person-centered and supports the infrastructure.***

Because funding drives policy it is important that reimbursement be reflective of the guiding principles of self-determination. The features of the reimbursement model should provide for:

- Fiscal responsibility and accountability;
- Efficiency;
- Flexible funding;
- Person-centered planning;
- Creating a safety net for individuals and for providers;
- Infrastructure support; and
- Provide incentives for further development.

Money *equals power, and therefore choice.*

♦ ***Assure that individuals and their families are fully informed about the options for services and supports that can be made available to them.***

The Olmstead Planning Committee is addressing the issue of informed choice, particularly as it relates to various living environments.

To assist them in their efforts to plan for individuals with mental retardation and other developmental disabilities, the Commission will send an official copy of the plan to the chairperson of the Olmstead Planning Committee.

PROMOTING QUALITY

*Individuals and families are **active, valued collaborators** in the development of policies, regulations, and practices to promote and ensure personal security.*

Agencies responsible for developing and implementing supports for persons with mental retardation and other developmental disabilities, whether at the state or local level, impact the daily lives and the future of the people, families and communities that depend on them. Their regulations and practices influence where the person lives, what they will do during their day and with whom the individual comes into contact in their social life. Quality is a concept which is difficult to define, but is obvious when it is exhibited. Regulations mandate minimal requirements with which providers must comply and their compliance is essential to assure the health and safety of the individual. However, in order to provide supports, which are considered of high quality, Kentucky will add an additional dimension of monitoring by including consumers, families and advocates in the monitoring process.

***Monitoring** should be based on each individual's circumstances and needs and be respectful of the individual's preferences.*

OUTCOME: THROUGH A COMPREHENSIVE MONITORING SYSTEM, WE WILL KNOW THAT INDIVIDUALS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES LIVE IN SETTINGS OF THEIR CHOICE, WHERE THEIR HEALTH AND SAFETY ARE ASSURED AND THEIR STRENGTHS AND DREAMS ARE SUPPORTED AND ENCOURAGED.

STRATEGIES:

- ***Develop and publish a monitoring report regarding service providers' compliance with regulations and quality of service delivery based upon the current monitoring activities conducted by state and local regulatory authorities.***

Several different regulatory authorities may monitor an agency. However, there is no current mechanism for sharing the information among the various agencies. Nor is there a mechanism for making this information about agency performance available to families or individuals when they are in the process of making decisions regarding their choice of service provider. The development of a standard, public document, which describes the overall performance of provider agencies, would give individuals and families the information needed when making important decisions about their future.

- ***Include family members, persons with mental retardation and other developmental disabilities and advocates in quality initiatives and monitoring activities at the state and local/regional levels.***

Although families are contacted regarding their satisfaction with services, there is no process for including families, advocates or individuals in quality assurance monitoring activities. At the state level, this strategy calls for the establishment of a central point of contact (consumer, parent, advocate, who has been trained and is paid) that is independent of service provision. This central point of contact would coordinate and report on the monitoring activities, as

"Quality of life issues are of major concern in Kentucky and in our nation. Kentucky is devoted to promoting activities and programs related to individuals with mental retardation and other developmental disabilities that will make improvements in everyday life experiences. Kentucky must continue to collaborate on basic needs for all Kentuckians with disabilities. This will require the commitment of more resources than ever before. I am determined to see this become a reality." Senator Tom Buford.

"They are often ***the best eyes and ears*** *that we have."* Margaret Pennington, in reference to families, consumers, and advocates. Lexington Herald-Leader, March 20, 2001.

***An improved quality of life** as defined by the individual is the central outcome that must be achieved.*

***A comprehensive and outcome-driven system** of services and supports provided to persons with developmental disabilities must be designed, coordinated, consistent and monitored to meet the self-determined needs of those persons as well as to protect their legal and human rights.* House Bill 144.

well as provide information through a publicized toll free number and web-site. An independent regional central point of contact, incorporating trained paid staff, should also be established to report on services and supports, participate in the Core Indicators Project, disseminate information, provide peer support, and assist in the development of peer groups.

- ***Expand the Core Indicators Project to incorporate a team process when conducting consumer satisfaction surveys.***

Kentucky is one of sixteen states participating in the Core Indicators Project, a nationally developed, consumer and family satisfaction survey with measures which are used to examine outcomes and the performance of service providers (the Department for Mental Health/Mental Retardation Services contracts with the Human Development Institute to administer this project). Currently a single interviewer conducts the individual satisfaction survey. The expansion of this project will incorporate a second team member who is either a consumer of mental retardation and other developmental disabilities services or a parent/guardian or family member of an individual with mental retardation and other developmental disabilities. The Human Development Institute should make every effort to focus on geographical, gender, racial, ethnic and age diversity in their hiring practices for all interviewers and include a family member or consumer in the recruitment and hiring process for interviewers. Training for interviewers should be expanded to include additional pertinent training.

OUTCOME: THE SERVICES AND SUPPORT NEEDS FOR PERSONS WITH DISABILITES WILL BE MET BY COMPETENT AND ADEQUATELY TRAINED STAFF.

STRATEGIES:

- ***Pass a legislative resolution for Licensing Boards to require specialized training regarding developmental disabilities.***

Licensing Boards require that professionals attain a particular number of continuing education units, in order to maintain their license. The addition of this specialized training could help professionals better understand people with developmental disabilities. This resulting awareness could also encourage more professionals to become providers of services for persons with mental retardation and other developmental disabilities.

- ***Support the development of a curriculum regarding developmental disabilities for awareness and skills training for undergraduates and para-professionals.***

This development could include a collaborative effort among the Department for Mental Health/Mental Retardation Services, other government entities, the Department of Education, and post secondary schools that are involved in training activities. This collaborative effort also should explore certification to assist in the development of a career ladder for direct care staff.

- ***Support the development of sensitivity training for transportation providers.***

Consumers have expressed the need for transportation providers to be more aware of their physical and mental needs and abilities. The Division of

***Direct care and professional employees** must have the skills necessary to meet the needs of the individuals and families they serve, and be responsive to their individual choices.*

Mental Retardation will collaborate with the Department of Transportation to develop a training curriculum to address this concern.

Most ***direct care*** *staff are women between the ages of 18 and 34 who make on the average of $7.50 per hour.* Hewitt & Larson, 1994.

- ***Develop incentives to encourage and increase the number of behavior support specialists in cooperation with institutions of higher education.***

People with mental retardation and other developmental disabilities at various times and phases in their lives may require specialty training or interventions to help them cope and be successful in their chosen activities. Behavior support specialists provide families and service providers expertise in evaluating environment, health and other factors that contribute to a person's success in community settings. Through their evaluation they can provide alternative approaches for communication or environmental changes and also help train staff or family members in these approaches.

Only eighteen percent (18%) of the direct care staff *remain with a single agency for more than 3 years.* Kevin Lightle, Doctoral Dissertation, 1992.

- ***Develop strategies to attract and retain skilled and committed direct care and professional employees.***

The starting salary for direct care staff in Kentucky's state facilities was increased from an average of $6.58 per hour to $8.54 per hour in 2000. Even with this substantial increase, the salaries are barely competitive with those in the fast food industry.

Attracting, retaining and recognizing qualified direct care staff is becoming a national crisis in the human service field. People who do choose direct service often do so because they find the work meaningful and rewarding. However, to receive better wages they are frequently forced to move out of direct services to administrative jobs that are sometimes less meaningful to them. This contributes to an annual direct support workforce turnover rate of fifty-seven percent (57%) to eighty percent (80%) in private community residential settings (Larson and Lakin, 1992).

- Provide adequate compensation.
- Implement effective, worker-centered orientation programs that help new employees in overcoming initial work-based learning and socialization difficulties.

- Provide new employees with mentors who are more “seasoned” co-workers.
- Provide workers who are in isolated locations with opportunities to network with co-workers.
- Ensure stability and effectiveness of supervisors.
- Create flexible benefit programs.
- Encourage commitment to organizational values and vision through participatory management practices (i.e., “team” decision-making).
- Assist employees in identifying relevant career paths within the agency and support these paths through competency-based training that leads to a valued credential, wage increments, and other forms of recognition.
- Link agency training with opportunities for higher education and career advancement.

Direct support professionals report that ***forty percent (40%) would most likely leave their employment*** *due to burnout, wages, or lack of support from management.* Kevin Lightle, Doctoral Dissertation, 1992.

PROMOTING ACCESS

1700 Kentucky citizens are on the waiting list *for services from the Supports for Community Living program. Many have been waiting over 10 years.*

"In a whole lot of these cases, the parents are too old to provide care anymore. It is a ***desperate situation****. We need to put up the money to solve it."* Representative Steve Nunn, Courier Journal, 1999.

Many Kentucky citizens with mental retardation and other developmental disabilities are waiting for assistance to participate fully in their local communities. Because of increased longevity and demographics, the numbers continue to grow. There are increasing numbers of elderly individuals with mental retardation and other developmental disabilities. People with mental retardation and other developmental disabilities who were born during the baby boom have elderly parents, and baby boomers have children who have developmental disabilities. These individuals are now leaving or getting ready to leave the school system. Demand for services is rising faster than the overall rate of population growth, and it is not expected to abate anytime soon.

All of us depend on family, friends, neighbors, and others to assist us in enjoying the benefits of a life in the community. However, circumstances develop in any family that require individuals and the local community to look beyond themselves for help. Then, help is sought from a wider support system in the community, including local and state government.

The issue of access to services and supports for people with developmental disabilities is critical, and the waiting list continues to grow. In order for individuals to have adequate access, it is crucial that there be additional funding for the Supports for Community Living (SCL) Medicaid waiver, as well as for state funded programs, that provide for a less comprehensive, and less costly, benefit. Unless these issues are addressed through careful planning, the waiting lists will continue to grow and people who desperately need supports and services will go unserved.

OUTCOME: PEOPLE WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES HAVE ACCESS TO SERVICES AND SUPPORTS THAT MEET THEIR NEEDS AND EXPECTATIONS.

STRATEGIES:

- ***Appropriate additional funding to serve individuals on the waiting list.***

At this time, an estimated 1700 people are waiting for services in the community from the Supports for Community Living Medicaid waiver program. There are also people with mental retardation and developmental disabilities who are not known to the public support system and who may need assistance. Research has indicated that in order to eliminate the waiting list, Kentucky needs to serve approximately 8,000 to 10,000 individuals. Even with the current funding, we will be serving fewer than 2000 people in the community. An additional 1000 people are being served in ICFs/MR.

- ***Establish collaborative linkages with other state Cabinets, programs and community associations to build their capacity for supporting citizens with mental retardation and other developmental disabilities.***

- ***Develop, increase and improve access to the following services and supports:***

Twenty-nine percent (29%) of primary caregivers *for people on the waiting list are 60 years old or older, and twenty-five percent (25%) are between the ages of 51-60 years old.*

"Every day *I wake up and I think about what would happen to Kevin if I weren't here."* Glenna Taylor, parent of an adult child with mental retardation or other developmental disability, Herald Leader, January 11, 2000.

Residential Supports *encompass a wide variety of living situations in the community, which range from living in your own home with periodic supports, to 24-hour care and supervision in a setting other than your own home.*

Eighty-six percent (86%) of individuals surveyed *on the SCL waiting list reported they did not have adequate transportation services.*

Transportation *should be timely, affordable, available, accessible, and be provided by individuals who have been sensitized about disability issues.*

Supported Community Residences

Individuals and their families currently have limited residential support options available, and those with aging parents and caregivers will need a place to live in the near future. Parents and caregivers should have the opportunity to see that their sons, daughters and loved ones receive services prior to their deaths.

Services and supports should be flexible and individualized in order for individuals with disabilities to have the same opportunity as other citizens to live in homes of their own, by themselves, with their family, or with caregivers of their choice.

- Develop residential supports that encompass a wide variety of living situations and that have long term flexibility to meet a person's changing needs across their life span.
- Develop an aggressive campaign with incentive packages to encourage existing providers to expand and attract new providers from across the country to provide support with an emphasis on residential services.

Accessible Transportation

Every Kentuckian should have the opportunity to participate fully in society and engage in productive work. Unfortunately, many Kentuckians with developmental disabilities are locked out of the workplace because they are denied the transportation necessary for access. Lack of adequate transportation remains a primary barrier to work and services for people with developmental disabilities.

- Establish pilot grants for several selected communities to develop a local consortium for the purpose of collaborating on the use of transportation dollars and resources within their community. Public and private partnerships should be explored. The Cabinet for Health Services should work with the Transportation Cabinet and other Cabinets to identify other funding sources for transportation needs.

- Develop a Good Samaritan Law related to the liability of transportation providers. This should allow for more varied transportation providers, such as non-profit organizations, churches, and schools to transport individuals with protection from adverse liability judgements.
- Review state policies to assure equity of transportation across county lines and to determine the feasibility of allowing providers of Medicaid transportation to transport individuals, who do not have access to Medicaid reimbursement, within the same vehicle.
- Support the development of a transportation system to serve individuals that is based on need, regardless of payor. Review all transportation systems that use public dollars and build a broader public transportation system.
- Address the recommendations concerning transportation from the Kentucky Developmental Disabilities Council contained in the report "Transportation Needs of Kentuckians with Disabilities."

Respite Services

Adequate and available respite services are needed to provide relief to families, reduce stress and to enhance the ability of families to support individuals with disabilities in their homes. Respite can often mean the difference in an individual being able to remain home with family, or needing a placement outside the home. Often, services and supports are not available until an individual or their family reaches a crisis. Respite services can enable families to stay together.

- Provide funds for respite services based on individual need that can be accessed without regard to funding source.
- Address the high turnover rate of respite providers. High turnover leads to frustration for individuals and families and instability of remaining staff.

Fifty-five percent (55%) of those surveyed on the waiting list indicated the need for ***respite services****.*

Respite *is a support that provides short-term relief to families and caregivers.*

A 27 year-old son*, who exhibits violent and self-abusive behaviors, is on the SCL waiting list, but is not considered to be in an emergency situation. His parents are unable to leave him alone even to run essential errands. Recently they have been able to access respite services once or twice a week which gives them relief from the constant care and supervision of their son for the first time in 27 years.*

Recreation

Recreational and leisure activities provide opportunities for self-expression. Currently, these activities are not readily available, individualized, age appropriate, easily accessible or integrated in the community. When there is a lack of leisure and recreational options, individuals have fewer opportunities to socialize, develop relationships and explore activities that interest them. The result is a less fulfilling life. In addition, individuals and families often do not feel comfortable or wanted in the community.

- Develop strategies to enable people with disabilities to experience all aspects of life in the community;
- Make available more consultants to educate families, individuals and providers on the variety of opportunities for recreation and leisure;
- Develop additional opportunities that provide a variety of options for self-expression; and
- Create a directory for recreation and leisure resources for individuals and families.

Behavior Supports

Behavior Support services are not available on a consistent basis, primarily due to the lack of an adequate number of qualified behavior support specialists. In addition, individuals with mental retardation and other developmental disabilities who also have mental health issues are often unsuccessful in obtaining needed services and supports from hospitals and other mental health providers. Consequently, individuals, families and providers lack the support they need to be successful. In some instances, the use of and reliance upon chemical restraints increase.

- Develop, in cooperation with institutions of higher education, incentives to encourage and increase the number of behavior support specialists.

Aging Out of Children's Services

A 22 year-old young man, with both mental retardation and mental health needs, "aged out" of Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. He was recently jailed and efforts to obtain a suitable program to assist him have been unsuccessful.

- Create a linkage with the planning efforts of the House Bill 843 Commission to address mental health issues for individuals with mental retardation and developmental disabilities in order to build the capacity to provide the comprehensive supports needed. These efforts should include training and awareness for mental health professionals, in both community and inpatient settings.

Employment/Volunteerism

Many supported employment providers are unable to accept new referrals and struggle to provide long-term support for those already being served due to insufficient funding. State dollars for long term employment support are extremely limited and access to supports through the Medicaid waiver is limited. Many rural areas of Kentucky have no employment options. Opportunities for additional supports during the day for individuals receiving supported employment services and working part time are often unavailable.

- Make employers aware of services and supports available to them if they hire individuals with mental retardation and other developmental disabilities.

- Partner with local community, civic, church, business and other groups to support volunteerism.

- Create a seamless system of long-term employment supports for people with mental retardation and other developmental disabilities. Support the Supported Employment Funding Initiative developed by the Cabinet for Workforce Development in cooperation with consumers, advocates, and service providers. This initiative will create a system of funding that will:

    - Direct new long-term support dollars to consumers of supported employment to ensure maximum choice and quality.

"At a time when the United States' unemployment rate is at an historic low and there is a crying need for workers, it is astounding to learn that the employment gap remains so wide. ***Over seventy-two percent (72%) of people with disabilities who are out of the workforce want to work and contribute to the economy****."* Alan A. Reich, President, National Organization on Disability.

More than ***2000 individuals*** *have been identified by the Department of Vocational Rehabilitation as needing and waiting for supported employment services.*

Eighty-three percent 83% *of those surveyed on the SCL waiting list report they* ***need a job or employment*** *of some sort*.

An individual residing in Logan County ***is unable to receive supported employment services*** *in his home county, as no supported employment services exist there*.

Thirty of the 120 Kentucky counties have one or more full time staff providing supported employment services.

  - Eliminate barriers based on disability type and/or where one lives.
  - Provide start-up funding to develop new service providers.
  - Increase the capacity for existing service providers to better serve customers.

- Explore the Ticket to Work (TTW) program. TTW is a voluntary program that will be phased in nationally over a three-year period beginning January 1, 2001, with the first tickets issued to certain states in early 2001. Recipients of Social Security and Supplemental Security Income (SSI) may elect to receive a ticket or voucher to obtain vocational rehabilitation and employment services from any participating public or private provider employment network.

- Implement the Medicaid State Buy-In program. This program expands states' options under Medicaid. This voluntary program became effective October 1, 2000. States must submit their plans to the Health Care Financing Administration (HCFA) for approval. States can cover working individuals with disabilities using income and resource limits set by the State. States can elect to allow individuals, who would otherwise be disqualified from coverage due to income limits, to pay a premium to obtain Medicaid coverage.

Transition through All Phases of Life

A lack of continuity of services and supports exists for children and their families as they transition through life. Choices are limited and many students graduate onto waiting lists for services. In order to facilitate a smooth transition from early intervention through school, the individual, family, family, advocates and the State Interagency Transition Council should collaborate to:

- Establish a designated point person for transition similar to a primary service coordinator with First Steps.
- Develop a shared funding source specifically for transitional services.
- Develop a system to collect data regarding transition age youth and their person-centered plan for post school outcomes.
- Include an individual or family member on the State Interagency Transition Council.

A 23 year-old woman who received ***transition planning*** *and graduated from high school is unable to obtain long term supported employment services. State general funds are unavailable and access to the SCL Medicaid waiver program is limited. She is on the SCL waiting list.*

Assistive Technology

Assistive technology is equipment, materials or other devices that persons with mental retardation and other developmental disabilities can use to assist them in learning to make their environment more accessible, compete in the work environment, enhance their independence or otherwise improve their quality of life.

Assistive and universally designed technologies can be powerful tools for Kentuckians with mental retardation and other developmental disabilities. Assistive technology devices and services can range from the simple (ramps, manual wheelchairs, large button phones, bathroom grab bars and remote control for lights and heating) to the complex (augmentative communication devices and computer access systems).

"For Americans without disabilities, ***technology*** *makes things easier. For Americans with disabilities, technology makes things possible."*
National Council
on Disability.

The major impact that an assistive technology device can have on an individual can be life-changing through increasing social inclusion, independence and productivity. Currently, limited funds are available to support the purchase of assistive technology devices. Additional funding needs to be made available for access to this support through:

- Exploring federal grant options;
- Supporting the Kentucky Assistive Technology Service Network;
- Partnering with volunteer organizations to help support individuals in their local community; and
- Promoting employer awareness of the Americans with Disabilities Act requirements.

The Kentucky Assistive Technology Service *(KATS) Network was designed to make assistive technology and related services more easily accessible to all Kentuckians with disabilities.*

Other Support Services

Other support services are needed to enable individuals and families to meet their specific needs, maximize individual growth, attain optimum health and empower them to live a meaningful life. These services are not easily categorized.

- Flexible funding is needed to enable individuals to choose the activities that would make up a meaningful day to that person and to support families that have a member with mental retardation and other developmental disabilities.

OUTCOME: ACCESS TO SERVICES AND SUPPORTS WILL BE EQUITABLE, AND WILL BE BASED ON CRITERIA THAT TAKE INTO CONSIDERATION BOTH TIMELINESS AND SERVICE NEEDS.

STRATEGIES:

- ***Promote regional access and input into the waiting list.***

For necessary planning to take place with individuals and their families, and to assure that no one slips through the cracks in the system, it is recommended that there be regional access to the needs of individuals who are waiting for services in that region. It has been suggested that a committee or council for each region be established that would be stewards of the waiting list for each region and coordinate access to appropriate services from any funding source.

- ***Develop a structured, weighted system to establish an individual's priority placement on the registry (waiting list) for services.***

The term “registry” should replace the term "waiting list" and is defined as a list that establishes order as well as identifies the need for services. There should be a transparent mechanism to match funding and access with individual need.

The weighted system should be based on verifiable risk criteria including age, time on the waiting list, and living situation.

OUTCOME: INFORMATION IS AVAILABLE AND EASILY ACCESSED.

Many Kentuckians do not know where to seek services and are constantly being shuffled from one agency to another for assistance.

***“We're tired of waiting**,” said Earl Campbell, 73, of Richmond, who said he had been waiting 8 years for funding for a community home for his daughter, Carolyn, 32, who has mental retardation. “My wife and I are getting too old to care for her. We need help.”* From the Courier Journal.

*A **weighted system** is one in which each of the verifiable risk criterion is assigned a numerical value, the sum of which determines an individual’s priority placement on a registry for services. This concept allows services and supports to be provided in a fair and equitable manner.*

Verifiable Risk Factors are:

1. *Age 20.5 and committed to the Department for Community Based Services;*
2. *Chronological (length of time on waiting list); and*
3. *Environment (living situation);*
    - *Substantiated abuse or neglect;*
    - *Homeless;*
    - *Loss of historic, primary caregiver;*
    - *Capacity of caregiver;*
    - *Personal safety; and*
    - *Availability of appropriate alternatives.*

Individuals and families should have ***timely and reliable access to information*** *about services and supports.*

STRATEGIES:

♦ ***Develop and implement a central point of contact, both statewide and regional, to be a source of information and referral.***

This would require a highly skilled team of cross-trained staff who would connect individuals with the appropriate information and services. Examples of activities of a central point of contact are:

- Provide information and referral;
- Provide training and education to consumers and families about accessing and directing supports and services;
- Conduct public awareness activities to connect individuals and families to needed services and supports;
- Screen to determine eligibility for support coordination;
- Help families choose support coordination and change support coordinators;
- Address complaints about all service providers by sending those complaints to the appropriate monitoring entity; and
- Support networking among families/individuals.

♦ ***Establish an accessible, toll-free telephone number statewide that would direct those seeking services to the central point of contact in their local region, for all individual/family services for individuals with mental retardation and other developmental disabilities available in their region.***

- ***Expand existing educational programs in the community such as County Extension, Vocational Rehabilitation and Adult Education to include information on mental retardation and other developmental disabilities and the services and supports available.***

People should have reliable and timely access to ***competent community health care****.*

OUTCOME: HEALTH CARE IS AVAILABLE, ACCESSIBLE, AND DELIVERED BY QUALITY PERSONNEL.

Some individuals with mental retardation or other developmental disabilities who also have intensive medical support needs have difficulty accessing these services in the community. Based on personal experiences expressed by consumers and parents there is a high level of need for medical expertise. People have reported the lack of sensitivity to people with mental retardation and other developmental disabilities and the need for structural modifications to assure accessibility.

Anecdotal stories indicate the ***lack of qualified or experienced medical, dental and therapeutic professionals*** *to serve individuals with mental retardation and other developmental disabilities.*

STRATEGIES:

- ***Fund a specialized outpatient clinic using existing facilities or organizations. The clinic would:***
    - Serve as a center of excellence for patients seeking medical care;
    - Serve as a pilot and prototype for developing services statewide;
    - Create a learning environment for allied health professionals, via affiliation for rotations with medical schools, nursing schools, etc.;

    - Provide training resources to regions with current providers; and
    - Establish a specific standard of patient care which all providers shall strive to provide.

- **Work with the Commission on Special Health Care Needs to explore the expansion of services to persons over age twenty-one (21).**
- **Support the concepts of a specialized clinic in other environments.**
- **Build on existing avenues of communications, such as the KyCARES Network, in order to educate the public on how to access qualified medical providers.**
- **Use current surveys and technology to gauge and report health care need.**
- **Identify and develop a single point of data collection and reporting for clinic data, which is provided to the central point of contact for information and referral.**

OUTCOME: CONTINUED SERVICES AND SUPPORTS ARE AVAILABLE TO INDIVIDUALS WHEN AGENCIES CHOOSE TO INVOLUNTARILY TERMINATE SERVICES AND SUPPORTS TO THEM.

KyCARES is an online service information directory and guide for federal, state, and community providers. This can help individuals connect with providers which offer basic services like housing, food, childcare, transportation, benefits information and much more. The address is http://www.kycares.org

STRATEGIES:

- ***Require the provider of services, prior to initiating transfer and discharge procedures, to demonstrate that a variety of interventions and efforts have been made to modify programs in order to meet the needs of the individual.***

- ***The Department for Mental Health and Mental Retardation Services, in coordination with people with mental retardation and other developmental disabilities, families and providers, will develop strategies and technical assistance to assist providers to support people who are at risk of losing their provider.***

- ***Develop regulations to specify the entity responsible for the individual after termination and to assure that continued services and supports are available for the individual after termination.***

FINANCING THE SYSTEM

Representative Jimmie Lee never missed a chance to remind legislators that they were ***"just providing a foundation"*** *and that it would take ten years to fully address the problem.* From "United We Stand," a publication of the Council for Retarded Citizens of Jefferson County, Kentucky, 1998-2000.

Kentucky's fiscal effort is approximately half that of the national average. Research has indicated that in order to eliminate the waiting list, Kentucky needs to plan to serve approximately 200-250 people per 100,000 population (approximately 8,000 to 10,000 people). In order to build an infrastructure for supporting individuals with mental retardation and other developmental disabilities, expansion funding should be appropriated during each of the next five biennia (ten years) to serve these individuals. As system capacity grows, the number of individuals to be served each year should be increased, along with the funds required.

The demand for supports during the 1990s has been increasing at a pace substantially greater than population growth alone would predict.

OUTCOME: THE WAITING PERIOD FOR SERVICES AND SUPPORTS WILL BE REDUCED AND ULTIMATELY ELIMINATED. PAID SUPPORTS WILL BE SEAMLESS, INTEGRATED, AND DRIVEN BY THE INDIVIDUAL.

STRATEGIES:

- ***Pursue an appropriation of funds to serve additional individuals.***

Growth in the number of individuals receiving services is the most critical and pressing need in this plan. Additional funding is necessary each year for this to occur. As discussed in the Promoting Access section of this plan, research has indicated that in order to eliminate the waiting list, Kentucky needs to serve approximately 8,000 to 10,000 individuals.

- ***Develop a model of reimbursement that is person-centered, and that also supports the infrastructure.***

In funding services we wrestle with two major issues. One has to do with the existence of an infrastructure. This requires startup and maintenance funding. The other has to do with person centered planning and the development of individualized services based upon the outcomes of the planning process. Our financing strategy needs to recognize both concerns.

To accomplish this, the reimbursement model should be developed based upon three (3) factors:

1. Adequate reimbursement for the provider's fixed costs (i.e., administrative salaries, depreciation, loan costs) which should be based on the number of individuals served by the provider;
2. Services the individual chooses during the development of his/her person-centered plan; and
3. Additional funds based on the care needs of the individual (i.e., intensity factor).

Additionally, grants should be available to new providers to cover initial startup costs.

Ultimately, the individualized service component of this model could evolve into a voucher system, in that an individual would be given an amount based on the services he desires that address his individual needs. He would then be able to negotiate with providers to get the most services for the funds available.

"I am not going to fund one new project or building *of any other entity until we take care of people who have waited for decades to get help from their state government."* Representative Bob Heleringer.

"If these services had been around a long time ago, ***I might have been able to keep her at home*** *a little longer."* Lina Byrd, speaking of her daughter who is 32 and lives at Oakwood ICF/MR.

The reimbursement system must be adequate *to support the existing infrastructure, while providing incentives for further development of both existing and new providers.*

The flexibility of the Supported Living program should be used as a model for flexible and individualized services. (The Supported Living program, unlike the Supports for Community Living (SCL) program, is funded with one hundred percent (100%) state general funds and is not restricted by federal rules.) Additional funding should be sought for the Supported Living program, to serve people who are not eligible for the SCL program or who are still waiting.

- ***Unexpended Supports for Community Living (SCL) waiver funds should remain in the system.***

Given the complexity of the needs of many of the individuals on the SCL waiting list and the time intensive nature of the individualized planning process, it often takes six months between the time an individual receives notice that they are eligible to receive services under the SCL program and the time that services actually begin. While individuals who were allocated the 250 slots during FY 01 have been working with their chosen provider to begin services, some have not yet fully accessed these services on a regular basis.

*"**It's been 10 years of waiting** and now some of them won't have to wait a day longer."* Louise Underwood, family member of an individual with mental retardation and other developmental disabilities.

Realizing the time and effort required in developing supports, Governor Patton announced on April 10, 2001, that funds would be made available immediately to serve another two hundred (200) people on the waiting list.

*Public dollars should be used to **give people the supports they need**—no more, no less.*

- ***Continue collaborative involvement of the Commission, the Department of Medicaid Services, and the Department for Mental Health and Mental Retardation Services, provider networks, and consumers in the process of awarding and contracting any studies regarding fees/reimbursement systems, and the development of alternative reimbursement methodologies.***

Priorities should involve examining current funding streams to revise them for efficiency, and then developing new waiver programs with additional or redirected funds. These activities would support a responsible level of funding and encourage providers to stay in the system and provide quality supports.

Reimbursement system modifications should be carefully examined to avoid jeopardizing the existing service delivery structure. Changes should "do no harm" to individuals currently receiving services or to providers.

- ***Build a rate/funding system to support and attract health care providers such as physicians and dentists. The current reimbursement system does not allow for the additional time associated with examination, communication, and treatment that may be necessary for a person with mental retardation or other developmental disabilities. This is a significant barrier to receiving quality, accessible health care services.***

- ***Support the Department of Vocational Rehabilitation's request for funding in the Supported Employment Funding Initiative.***

Dollars will be used on an on-going basis to support individuals in maintaining employment, and to serve additional consumers. Kentucky would be able to serve new, supported employment candidates as they transition from school-provided services to community-provided services. Waiting lists would be avoided, and consumers placed in previous years would continue to receive the support services needed to maintain employment.

*"**New technology** has provided multiple employment opportunities for those with developmental disabilities or mental retardation, thereby enhancing their self-esteem and independence, improving their own quality of life as well as that of their family. Employers are better able to access a quality workforce."*
George Warren,
President,
Henderson
Chamber of
Commerce.

NEXT STEPS

"I have learned that, in order to bring about change, ***one must take the first step,*** *or else it will not be done."* Rosa Parks.

"We're going to do this because it's the right thing to do," *Governor Patton said to cheers and applause from the group of legislators and mental health advocates gathered in the Capitol Rotunda.* November 17, 1999 in reference to the funding in HB 144.

During the upcoming months, immediate steps will be taken in order to move forward on this plan. In alignment with the Governor's strategic planning process action will be taken to confirm objectives or strategies.

To that end, the Commission will conduct statewide focus groups to gather consumer, providers, and parental input. They will validate its concepts and gain additional public comments for plan refinement and consideration in future Commission discussions.

Based on the plan's recommendations and comments from the public, new workgroups may need to be formulated. The Finance Subcommittee will continue to function and representatives of that Subcommittee will continue their efforts to refine the estimated costs. These projected costs will be available, along with the plan to the General Assembly and Governor. Additionally, the Finance Subcommittee will provide input to the Cabinet for Health Services on reimbursement strategies associated with the various funding sources for mental retardation services.

The Commission is dedicated to seeing this plan to fruition. With the help of the Governor, legislators, advocates, providers, state agencies and the individuals affected by the plan, the dream will become a reality.

This commitment will require a great deal of work and collaboration on everyone's part, but most of all, it will require that we be committed to "doing the right thing."

The effort must be equal to that which was demonstrated during the 2000 Legislative Session that resulted in the passage of House Bill 144. During this time of expected revenue shortfalls, the challenge will be even more difficult. Thankfully, the dedication of those who have participated in this process is as extraordinary as the challenge and the 'yet to be met" need.

This dream will become a reality only when we continue what we have begun and support people with mental retardation and other developmental disabilities, one person at a time.

"For the first time, Kentucky is going to be providing choice and treatment with ***dignity for all*** *who need help."* Representative Steve Nunn.

"This has been a hard-working Commission that has tried to really improve our system of services. Adequate funding to meet the needs of these individuals remains a concern." Senator Marshall Long.

Throughout history people with physical and mental disabilities have been abandoned at birth, banished from society, used as court jesters, drowned and burned during the Inquisition, gassed in Nazi Germany; and still, continue to be segregated, institutionalized, tortured, in the name of Behaviour management. abused, raped, euthanized, and murdered. Now, for the first time, people with disabilities are taking their rightful place as fully contributing citizens. The danger is that we will respond with remediation and benevolence rather than equity and respect. And so, we offer you

A Credo for Support

Do Not see my disability as the problem.
Recognize that my disability is an attribute.

Do Not see my disability as a deficit.
It is you who see me as deviant and helpless.

Do Not try to fix me because I am not broken.
Support me. I can make my contribution to the community in my way.

Do Not see me as your client. I am your fellow citizen.
See me as your neighbour. Remember, none of us can be self-sufficient.

Do Not try to modify my behaviour.
Be still & listen. What you define as inappropriate
may be my attempt to communicate with you in the only way I can.

Do Not try to change me, you have no right.
Help me learn what I want to know.

Do Not hide your uncertainty behind "professional" distance.
Be a person who listens, and does not take my
struggle away from me by trying to make it all better.

Do Not use theories and strategies on me.
Be with me. And when we struggle
with each other, let that give rise to self-reflection.

Do Not try to control me. I have a right to my power as a person.
What you call non-compliance or manipulation may
actually be the only way I can exert some control over my life.

Do Not teach me to be obedient, submissive, and polite.
I need to feel entitled to say No if I am to protect myself.

Do Not be charitable towards me.
The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me for their own gratification.

Do Not try to be my friend. I deserve more than that.
Get to know me. We may become friends.

Do Not help me, even if it does make you feel good.
Ask me if I need your help. Let me show you how you can best assist me.

Do Not admire me. A desire to live a full life does not warrant adoration.
Respect me, for respect presumes equity.

Do Not tell, correct, and lead.
Listen, Support, and Follow.

Do Not work on me.
Work with me.

Dedicated to the memory of Tracy Latimer

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ACKNOWLEDGEMENTS

The Commission acknowledges, with appreciation, the extraordinary efforts of Dr. Kevin Lightle and the staff of the Division of Mental Retardation. They coordinated the work of the Commission and its seven workgroups. They took minutes, responded to innumerable requests from Commission members and other stakeholders, put our ideas into the logic models, and drafted the language for this plan. They fed us, scheduled meeting rooms for us, found chairs for our friends, and made copies, and copies, and more copies of our meeting materials.

KENTUCKY'S PLAN

FROM DREAMS TO REALITIES FOR QUALITY AND CHOICE FOR ALL INDIVIDUALS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES

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