The Arc of New Jersey presents

A Guide to

Community-Based Services and Supports for Adults with Intellectual Disabilities

by: S. Paul Prior, Esq.





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The Arc of New Jersey presents:

A Guide to Community-Based Services and Supports for Adults with Intellectual Disabilities in New Jersey

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Friends....

Just as each of us has a right to take part in choosing our work, where we live and how we spend our leisure time, so do individuals with intellectual disabilities. They should have the opportunity to direct their own services to the greatest extent possible and receive the supports they need to become contributing members of their communities.

But successful integration into the community does not occur in a vacuum. It depends on effective collaborations between families, educators, service providers, policy makers, and more importantly, individuals with disabilities themselves, working together to enhance the independence and participation of the individual in his or her community.

My son, Patrick, has developmental disabilities. My wife Nancy and I have been overwhelmed by the amount of information we must wade through to understand the service system that will serve Patrick when he turns 21 in less than 4 years. We consider ourselves to be "in the loop" thanks to our long association with The Arc, but still find the information confusing and, at times, contradictory. This guide to community based services and supports is one way that individuals with intellectual disabilities and their families can begin to sort out the details and formulate a plan for the future.

I hope you find the information in this guide as helpful as we have, and that it fosters the development of independence, self-direction and quality services.

> Bruce A. Bird, Ph.D. President, The Arc of New Jersey

Introduction

Local school districts are responsible for providing services to students with disabilities through age 21. Other state funding sources assume the responsibility for services after individuals graduate from school.

Services for people with disabilities over age 21 are referred to as 'adult services' and are designed to meet the needs of individuals with wide range of functional abilities.



Part 1 The Division of Developmental Disabilities

The primary source of services for adults with intellectual disabilities is the New Jersey Division of Developmental Disabilities (DDD).

Eligibility for DDD Services

Eligibility for DDD is governed by state statute. In order to be eligible, a person must have a mental or physical impairment that occurred before age 22, and which substantially impairs at least 3 of 6 major areas of life activity (self-care, learning, mobility, receptive and expressive language, self-direction, capacity for independent living and economic selfsufficiency). Eligibility is determined without regard to I.Q.

Application Process

To apply for DDD services, families should contact DDD (see Resources on page 18) to request an application. Once an application has been submitted, DDD must send a response letter indicating its determination of eligibility. If specific services such as residential services are requested, families may receive a letter advising them of the status of the request.

The application process can take several months.

If families disagree with DDD's findings on eligibility, they may appeal through a formal appeals process.

To Do:

- Keep copies of all documents and letters received from DDD on file for reference.
- While your child is still in school, ask your Child Study Team case manager to gather adult service information and discuss it with you at an IEP meeting during your child's transition years (age 14 and up).
- It is a good idea to document every telephone call with a government agency by sending a follow-up letter to confirm your conversation and any decisions made.

To Do:

Invite DDD staff to participate in the transition planning process.

□ Families should insist that the Individual Habilitation Plan (IHP) fully describes all of an individual's needs, and the goals and objectives needed to maximize the individual's potential.

When DDD offers a placement or service, examine it carefully to make sure it maximizes the needs of the individual. For example, a generic workshop program may not be appropriate for an individual who has challenging behavior or who has been successfully employed in the community.

Service Rights

Even when an individual is found eligible for DDD services, DDD can require that the individual be placed on a waiting list before receiving them. When an emergency exists, however, DDD must provide immediate residential services.

There are entitlements to DDD services under certain conditions: Once DDD agrees to provide services (such as when an individual reaches the top of the waiting list), its services must meet stringent legal standards. Under the New Jersey Developmental Disabilities Rights Act (N.J.S.A. 30:6D-1, et seq.), services must maximize developmental potential and be delivered in a manner and setting that least restrict the individual's personal liberty. These standards apply to both day and residential services.

A 1994 decision by the New Jersey Supreme Court illustrates how the law works:

B.F. was a 21 year old man with autism. School funding for his residential placement in New England was ending. DDD agreed to serve him, but for reasons of cost, proposed placement in a state institution. The record demonstrated that B.F. would regress in an institution, and that it did not meet the requirements of his transition IEP, which DDD helped develop. The Supreme Court concluded that cost could not be a factor if the person would regress without proper services. The court ordered DDD to fund the out-of-state placement.

Service Planning

Federal law recognizes that families are the "primary decision makers regarding services."

The Individual Habilitation Plan (IHP) - The purpose of the IHP is to establish goals and objectives that will enable the person with a disability to maximize his or her developmental potential in the least restrictive environment.

The IHP can be used as a long-range planning tool to guide the individual to a specific program. The IHP can also be used to obtain other types of services such as respite care, family support cash stipends, summer camp stipends, and financial assistance for securing guardianship through a private attorney.

State law also requires that guardians, family members, DDD staff, service providers (e.g., day program or group home staff), and, to the extent possible, the person being served by DDD, work together to develop an annual IHP, regardless of whether the individual is currently receiving specialized services from DDD.

The Essential Lifestyle Plan (ELP) is the plan of care document that is used in place of the IHP when an individual chooses self-directed service options (discussed on page 8). This planning document is based more on the individual's strengths and preferences than the IHP, which centers around a person's challenges and needs.

Training on the philosophy of person-centered planning is available to family members and other caregivers to assist them in participating effectively in the writing and implementation of both the IHP and the ELP.

You should know...

Often, the IHP is viewed as a formality and many are written simply to echo an offered service. However, the IHP is a very important document for planning and legal purposes.

Although the law governing DDD operates differently than the law governing special education, eligible adults with developmental disabilities **do** have service rights that impose mandatory responsibilities upon DDD.

It is misleading to say there is no entitlement to services from DDD.

To Do:

 Be sure your son or daughter is on the DDD waiting list for day services well in advance of graduation from school. DDD regulations permit a person to be placed on a waiting list for day services five years prior to graduation.

Although case managers are trained by DDD, their level of knowledge and experience varies widely. Ask your case manager about his or her experience with adults with intellectual disabilities. The Arc can help.

Whenever possible, have a family member serve as guardian. Talk to family members about assuming this role.

DDD Services

Case Management assists in the individualized planning of services to meet the person's needs and abilities. DDD assigns a case manager to each eligible person to help identify, access, and coordinate services.

Family Support is a coordinated system of services, resources, and other assistance for families caring for individuals with intellectual disabilities who live at home. The Family Support Act of 1993 expanded the list of services to include any service defined by the family. Services vary by county and funding is typically modest and subject to waiting lists.

Contracted Professional and Support Services can help meet acute and regular health care needs including medical specialties and dentistry. Certain legal services, integrated therapies, and case management also may be available through DDD.

Professional Supports include a DDD staff of psychologists, nurses, behavior management specialists and other professionals who can assist in meeting the social, medical, vocational and training needs of individuals. The staff can provide referrals, develop behavior management plans, and provide training to contracted agencies, families and staff.

Guardianship Services are available, if needed, to protect the rights of an adult with an intellectual disability and ensure that care and treatment are appropriate. DDD can provide a state-appointed guardian through its Bureau of Guardianship Services, or provide a process for the appointment of a family member to serve as guardian.

Adult Day and Vocational Services

Adult Day and Vocational Services are designed to provide an opportunity for individuals with intellectual and other developmental disabilities to earn wages or become part of their community through work, volunteerism, and social participation.

Services include:

Supported Employment Services are designed to assist individuals secure and maintain competitive employment in the community. The individual receives on-the-job training from a job coach until proficiency is achieved. Follow-up or support services are provided as long as necessary.

Adult Training Services train individuals in personal, vocational, social, and community-living skills. Typically, services are delivered in a center.

Crew Labor Programs train individuals to work on supervised, mobile work crews that are available for hire, specializing in service areas such as maintenance and landscaping.

Extended Employment (Sheltered Employment) provides long-term employment within a private facility. Programs specialize in contract work such as packaging products, stuffing envelopes and collating literature, secured through local businesses, paying per piece or below minimum wage. DDD has limited funding for individuals in need of extended employment, and who do not meet DVRS' criteria for continued workshop employment.

You should know...

Adult training services are typically centerbased.

Some extended employment programs include some time in community settings.

Sheltered workshops provide job-related evaluation, training and counseling.

Adults with significant, complex needs have been successful in supported employment.

You should know...

The law requires that DDD services be designed to *maximize developmental potential and be delivered in the least restrictive manner* (N.J.S.A. 30:6D-9).

Usually, group homes are for individuals who are functioning at lower levels of independence and self-sufficiency.

Usually, supervised apartments are for individuals able to live independently, with support from 24hour staff living separately, but nearby.

Most group homes and supervised apartments are operated by a community-based nonprofit organization under a contract from DDD.

DDD Residential Services and Supports

DDD funds most residential programs for adults with intellectual disabilities in New Jersey. There are a variety of community-based residential programs and residential supports for those in emergent need of housing or incapable of living with family.

Community-based services include:

Community Care Residences (formerly, skill development homes) provide care and training for an individual who lives in the home of a trained provider, and who implements a formal training program developed with and supervised by the DDD case manager.

Family Care Homes are similar to community care residences, but are available for individuals who are more independent. The provider offers room, board and supervision.

Group Homes are households typically shared by six or fewer individuals. Supervision and training are provided by a house manager and trained staff. Supervision is generally provided around-the-clock.

Supervised Apartments are occupied by one or two individuals and monitored by a trained staff person who regularly visits and may live in the same complex. In some unique situations, a supervised apartment may have live-in staff.

Supportive Living refers to arrangements for individuals who receive support services such as training and tutoring, and need access to on-call assistance 24 hours a day.

Independent Living Arrangements, while not licensed or funded by the Division, can be planned to permit the least restrictive housing. Individuals can receive regular visits from their case manager, agency staff, or others, and receive emergency assistance.

Private Homes are one of the least restrictive housing options. An individual can use his/her own resources to live alone or with family and/or pool funds with other residents to purchase or rent a house. Support services are funded by DDD.

Self-Directed Services

Self-Directed Services are guided by the individual with a disability and his or her family.

Real Life Choices (RLC). Individuals become eligible for RLC when they reach the top of DDD's priority waiting list. At that time, he/she is assigned to one of four levels of monetary support (ranging from approximately \$14,000 to \$63,000 annually) based upon assessed need. The individual and family uses these funds to purchase services based on their individual budget and Essential Lifestyle Plan. DDD uses support coordinators trained in Essential Lifestyle Planning to assist families in planning and implementing services. Because of the limited funding, most individuals in RLC remain living at home with family. The funds are used for flexible day and inhome support services.

Institutional Care

Developmental Centers are large, state-operated institutions. Hundreds of people live together in a self-contained, campus-like facility.

You should know...

Many individuals in private homes use self-directed services to pay for the supports they need.

Through a new program, DDD uses other Self-Directed Services for special education students aging out of the school system to offer them day and vocational services.

Across the county, reliance on the use of developmental centers is being reduced.

To Do:

Waiting lists exist for most DDD services. It is important to make sure that your child, regardless of age, is on the appropriate waiting list.

 Your request to be placed on the waiting list should be made in writing, through a dated
letter sent with delivery confirmation (return receipt requested).

□ Placement off the priority list is based on the chronological order in which one requests services. Therefore, even if residential placement is not needed now or in the foreseeable future, families are encouraged to request to be placed on the waiting list.

DDD's Waiting Lists

Residential Services

DDD's regulations allow the agency to assign people to waiting lists when services are not immediately available. At this time, roughly 6,000 people with disabilities are on various waiting lists for residential services.

The waiting list has three categories:

"Priority" is the top category and is for people who meet any ONE of the following criteria:

- both parents are 55 years or older;
- the person is living with someone other than the parent who is not willing to provide care any longer;
- there is a risk of abuse, neglect, or exploitation;
- one parent has a chronic condition, which significantly limits the ability to care for the person; or
- the person's health or safety is at risk because of behavior or physical needs.

The *"Priority"* category is the only DDD waiting list that actually places people into services.

"Priority-deferred" is for people who are offered out-of-home placement but who decline or accept support services through Real Life Choices (see page 8).

"General" functions as a *"registry"* for people who may, at some time, want residential services, but who do not meet the criteria for *"priority."*

Day Programs and Vocational Services

DDD also uses a waiting list for day programs and vocational services. DDD regulations permit a person to be placed on a waiting list for day services five years prior to graduation. Therefore, for families of school-age children who have planned well, a waiting list should not be a problem. However, for individuals who are still on a waiting list upon graduation at age 21, it may still be illegal for DDD to refuse immediate services despite its waiting list, particularly if serious regression is likely.

Financial Contributions

DDD currently requires individuals who receive DDD residential services or supports to contribute approximately 75% of their Social Security benefits and other unearned income, as well as 30% of their wages to the cost of those services.

DDD allows individuals to retain more than 25% of unearned income to pay for guardianship and "extraordinary needs" such as excess shelter costs, "unavoidable" medical costs, replacement costs of personal items, an irrevocable funeral trust, and costs of moving into an independent living arrangement.

DDD will also seek reimbursement for residential services from an individual's assets. By law, parental income is not subject to collection unless the individual is under age 18 and in a residential program funded by DDD, and the parents are under age 55.

You should know...

DDD will place people in an emergency situation. These are people who are seriously at risk or are homeless, and must be served immediately.

Anyone who applies for DDD eligibility must also apply for all other benefits for which they may be eligible, primarily Medicaid and SSI.

Parents under age 55 can have their child placed in the "Priority" category when circumstances warrant: such as when the physical or emotional needs of the child are too great, there are health and safety risks to the child, the ability of the parents to care for the child is compromised, or there is only one parent to care for the child.

Part 2

The Division of Vocational Rehabilitation Services (DVRS)

To Do:

DVRS

involvement should begin while a student is still receiving special education services. Parents should request that the Child Study Team case manager contact DVRS during the student's transition years.

Funding for longterm follow-up support services should be explored at the time of the initial IPE. If an individual is eligible for services through the Division of Developmental Disabilities (DDD), he or she can receive follow-up support services through a DDD- funded provider agency.

Eligibility for DVRS Services

To be eligible, an individual must have a physical or mental impairment that is a substantial impediment to employment. DVRS' services are limited to employment and employment-related training and are geared toward successful employment. DVRS services, while sometimes long-term, are generally not of lifelong duration.

Application Process

Individuals interested in vocational rehabilitation services must complete an application available through one of eighteen DVRS local offices throughout the state. (See Resources on page 18.)

A DVRS counselor will arrange an intake appointment no later than fourteen days after the application is submitted. Eligibility for DVRS is determined within sixty days of the intake interview.

Service Planning

DVRS offers vocational evaluation services to determine strengths, interests, and support needs of the individual. The assessment considers the assistive technology needs of the individual to be successfully employed, and must be completed prior to the development of a service plan.

DVRS uses an *Individualized Plan for Employment (IPE)*, which outlines the necessary services and supports for the individual.

DVRS Services

Vocational Rehabilitation Counselors can assist an individual and his or her family members to understand available services as well as to develop and implement an IPE that should outline the necessary services and supports for the individual.

Individual Counseling & Guidance can help the individual and his or her family to understand the local job market and competencies required for successful employment.

Job-seeking Skills Training & Selective Job Placement can be done with the DVRS counselor or through a DVRS-approved Community Rehabilitation Program (CRP).

Follow-up Support Services are provided once an individual is successfully placed in a competitive job in the community to maintain employment.

Physical Restoration Services can include corrective surgery or therapeutic treatments, prosthetic and orthotic devices, diagnosis and treatment for mental and emotional disorders, eye glasses and vision services, interpreter services, transportation (after all options have been explored), telecommunications, sensory and other technological aids, and other areas that, if not corrected, could be an impediment to employment.

Job Coaching, Vocational, and On-the-job training is provided by a DVRS-approved community rehabilitation provider to support the individual in developing a competitive job based on his or her preferences, strengths, and support needs.

You should know...

DVRS is required to consider *all* individuals seeking employment regardless of the severity of their disability.

An effective, comprehensive assessment increases the chance of identifying the right kind of job for the individual.

DVRS and DDD have collaborated on interagency agreements to ensure communication and resources are used between Divisions in the most effective manner.

People with intellectual disabilities have been and continue to be successfully employed in the community through supported employment services using DDD and DVRS funding.

You should know...

Post-employment services can be provided if an individual's case is successfully closed and some support need arises. DVRS can provide that support need on a short-term basis without reopening the case.

Long-term followalong services provide communication among employers, the community, the person with a disability and a job coach, to help ensure that appropriate supports are in place.

Both DDD and DVRS contract with provider organizations. **Funding for higher education** (post-secondary education and training) can be considered after extensive efforts were made to secure grant assistance or other funding.

DVRS' Waiting Lists

In the event of the need for a waiting list, DVRS must invoke an order of selection that prioritizes individuals with the most severe disabilities to be served first.

Financial Contribution for Services

Individuals are required to fill out a Financial Need Assessment form prior to the IPE conference to determine the financial contributions, if any, for which the individual is responsible. DVRS may waive financial participation if the individual has extraordinary medical and disability-related expenses or other unusual circumstances, which significantly affect the quality of family life and would preclude his or her participation in the cost of services.

Services not based on economic need include:

- Assessments
- Counseling
- Placement
- On-the-job training
- Supported employment
- Work-adjustment training
- Job coaching

Part 3 Medicaid & Supplemental Security Income

Medicaid Services

Medicaid is a federal funding system that is administered in New Jersey by the Division of Medical Assistance & Health Services (DMAHS). Medicaid pays for a wide array of services for people with disabilities and their families and provides government-funded health insurance, including prescription coverage and personal care services, for children and adults with disabilities who have limited financial resources.

Medicaid also provides government funding for long-term services and supports, including institutional care and community-based services (such as group homes and self-directed services). These community-based services are funded through a "waiver" known as the Community Care Waiver (CCW).

In New Jersey, the CCW is the primary funding source for adult services through DDD. The CCW allows the state to use federal and state funding for flexible services that are more person-centered. The CCW is for individuals with developmental disabilities who would otherwise require an institutional level of care, but who can be served in a less restrictive setting.

The CCW funds case management, respite care, habilitation (including pre-vocational, educational, and supported employment services), home and vehicle accessibility adaptations, personal emergency response systems, therapies, and other individual supports.

To Do:

 Families should establish a special needs trust in order to protect assets and ensure continued eligibility for important Medicaid benefits.

 Talk to family members and loved ones who may be planning to leave money to your child. Advise them on the need to put any gifts for your child into a special needs trust.

To Do:

- Parents and other family members should not place assets in excess of \$2,000 in the name of the person with the disability.
- If the individual has assets in his or her name in excess of \$2,000, and the value is modest,
 spend them or reimburse the family for expenses already incurred.
- Inheritance and lifetime gifts should be made to a special needs trust and not the individual with an intellectual or other developmental disability.

Even if a person has private health insurance, Medicaid may pay for services that most private insurance plans do not cover such as private duty nursing, medical supplies, or even residential placement.

In order to maximize federal funding, DDD requires all participants to maintain Medicaid eligibility.

Eligibility

Eligibility for Medicaid is based on assessment of both disability and financial resources. Most adults who are DDD-eligible will meet the Medicaid definition of disability.

Medicaid has stringent asset and earnings guidelines. Generally, Medicaid eligibility depends upon a person's satisfying the requirements for the federal Supplemental Security Income (SSI) program *(see page 16)*. Medicaid "waivers" permitting higher monthly earnings may apply in some circumstances. With the exception of these waiver programs, the income and resources of parents of children under age 18 are considered.

Service Rights

Once eligible for Medicaid, a person must receive services and cannot be placed on a waiting list. Under Medicaid regulations, a state cannot limit access to covered medical services simply because the cost of service exceeds the state budget. In New Jersey, certain "waiver" programs limit the number of participants.

Financial Contributions for Services

If an individual acquires assets or resources, such as in the case of inheritance or earnings, they may become ineligible for Medicaid/SSI and be required to reimburse Medicaid for services.

Supplemental Security Income

Supplemental Security Income (SSI) is a program of monthly cash benefits that is available to many people with significant disabilities who have limited income. The SSI benefit usually ranges between \$450 and \$650 per month. A person who qualifies for SSI also will qualify for Medicaid.

Eligibility

To qualify for SSI, a person with a disability can have no more than approximately \$700 to \$800 in monthly income and no more than \$2,000 in countable resources. Countable resources are the person's property (other than certain exempt resources, such as the house one lives in and one car). The person also must have a disability that prevents gainful employment.

When the person is under age eighteen and living at home, family income and resources will be counted. However, once the applicant turns eighteen, family resources are not counted, even if the applicant continues to live at home. Only the income and resources of the person are considered. For this reason, most people with intellectual disabilities qualify for SSI for the first time at age eighteen.

There are several additional ways to qualify for Medicaid, even if the applicant cannot meet the SSI

You should know...

Many parents and well-intentioned relatives will open a bank account or purchase savings bonds in the name of a minor with a disability, only to realize at age 18 that their child is not eligible for certain government-funded services because savings are in excess of \$2.000. As harsh as it may sound, a child with a significant disability should not have assets in his or her own name. A special needs trust should be considered.

A bank account or other assets held in the name of the person with a disability, which causes SSI disqualification, also will cause Medicaid disqualification.

You should know...

There are waivers and work incentive programs that allow an individual to remain on SSI and Medicaid and still have earnings in excess of the maximum monthly allowable requirements. Families should inquire directly with SSI and Medicaid about these programs.

For information on Social Security Work Incentive Programs, contact NJWINS (see Resources on page 18). income and resource tests. For example, an applicant who loses SSI because he or she is collecting regular Social Security (SSA) as a dependent of a parent who dies or retires will continue to receive Medicaid benefits. Also, applicants whose income places them slightly over the Medicaid limit may still be eligible under alternative eligibility criteria.

Part 4: New Jersey State Resources

Your first call should be to The Arc. We can help you get started...

> (732) 246-2525 www.arcnj.org www.thearclink.org

GOVERNMENT OFFICES AND RESOURCES

New Jersey Division of Developmental Disabilities (800) 832-9173 www.state.nj.us/humanservices/ ddd/index.html

New Jersey Division of Vocational Rehabilitation Services (609) 292-5987 www.wnjpin.org

> New Jersey Center for Medicaid Office (800) 356-1561 www.njmmls.com

Division of Disability Services (888) 285-3036 www.state.nj.us/humanservices/dds

Social Security Administration (800) 772-1213 www.socialsecurity.gov

Center for Medicaid & Medicare Services (877) 267-2323 www.cms.hhs.gov New Jersey Work Incentive Network Support (NJWINS) Provides current information about how work can impact your Social Security benefits.

> (866) WINS4NJ www.njwins.org

New Jersey Council on Developmental Disabilities (800) 792-8858 www.njddc.org

The Boggs Center on Developmental Disabilities (732) 235-2688 www.rwjms.umdnj.edu/boggscenter

New Jersey Protection & Advocacy (800) 922-7233 www.njpanda.org

STATEWIDE SUPPORT AND INFORMATION RESOURCES

New Jersey Ease for Caregivers

Provides information about supports for a caregiver of an adult with a disability. (877) 222-3737 www.caregivernj.nj.gov

Family Support Center of

New Jersey One-stop clearinghouse for disability resources in New Jersey. (800) FSC-NJ10 www.fscnj.org

About the author...

S. Paul Prior has spent his legal career representing people with disabilities. As the younger brother of a man with autism, he has a life-long commitment to disability law. His legal work has focused on special education, guardianship, financial entitlements, and access to appropriate services. A substantial part of his practice is devoted to assisting families in estate and trust matters. He has argued cases before the New Jersey Supreme Court, Third Circuit Court of Appeals, as well as other state and federal courts. He served as a federal monitor overseeing conditions at state-operated institutions. He serves on the board of directors of for the Arc of New Jersey, Special Olympics New Jersey and the Eden Foundation. Paul holds a JD from Seton Hall University School of Law, and is a member of the Elder Law Section of the New Jersey Bar Association. He writes and lectures frequently on topics concerning the law and disability as well as issues affecting siblings.

The Arc of New Jersey thanks Hinkle, Fingles & Prior, Attorneys at Law for their support of this guide:

The attorneys at Hinkle, Fingles & Prior, Attorneys at Law have more than seventy years of combined experience providing expert counsel and legal services to families of people with disabilities and seniors. The firm's attorneys have argued many of the precedent-setting cases affecting people with disabilities.

The firm has a deep commitment to supporting the disability community. Attorneys volunteer their time and expertise as members of the board of many state-wide non-profit organizations, including the Arc of New Jersey, where S. Paul Prior serves. They provide workshops and lectures to parent groups across New Jersey and Pennsylvania at no charge.

Hinkle, Fingles & Prior is a multi-state practice with offices in Lawrenceville, Marlton and Florham Park, New Jersey, and in Yardley and Plymouth Meeting, Pennsylvania.

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