

A watercolor illustration of a neighborhood. In the foreground, there is a white picket fence. Behind it, several houses with different colored roofs (red, blue, brown) and gables are visible. The style is soft and artistic, with visible brushstrokes and a slightly blurred background.

# Everyday Lives

*Making It Happen*

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Pennsylvania Department of Public Welfare  
Office of Mental Retardation

# Message

We are pleased to present *Everyday Lives: Making It Happen*. This is an updated version of the original *Everyday Lives* booklet that was an expression of the concept of people having a life like other people in the community. Since the concept has been the framework for the system for ten years, The Planning Advisory Committee to the Office of Mental Retardation believed this to be an appropriate time to evaluate whether people's lives have changed. The Planning Advisory Committee is pleased to report that progress has been made, and we support this updated vision statement.

At our request, the Self-Determination Consumer and Family Group agreed to take on this project that included evaluating what has changed since ten years ago, what challenges remain, and how do we make the vision of an Everyday Life for everyone, a reality. Thank you for a job well done. We would also like to thank Evelyn Wermuth for providing guidance with the project and writing this booklet.

*Sheila Stasko and Nathaniel J. Williams,*  
Co-Chairpersons  
*Planning Advisory Committee*

## *Pennsylvania Self-Determination Consumer and Family Group Members*

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<b>Donald Angermier</b> , Blair County	<b>Susan Fay McCloskey</b> , Mercer County
<b>Rosemarie Appel</b> , Westmoreland County	<b>Kim McMillian</b> , Warren County
<b>Mooneen P. Bielecki</b> , Luzerne County	<b>Suzanne Miller</b> , Cambria County
<b>Kathy Brill</b> , Dauphin County	<b>Bonnie Miller</b> , Franklin County
<b>Janet A. Brouse</b> , Schuylkill County	<b>Melissa A. Morgan</b> , Butler County
<b>Peter Buhr</b> , Lancaster County	<b>Carolyn Morgan</b> , Philadelphia County
<b>Sherry Byrne</b> , Cumberland County	<b>Jack Morrone</b> , Lehigh County
<b>Dee Coccia</b> , Philadelphia County	<b>Nancy Murray</b> , Allegheny County
<b>Wanda Davis</b> , Blair County	<b>Toni E. Newcomer</b> , Westmoreland County
<b>Maureen A. Devaney</b> , Philadelphia County	<b>Nancy Norwood</b> , Franklin County
<b>Oscar Drummond</b> , Philadelphia County	<b>Mary Ohl</b> , Pike County
<b>Marielynn Fairman</b> , Jefferson County	<b>Kim T. Rhodes</b> , Clarion County
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<b>Kim Garretson</b> , Somerset County	<b>Kathy L. Smith</b> , Erie County
<b>Pedro Geraldino</b> , Montgomery County	<b>Julie Ann Smyser</b> , Cumberland County
<b>Dana Hughes</b> , Fayette County	<b>Sheila Stasko</b> , Lehigh County
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<b>Teddi W. Leiden</b> , Blair County	<b>Marybeth Zahorchak</b> , Butler County
<b>Leah C. Leiden</b> , Blair County	

# Introduction

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Ten years ago the concept of having an “everyday life” was explored and expressed in the first Everyday Lives booklet. Since then, Everyday Lives concepts have provided the framework for the Multi-Year Plan, the Plan to Address Pennsylvania’s Waiting List and system changes to support self-determination.

The Pennsylvania Self-Determination Consumer and Family Group was asked, by the Planning Advisory Committee to the Office of Mental Retardation, to review how lives have changed from ten years ago and create an updated booklet called *Everyday Lives: Making It Happen*. The Group is comprised of self-advocates and families from across the state. The following questions have guided the task:

- Have we made progress towards people having Everyday Lives?
- What is life like now for people with mental retardation and their families?
- What still needs to be done?
- How do we move forward?

The concept of Self-Determination has spread throughout the nation in recent years and it is the basis for people having everyday lives. An everyday life is having a life that is typical of the general population. Self-Determination is not just for a limited group of people. It is for *everyone* including children, young adults and older adults whether they need a lot of support or they can live on their own. It means having friends to play with as children, having jobs and serving in their churches as adults, and choosing how to spend their time in retirement. Individuals and their families want to have everyday lives. Parents, who are providing care for their sons or daughters with disabilities, often do not have the opportunity to do ordinary things that other people in society take for granted such as going to the movies or out for dinner together and attending community or school meetings. As the person with a disability grows older, his or her life and consequently the life of the family do not follow the typical path. In our society, children typically grow up to become independent and then move out of their family’s home. But as many individuals with mental retardation age, they continue to live in their family’s home relying on their aging parents and siblings for support.

# History

## **1940's**

Families across the Commonwealth formalized their support and advocacy network with the incorporation of the Pennsylvania Association for Retarded and Handicapped Children, 1949

## **1960's**

The Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L.88-164) provided money to build community facilities, 1963

Social Security Act Amendments (P.L. 88-97) established Medicare and Medicaid, 1965

The Pennsylvania MH/MR Act established a system of community services, 1966

## **1970's**

Right to education with right of due process was established in PA as result of PARC vs. Commonwealth of Pennsylvania, 1971

Family Support Services (FSS) funded for the first time, 1971

Community Living Arrangements (CLA) funded for the first time in Pennsylvania, 1971

The Federal Education for All Handicapped Children Act (94-142) mandated free, appropriate and individualized education for all children in the least restrictive environment, 1975

Protection and Advocacy system mandated (P.L. 94-103), 1975

Federal Court rules that institutionalization is a violation of constitutional rights to equal protection in the case of PARC vs. The Pennhurst State School and Hospital, 1977

## **1980's**

Self Advocates in Pennsylvania formalize their peer support group and incorporate as Speaking for Ourselves, 1982

Fair Housing Act, 1988

Family Driven Support Services (FDSS) begin

Office of Mental Retardation, Planning Advisory Committee originated, 1988

## **1990**

Americans with Disabilities Act (ADA)

Early Intervention Services System Act, Governor Robert P. Casey

## **1991**

*Everyday Lives*, Governor Robert P. Casey

## **1992**

The Arc-Pennsylvania became new name for the Association for Retarded Citizens, in response to self advocates' criticism of the use of the word retarded

## **1997**

*A Multi-year Plan for Pennsylvania's Mental Retardation Service System*, The Planning Advisory Committee to the Office of Mental Retardation

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**1998**

Waiting List Campaign: Individuals and families advocate for services for people and families who have been waiting for a long time

Governor Thomas J. Ridge Five Year Plan to Address the Waiting List, 1998; commits \$850M to expand services for those waiting

**1999**

Pennsylvania Self-Determination Steering Committee as subgroup of the Planning Advisory Committee begins

*A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania,* Planning Advisory Committee to the Office of Mental Retardation

Self-Determination in services made possible through a grant from the Robert Wood Johnson Foundation and implementation of the Person/Family Directed Support Waiver

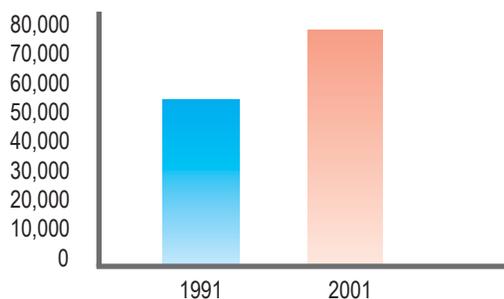
**2001**

Governor Thomas J. Ridge Direct Service Professionals Initiative; allocation of about \$22M to help providers recruit and retain the workforce needed to assure quality services

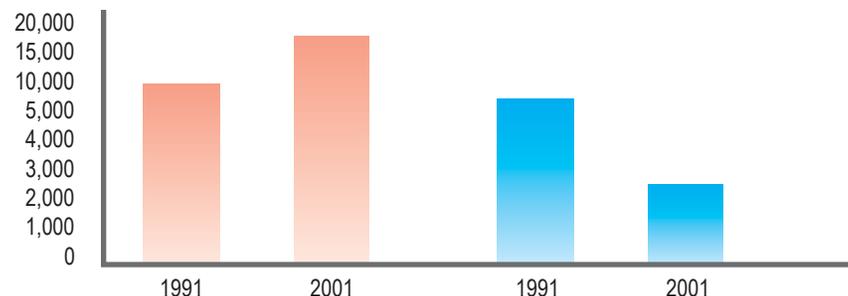


# Life at This Time

There are many things in the mental retardation system that have changed over the past ten years. Following are some graphs to show the changes:

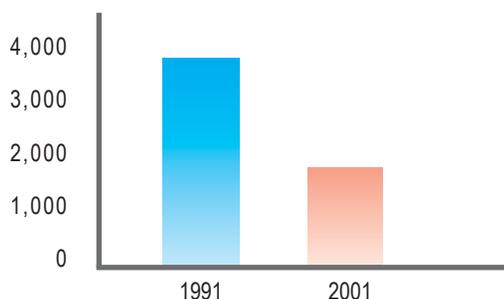


**People Receiving Supports and Services**  
55,300 (1991) – 77,616 (2001)

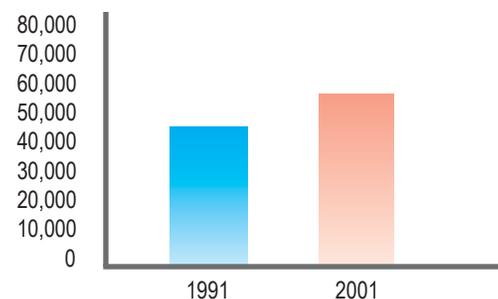


**People Living in Community Settings**

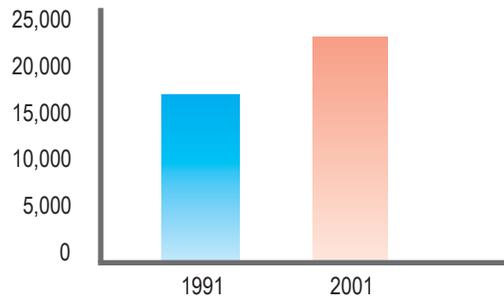
**Small Settings** 8,776 (1991) Includes ICF's/MR – 16,022 (2001)  
**Large Settings** 5,479 (1991) Includes private ICF's/MR – 2,146 (2001)



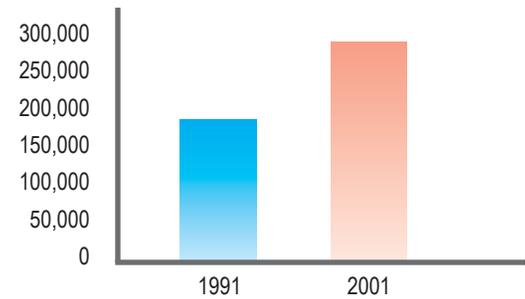
**People in Public Institutions**  
3,900 (1991) – 1,700 (2001)



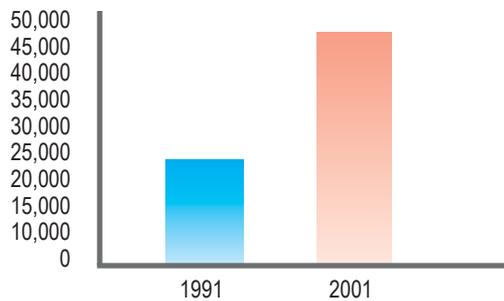
**People Living at Home Receiving Services**  
43,000 (1991) Includes employment and day services – 57,730 (2001)



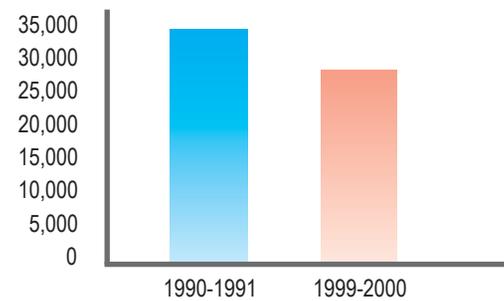
*Families Receiving Family Support Services/In-home Waiver Services*  
15,800 (1991) – 23,261(2001)



*Children Age 6-21 in Special Education Classes*  
193,000 (1991) – 298,524 (2001)

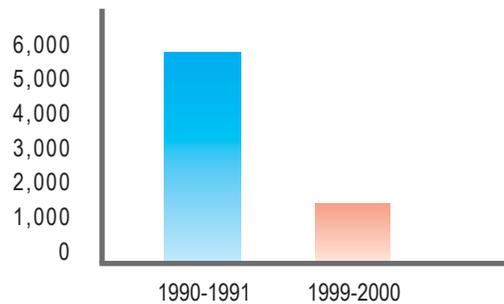


*Children Birth to School Age Receiving Early Intervention Services*  
24,000 (1991) –  
47,000 [18,000 birth to 3; 29,000 age 3 to school age] (2001)

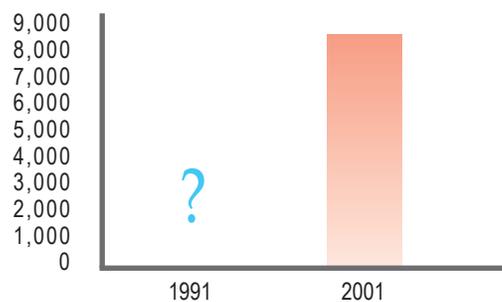


*Children Age 6-21 in Special Education Classes With Mental Retardation*  
34,380 (1990-1991) – 27,547 (1999-2000)

# Life at This Time, continued



**Children Age 6-21 in Special Education Classes In Segregated Placements**  
5,801(1990-1991) – 1,391 (1999-2000)



## People Waiting for Services

The number was not known in 1991.

An estimated equal number of people emerge every year; this is sometimes called the "Shadow List." – 8,320 (2001)

## Where People Live

- More people are living in the community now rather than in institutions.
- Most people live with their families. Many are living with their aging parents. Some live with siblings or other relatives.
- Some people live in a family living situation in which an individual is matched with a family so they can share their lives.
- Some people rent their own apartments or own their homes.
- Some people live in houses or apartments operated by an agency in the community.
- Some people live alone and some people share their home with other people.
- Some people choose where they live and the people who share their home.
- Some people live in private schools and institutions, nursing homes and personal care boarding homes; others are in hospitals and jails.

*And 1,700 still live in state funded institutions and approximately 1,760 live in large private institutions.*

## Education

- Nearly 96% of children eligible for early intervention services birth to age 3 receive early intervention services at home or in the community.
- Other young children are in Head Start, day care, community or segregated pre-school programs.
- Over 27,000 school-aged children with mental retardation are enrolled in special education classes, many in segregated environments.
- Some children are in regular classes in their neighborhood public school and have opportunities to interact with their peers.
- Some children are attending private schools.
- Children have several transitions in their lives. At age 3, they leave the Public Welfare early intervention system and transition to pre-school early intervention. At age 5 or 6, they enter the public school system. Some children choose to stay in school until age 21 and others leave school at age eighteen. Some schools have individualized work experience programs to prepare students for life after graduation.
- Some people go to technical schools after leaving high school.
- A few adults audit courses at community colleges.
- Some adults graduate from a community college with an Associate Degree.

*Most young adults do not have the opportunity to continue their education after they leave high school.*



# Life at This Time, continued

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## **Paid Employment and Daily Activities**

- Some people get jobs on their own or through county programs. They work at different kinds of jobs. Some people work outdoors, others work in offices or stores.
- 9,570 people have obtained jobs through supported employment programs.
- 16,442 people attend day care centers or work activity centers.
- Some people are contributing to their communities through volunteering.
- Some older adults have individualized retirement supports.
- Some older adults choose to participate in generic community senior services.
- Many people are struggling to find things, that are important to them, to do every day.

*Many people have nothing to do during the day.*

## **Recreation and Leisure Activities**

- More people are participating in community recreation. Children are involved with religious youth groups, Little League, play-ground activities, Scouting programs, 4-H, dancing and after school activities. Adults go mall walking, join baseball teams, bowl in community leagues, go horseback riding, shop, go dancing, go out with friends to local restaurants and bars, visit friends, are members of religious/spiritual groups, participate in community senior activities and work on crafts and hobbies.
- Some recreation is individualized with individuals choosing to attend an exercise class or use a community swimming pool or fitness club.
- Some people have memberships in the public library, local service clubs, and senior groups including travel groups.
- Some people have subscriptions to magazines related to their interests.
- Some people have driver's licenses.
- Some people plan for and take vacations.
- Dating is difficult and sometimes discouraged; however, some people do date, get married and have children of their own.

*Most recreation opportunities are still segregated and group structured rather than individualized.*

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## Transportation

- Transportation remains a big challenge for people. Public transportation is not available in rural areas. Where available, accessible transportation may not operate when individuals need to go to work, to medical appointments or to recreational events.
- Often adequate and affordable transportation is not available or is not accessible.
- Agency provided transportation is generally tied to segregated programs.
- Some counties provide paratransit services.
- When transportation is available, sometimes the cost is prohibitive.
- Some transportation services are starting to become available through the mental retardation system and other service systems such as aging.

*Parents and family members still provide most of the transportation for people, regardless of their age.*



# Real Lives

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People are beginning to have lives that are similar to that of other people who do not have disabilities. They have more control over their lives and have the opportunity to make choices in their lives. This is happening even for people who at one time had no way to express their wishes.

- Some people know how much money is spent on the supports and services they need.
- Some people have control over how the money in their budget is spent.
- Some people have individual plans, created with help from people they choose, that include what they need in order to have the kind of life they want.

## Lynda Jane: Self-Determination

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Lynda Jane is 35 years old. She lived at home with her family until she was 18 when she moved to a community home in Lancaster, Pennsylvania. Lynda Jane needs assistance with everyday activities; she does not speak and she has an uncontrollable seizure disorder.

Lynda Jane attended a facility based day training program for many years after she finished school at age 21. She wasn't interested in some of the activities and the ones she enjoyed at first (assembling things) she eventually became bored with and would take apart what she had assembled. Lynda Jane then was given the opportunity to do volunteer work in the community, with staff assistance, for two days a week. This later was expanded to five days a week. One job is folding towels and wash cloths at a nursing home. One of the residents has become Lynda Jane's friend and comes to see Lynda Jane each week when she is

there. By volunteering at different places during the week, Lynda Jane gets to be with many more people in the community and she is much happier now.

Throughout her life various kinds of communication aids had been tried with no success. The people working with Lynda Jane pay attention to her body language and have developed good relationships with her. About a year ago her supervisor got a programmable communication pod (device) to try with Lynda Jane. It has a bright top that you press to activate it. Lynda Jane loves the ceiling fan in her living room and would look at it when she wanted someone to turn it on. The device was programmed to say, "Please turn on the fan." It didn't take Lynda Jane very long to learn that if she would press the pod, then the fan would be turned on. A second pod with a different colored top was added a while later. This one is used in the van

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she rides on the way to her volunteer activities. Lynda Jane loves brochures and knew they were kept in the glove compartment for her. This new pod says, "Please give me my brochures." Recently a third pod has been added that says, "Please come and talk with me." People who support Lynda Jane always respond promptly when Lynda Jane presses a pod. For the first time in her life, Lynda Jane has a voice.

Lynda Jane in recent years has also been given the opportunity to make choices in her life. Lynda Jane has long pretty hair and often wears part of it in a ponytail. She goes shopping with people who support her to pick out hair accessories and chooses the one she wants for the day by picking it up. Next they worked on Lynda Jane choosing blouses. They put several on her bed and she looks at the one she wants to wear and ignores the ones she doesn't want. After a while, they

added slacks that she chooses the same way. Recently the supervisor has begun to ask the three ladies in the house if they want to hire people who are interviewed to work there. After a person who was interviewed leaves the house, the supervisor asks Lynda Jane, "Do you want to give (person's name) a chance?" If Lynda Jane looks directly at the supervisor, the answer is yes. If she looks away, the answer is no. Just to be sure, the supervisor goes through the same procedure about five minutes later. Lynda Jane now has a voice and is able to make choices in her life including the people who work with her. Lynda Jane has an individual plan and the people who are paid to support Lynda Jane work together with her parents as a team. The team discusses ways to expand Lynda Jane's opportunities for choice and ways to expand her communication when they meet.



# Real Lives, continued

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## MichaelAnn . . . Communicating in Her Own Way

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MichaelAnn is four years old and lives at home with her mom, dad, and their dog, Webster. Her dad says, "She has a smile that melts away a tough day at work, and a determination that inspires you." MichaelAnn cannot talk and needs almost total assistance with her daily living activities.

MichaelAnn loves telling people around her what she wants and sometimes can be very demanding if she wants something right now. She does not speak and has her own unique way of communicating. She communicates through her body language, sounds and eye gaze. People need to spend some time with her before they can understand what she is saying.

MichaelAnn's parents have seen improvements since she has been attending pre-school and they feel the teachers and therapists are doing a wonderful job. One of the tools to help teachers, aides, and others who work with MichaelAnn is her individual plan. This document is a collaborative effort of people involved in MichaelAnn's life and it helps people who work with her know how to best understand and support MichaelAnn. The sections called, "How MichaelAnn

Communicates" and "What People Need to Know and Do to Support MichaelAnn" have helped to give her a voice.

MichaelAnn received a musical "Sit and Spin" toy from Santa but because of some motor planning problems she is not able to play on it without assistance. In learning MichaelAnn's language, her parents know that if she stands by it or paces back and forth to it, she wants to play on it. They help her onto it and assist her in spinning. MichaelAnn shows her enjoyment through laughter. After a few months of doing this, sometimes when her parents started spinning her, she would get fussy. Her parents had to figure out what MichaelAnn was saying. They learned that if MichaelAnn didn't keep her legs crossed on the "Sit and Spin," then she just wanted to sit on it and play the music.

MichaelAnn didn't laugh very much before her parents took the time to understand her communication. Her mom says, "Learning MichaelAnn's language and sharing it with others in her life has made my daughter blossom. She participates in her life more and is happier."

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## Jeremy “ We work as a team. They help me and I help them.”

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Jeremy lives in a rural area with his Mom, Dad, sister, niece and nephew. At home Jeremy puts his clean clothes away (his sister does the laundry), cleans and dusts his room, takes out the trash, unloads the dishwasher, and feeds and waters the chickens. He also gathers the eggs. In the winter he helps bring in wood using his four-wheeler.

Jeremy graduated from high school in 1997 and then had a summer job. When that job was finished, he began work at the Seton Corporation in Saxton, Pennsylvania where leather car seats are made. Jeremy works five days a week. Jeremy had a job coach with him until he learned his job. Now his coach only sees him once in a while to see how he is doing. His Mom takes him to work at 6 a.m. and his sister picks him up after work at 2 p.m. Sometimes he rides home with one of his friends. Jeremy goes out to eat breakfast or lunch with his friends from work. Sometimes they go boating, attend ice hockey games, go bowling and go shopping. He has a lot of friends at work. As Jeremy says, “We work as a team. They help me and I help them.”

Jeremy regularly is involved in community activities. He either walks or rides his four-wheeler to town to participate in activities. Jeremy enjoys visiting the Fire Hall where he sometimes has dinner and helps with Bingo or washing the fire equipment with the men. He also enjoys helping with town sales and enjoys buying tools for his shed and fruit for his Mom. Dances are held in town on Friday evenings and Jeremy enjoys going dancing.



# Real Lives, *continued*

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## Alexa Makes the World a Better Place

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Alexa's parents have always wanted her to be fully included in school and in the community. Although Alexa is only twelve years old, her parents have been focusing on her future as an adult. They want her to have the know-how and confidence to be able to make good decisions about her own life and the supports she may need in the future. In order to make those decisions many skills need to be learned. Alexa needs to have good communication about her wants and needs and good relationship-building and problem-solving skills.

Alexa's parents believe that being overly protective of Alexa or giving undue attention to her will not contribute to her independence. As difficult as it was at times to overcome obstacles they faced, her parents felt it was necessary to persevere. They worked to convince communities, schools, friends and relatives that they want the same things for Alexa as they want for her two sisters, and they all need to treat Alexa no differently.

The persistence and vision of her parents have paid off and Alexa truly is part of her community. The regular school bus is equipped

with a wheelchair lift so Alexa can ride to her neighborhood school with her friends and neighbors; Alexa goes to regular physical education classes rather than adapted ones; and Alexa gets phone calls from friends asking if she is going to school dances. The neighborhood children use duct tape to attach a street hockey stick to Alexa's power wheelchair so she can play the game with them in the evening. The people from a local clothing store apologized for not having accessible floor space for Alexa and promptly corrected the situation. Her mom says, "All of these instances have not only helped to assist in reaching Alexa's goals and visions for the future, but they also help to change attitudes about the realities and capabilities of people with disabilities. As parents, professionals, community members and friends all work together to ensure that our world is a welcome place for ALL people, we will invariably prove to ourselves that for every obstacle we face, we can indeed find solutions. Alexa feels very comfortable in her school and community."

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## Amy Enjoying the Community

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Amy is 33 years old and lives with her family in a suburb of Pittsburgh. Her family saw a change in her personality when she was 15 years old and she was diagnosed with depression with psychosis when she was 19. She also has hyper-sensitive hearing and crowds make her anxious. Periodically she has had episodes of depression that have prevented her from enjoying the life she had previously. When Amy was about 18 years old, she left school because she couldn't handle the stress. She received home schooling and worked mornings at the school assisting the maintenance staff with cleaning classrooms until she was 21 years old.

When her high school education was completed, Amy was on a waiting list to receive day services. Funding became available after six months of waiting and Amy then attended a day program five days a week. She was in an environment where she was able to help other people and this helped to elevate her self-esteem. After participation in this program for five years, Amy decided that she wanted to get a job. First she did volunteer work for one year

and then she obtained a paying job at a convent where she did various kitchen jobs and fixed trays for nuns who were in the infirmary. Amy worked at this part-time job five days a week. When she wasn't working, Amy did jobs around the house and relaxed. She was capable of staying alone at this time. Amy was able to use public transportation and do things she enjoyed in the community such as bowling and going out to eat in restaurants with friends.

Things changed and Amy's life became limited by her mental illness and once again she was on a waiting list for supports. Amy has a person-centered plan and a circle of friends who are not paid. About five of them meet with Amy once a month and they do things together. They go out for dinner, to movies, bowling and they had a holiday party. Amy has very long hair and even though her mother suggested that it might look nice if it were cut shorter, Amy decided that she wants to keep it long. Amy chooses her clothing and the food she eats. She makes her own lunch and shops for food with assistance, chooses the restaurants when she eats out and the movies she sees. She also attends

a day activity program at the local community college three days a week.

Amy is no longer waiting for supports since funding recently became available that makes it possible for Amy to be involved in community activities on a regular basis. Having one-on-one companionship is important for Amy because it makes her feel secure. One companion and Amy go out for dinner and to the movies; they go shopping and they attend a religious group for single people together. Amy has the opportunity to participate in activities like singing, attending cook-outs and baking cookies with the group. In addition, Amy stays with this companion at her house one weekend a month. There are two other young ladies who also are companions to Amy for a total of eight hours a week. They do things together that include going for long walks, shopping and going to the library. Even though her life is not easy, Amy now looks forward to having people come to spend time with her and the opportunity to regularly get out in the community to do the things she enjoys once again.

# Real Lives, *continued*

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## Brian . . . Doing the Undoable

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Brian is 28 years old. After he graduated from school in 1994, he worked at a sheltered workshop. He was not allowed to do much there because people saw his limitations and not his abilities. He wanted a job in the regular workforce but was told he had too many handicaps since he has low vision, cerebral palsy, scoliosis and he learns slowly. Brian and his family didn't give up. In January of 1999, a company hired Brian to form shipping boxes. Now he also shreds paper and stuffs envelopes there. Brian works ten hours a week and loves his job.

However, Brian wanted to do more and wanted to meet people. In January of 2000, he began to receive funding that enables him to have a support person with him two days a week. Tuesday mornings they go to the local hospital where they shred paper. Friday mornings they go to Brian's church and stuff bulletins. In the afternoons they pursue other interests. Brian has learned computer skills and can find radio stations on the Internet. This is his favorite activity when he is home. He also goes bowling, miniature golfing and visits video arcades. Brian is interested in different

places in the community and he has taken tours of fire stations, a newspaper company, a post office, a bank, and his local airport – including the air traffic control tower.

Brian likes to watch the planes and visit with the people he has met at the airport. He has been invited to board a lot of planes and learned that most executive jets have tiny kitchens, a small television for each passenger, lounge chairs and some even have a bedroom. Brian has met many nice pilots who have shown him the cockpits of the planes and told him a lot about flying. He has also ridden on the truck that fuels the planes and on the tug that pulls planes into the hangar. According to Brian, "I've made friends in my community, and I now have a job and two hobbies, airplanes and computers. I'm a very happy person."



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## Jeanette . . . We Are Never Too Old

Jeanette is 91 years old and retired. She lives in an apartment with a roommate and has an active life. She has been supported by the same provider agency for over 75 years but has been living without direct supervision for the past seven years.

Jeanette walks to the Downingtown Senior Center four days a week. While there, she works in the kitchen, prepares for parties, and plays cards and other games. When she learns a new card game that she particularly enjoys, she teaches it to other people she knows who do not attend the senior center. Jeanette also goes on senior center trips.

When Jeanette is not at the senior center, she does other things in the community. She is a member of a winter bowling league; she has many friends and uses paratransit to visit them; and she walks to her bank, a restaurant and a drugstore. One of her favorite hobbies is stenciling and she makes all of her own cards and stationery.

Staff provide support with her medical needs and take her grocery shopping. When they invite her to activities, Jeanette often declines the invitations saying that she is much too busy.

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## Carolyn: Self-Determination is for Everyone

Carolyn has lived in Philadelphia County all of her life. For 13 years she was receiving attendant care services through a provider agency. Now things have changed for her and she is in control. Carolyn said, "I told them who I wanted to be in my circle and what I wanted them to do." She told the people who support her what she wanted out of life and together they developed a plan. Carolyn's plan focused on making it possible for her to help people and to have her own apartment.

They put together a budget based on the cost of Carolyn's daily life and her support services. Then the plan and budget were submitted to the county for approval. For the first time, Carolyn's income was included in her budget. Because she was now in control of the decision, it was possible for her to pay her staff more. Instead of using a provider agency, Carolyn interviewed and hired the staff that would work for her. A payment agent, established by the county, keeps all of the personnel records on file to ensure compliance with federal, state, and local requirements.

Since the switch in control from the agency to Carolyn herself, things have not all been smooth but Carolyn now has the power to make decisions that affect her. She is able to go when and where she wants to go and do the things she needs to do. Carolyn believes, "It can work for everybody, even people who cannot talk, because their circle can help them take control of their lives. They know the person best and know how to support them in finding their own voice."

# What Do People Want?

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People and their family members want to have an everyday life that is typical of the general population. They want more in their lives and they have greater expectations of the system than they did ten years ago. People want to have self-determined lives. This means with the support of family and friends, they decide: how to live their lives; what supports they need; and how they want to spend the money in their individual budgets. It also means **they are responsible for their decisions and actions.**

**Choice** - in all aspects of life including the services they 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.

**Control** - over their life including relationships, budgets and how money is spent, supports and services they receive, medical issues and planning.

**Quality** - of life determined by individuals. People want quality supports and services to enable them to have the life that they want. When they pay for high quality supports, they expect to get high quality.

**Stability** - feeling secure that all changes in their lives are made only with their input and permission – “nothing about me without me.”

**Safety** - to be safe at home, work, and school, 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.

**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.

**Relationships** - with family, partners, neighbors, community people such as pharmacists, barbers and grocers, support staff and having friends they choose.

**Freedom** - to have the life they want and to negotiate risk. People want freedom from labels and other people to use “People First” language. Individuals have the same rights afforded to all citizens. They want to exercise the freedoms of choice, to associate with people they choose, to move from place to place, and to use complaint and appeal processes.

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**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.

**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.

**Accountability** - government (state and county), agencies, and support people will do what they are supposed to do. This includes providing supports that people need when they need them and making sure that they don't lose supports that they already have.

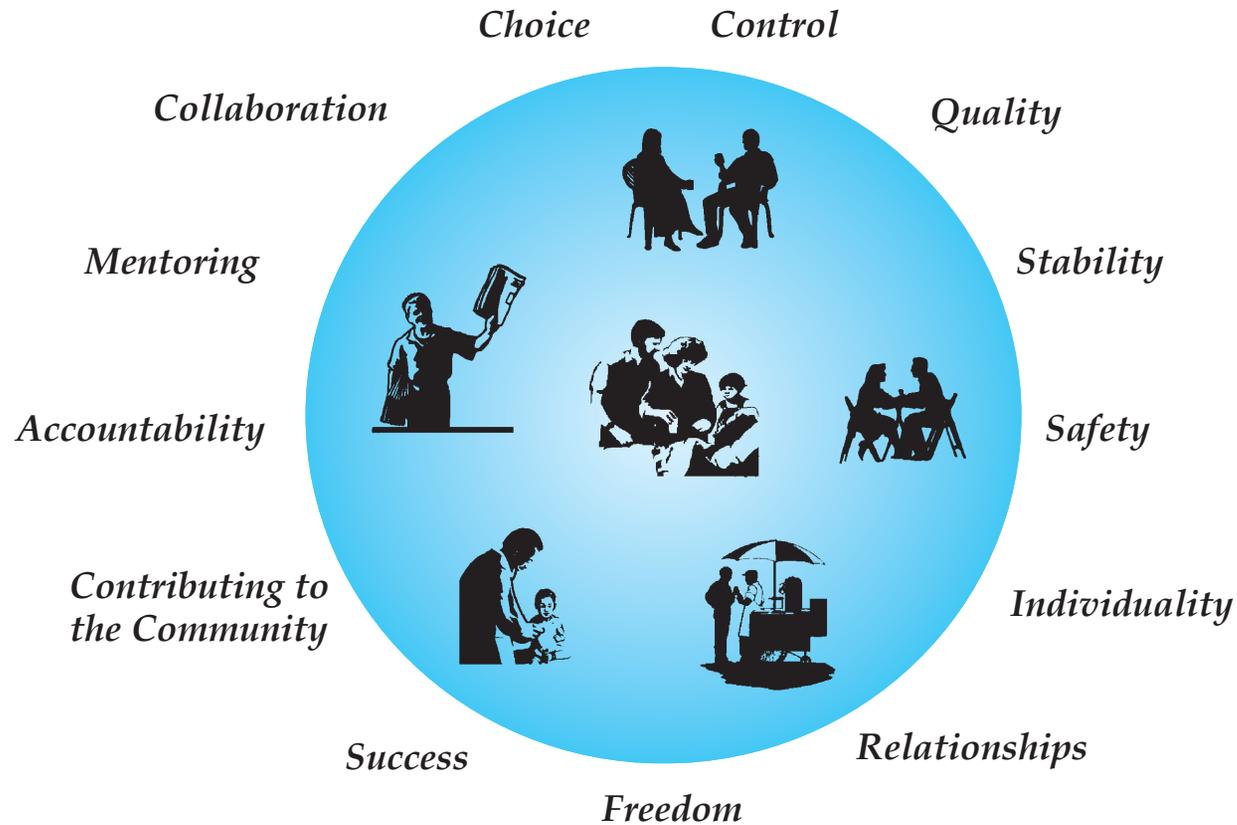
**Mentoring** - individuals and families trained as mentors to help other people and families by providing information and working with them until they can do things on their own; experienced supports coordinators mentoring new supports coordinators; senior support staff mentoring new support staff; and individuals and families mentoring support staff.

**Collaboration** - between the Office of Mental Retardation and other Offices within the Department of Public Welfare and between the Department of Public Welfare and other state Departments. People want collaborative planning during times of transition. They also want a seamless system that bridges from education to adult services. In addition, people want to have just one plan to be shared by all people/services/systems that are involved with them.



# People Want Everyday Lives

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Individuals and their families have the passion to make everyday lives a reality.

# Beliefs

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In order to change the system to make Everyday Lives a reality for everyone, then we all must keep in mind the following beliefs:

- Self-determination is for **everyone**.
- Everyone can make choices.
- Everyone should have control over his or her life.
- Everyone is different and there is value in difference; therefore supports need to be individualized.
- Everyday Lives are for **everyone**.



# Remaining Challenges

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Even though more people are beginning to have everyday lives, many challenges remain.

- Self-determination needs to be a way of life.
- Communication on all levels of the service system needs to be improved. Individuals need to have low and high technology devices available to assist them in communicating with other people.
- Transportation needs to be accessible, affordable, and available where and when people need it.
- The waiting list for supports and services needs to be eliminated.
- Capacity needs to be expanded to accommodate more people and meet more complicated needs.
- Local systems and individuals and their families need to work together.
- Quality needs to be continually improved.
- All people with disabilities need to be accepted as valuable members of the community.

# Framework for the Future

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Our vision for the future is a time when everyone has an everyday life. There is still much work that needs to be done before this will become a reality for all people. The system needs to move to an individual basis from a collective program model. Self-determination needs to be a way of life for everyone. Pilot projects make people think that it is only for a limited number of people but everyone can make choices and have control over their lives.

*Everyday Lives* and *Self-Determination* need to be the basis for everything.

## Communication

- Individuals and families need to have more information and be informed in language they can understand.
- Individuals and families need to receive information in a timely fashion.
- Communication needs to continue in forms other than technology, for example, paper format and by telephone where an individual or family member can call and talk with a person who can explain things.

- Supports coordinators need to *meet* with all individuals/families to complete forms that are used in the evaluation of need of services.
- Individuals need to have low and high technology devices available to assist them in communicating with other people.
- There is a need to listen to what people are saying through their words and actions.
- There is a need to listen to what families and support people are saying.
- Computers should be used to eliminate the need for individuals, families, and agencies to repeat the same information.
- People need access to a great deal of information without jeopardizing confidentiality.

# Framework for the Future, *continued*

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## Individualized Planning and Supports

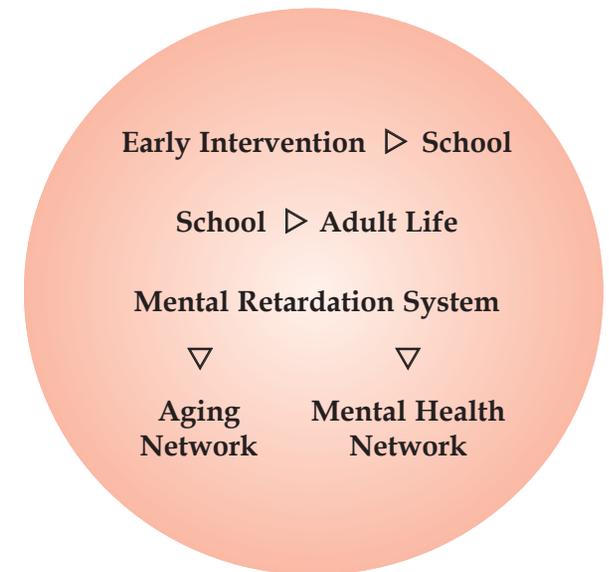
- Everyone should have the opportunity to have an individual plan that can be either informal or formal and a budget they create with help from people they choose. The plan can be as simple as a list or formal such as a Person-Centered Plan, Essential Lifestyle Plan or a MAP. The plan needs to be valued and followed by everyone providing supports. It should be used as a tool to promote action and it should dictate staffing needs for the person. Some people will choose not to do formal planning and they should receive the necessary support to help them identify and list some short-term needs.
- Supports must be there for individuals and families too.
- Families need “future planning for families” education.
- People need information about providers of supports and services so they can make good choices.
- Individuals and family members want to have their own lives. Supports are needed all week long, including weekends and in the evening. There needs to be an emphasis on building relationships with friends, family members, neighbors, and other people in the community.
- Real jobs with good wages and benefits need to be promoted.
- Transportation needs to be available where and when people need it, at a reasonable cost.
- Community employers need to value workers with disabilities and make accommodations to people’s needs.

## Control

- People need the opportunity to make choices in all aspects of their lives.
- More choices need to be provided in living, working and having fun.
- People need to have more opportunities to make decisions.
- People need to be in control of choosing agencies and individuals to provide supports, hiring and firing staff and choosing supports coordinators.
- People and their families need to be involved in all decisions about their lives.
- Individuals and families need to be respected and have input into the system. They need to be equal participants in all levels of decision making, such as serving on governing boards.
- Local mental retardation systems need to build relationships with individuals and families. They need to provide enough information to individuals and families to empower them so they can gain control of their lives.

## System Issues

- The system needs to have adequate capacity and funding so the waiting list is eliminated.
- Outreach needs to be done to find individuals unknown to the system and information on their needs must be collected before a crisis occurs.
- Local systems need to work together with individuals and families and respect them.
- Efforts need to continue in recruitment and retention of direct care staff.
- Quality of life and supports need to be evaluated from an individual's and family point of view.
- The system needs to be visionary. (Imagination and creativity must be encouraged to develop unique support options that meet individual needs.)
- Supports coordinators need to be limited to 35 or less people they support so they can provide a quality service.
- Support people need to have appropriate training and to be better informed.
- People who provide supports and services need to be paid a living wage.
- The system needs to recognize that all jobs, full time, permanent part-time and volunteer jobs are real jobs and not a social service. Supports coordinators should not visit people at their jobs or take them away from work.
- The public needs to be educated concerning the value of people with disabilities in the community.
- Mentoring needs to be expanded so it includes experienced supports coordinators to new supports coordinators; senior support staff to new support staff; and individuals and families to support staff. Supports coordinators who are mentors need to be relieved of other duties.
- People should not be identified in such a way that it sets them apart from others in the community and draws undue attention to them.
- Agencies need to be educated on providing consumer/family directed supports and services.
- Counties and agencies need assistance in making the transition to consumer directed services.
- The system needs to provide access to appropriate health care for people and assure their safety.
- Better inter-systems communication is needed. Early intervention to school; school to adult life; mental retardation system and aging network and mental health network.



# Framework for the Future, *continued*

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*When the remaining challenges are finally addressed, this is the story we will tell:*

All children go to school with neighborhood children and spend leisure time with them as well. People who provide supports and services are paid a living wage and are chosen by the individual and their family. Supports coordinators work with few enough individuals that they periodically call to ask, "Is there anything I can do for you?" and they develop a relationship with the person and his or her family and friends. They listen to individuals and families and they see the capabilities of individuals. Supports coordinators work flexible hours so they can meet with individuals and families when it is convenient for individuals and families.

Planning for the transition from school to work or school to higher education begins in the early teen years. Students and their families learn about possible options for after graduation and students get real life experience in a variety of settings while still in the school program. There is a seamless transition from school to adult life and people have the support they need to be successful at a job or in continuing their

education. Those who traditionally could not get jobs, are given the opportunity to do "job sharing" where each person sharing the job, does the part he or she is able to do with necessary support being provided.

Young adults decide who will help them with planning. Together they create a plan focused on the life they want, what kinds of supports they need, how much they cost, and how they will spend their individual budget. Individuals, along with family and friends they choose, have control.

People have friends of their own, not their parents' friends, with whom they go out for lunch and socialize. They go on dates and some will marry. Transportation is available and affordable to get people where they want and need to go, when they want. It is available on weekends and evenings so they can have a social life.

When they become adults and decide they want to move from the family home, the people who provide support work together with the individuals to make it happen. People receive assistance in learning about housing options and how to have a home of their own.

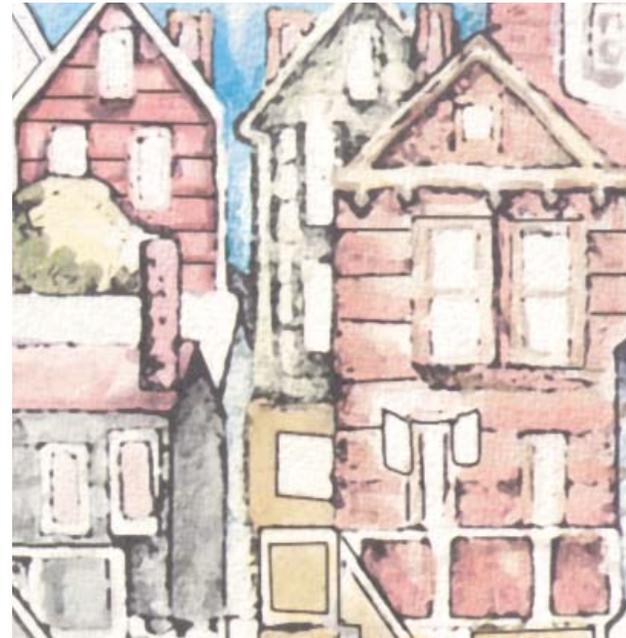
As people age and would like to retire there is another transition. Perhaps they work just a few days a week or shorter hours each day and they are given the opportunity to explore what the community has to offer for retirement on their days off. They have the support they need so they can plan how to spend their days and evenings doing what they enjoy.

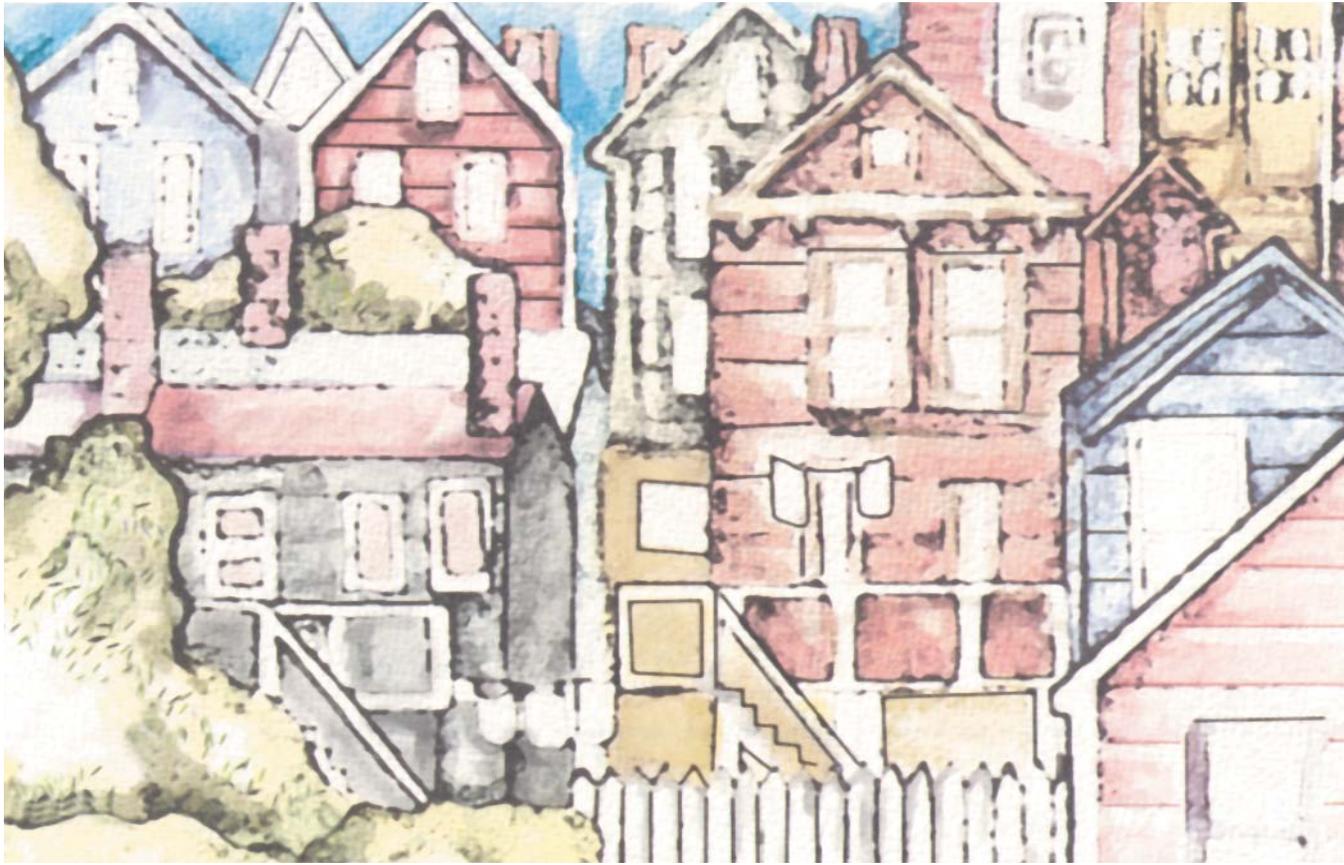
Paid support people work flexible schedules so individuals have an everyday life, every day of the week including evenings.

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After comparing what life was like ten years ago and what it is like now, we can say that we have made progress. Everyday lives are beginning to happen for people in Pennsylvania.

**Making Everyday Lives happen  
for *all people* is our goal!**





# Planning Advisory Committee Members

November 2001

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