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ABSTRACT

This guide is intended to help Pennsylvania parents of infants and toddlers with disabilities to understand their rights and assist in the design of an appropriate early intervention preschool educational program. An overview of special education laws focuses on the Individuals with Disabilities Education Act, Parts B and C. The main sections of the guide provide information on: (1) the evaluation process, including the role of the service coordinator and required assessment areas; (2) eligibility; (3) the Individualized Family Service Plan (IFSP) and federal law requirements; (4) carrying out the plan, such as determining where, who, what services, and how much the IFSP requires; (5) the services, ranging from assistive technology to vision services; (6) important aspects of the IFSP, such as fee services and the parental right to be informed; (7) community childcare, including obligations of the mental health/mental retardation agency; (8) conflict resolution, including complaints, mediation, and hearings; and (9) transition at age 3, including the systematic transfer of responsibility from the Department of Public Welfare to the Department of Education. Appendices provide a checklist of steps in preparing for the IFSP meeting and a glossary of abbreviations. (DB)

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*A PARENT GUIDE TO*

***EARLY INTERVENTION  
in PENNSYLVANIA  
for infants and toddlers***

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***PARENT EDUCATION NETWORK 333 EAST 7TH AVENUE YORK, PA 17404  
800-522-5827 V/TTY***

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## INTRODUCTION

When raising a child with special needs, a parent is often faced with joys and challenges that were never expected. There are no instructions or maps, but many times there is a network of other parents, agencies and services that resourceful parents eventually find and use in their own communities or regions.

The parent is certainly the expert on the child and, as such, has the potential to be the child's most effective advocate in the education system. No one needs to "empower" you, or give you power. Because you are a parent, you already have power that is recognized in special education law. With that power comes not only opportunity but also responsibility! In order to be a truly effective advocate you must understand the effects of your child's disability on learning and social development and know your rights and the rights of your child in the education system. This involves becoming familiar with special education and civil rights laws and also seeking resources that you can use to ensure your child's success.

*This guidebook is written for you, the parent, to assist you in understanding your rights so that you can design an appropriate early intervention and preschool educational program and a strong network of support and resources for you and your child.*

### **OVERVIEW OF SPECIAL EDUCATION LAWS**

In 1975, the U.S. Congress passed Public Law 94-142, requiring that school-age children with disabilities receive a "free and appropriate public education". This marked the end of a long struggle by parents and advocates who believed that children with disabilities should receive an education in public schools. In 1986 this federal law was given a new name, the **Individuals with Disabilities Education Act** or **IDEA**, and it was changed to include younger children with disabilities. The **IDEA** was changed again in 1997 through a process called "reauthorization".

**IDEA** is divided into Parts A through D. Under **Part C of IDEA**, Pennsylvania is funded to provide services to infants and toddlers with disabilities (birth to age 3). **Part C** is the responsibility of the **Pennsylvania Department of Public Welfare**. **Part B of IDEA** provides funding to Pennsylvania for special education services to children with disabilities who are ages 3 to 21 and these services are the responsibility of the **PA Department of Education**.

Regardless of your child's age, providing an appropriate education program involves four basic steps:

- 1) An **EVALUATION** of your child's learning strengths and unique learning needs;
- 2) The **DEVELOPMENT** of a **PLAN** for using your child's strengths to overcome needs: deciding how the plan will be achieved, where the plan will be carried out, who will do it and how much service time will be needed so that your child will be successful;
- 3) **CARRYING OUT** the **PLAN** as agreed to;
- 4) **REVIEWING** the **PLAN** periodically.

These steps are outlined in federal and state laws and regulations. Understanding these four steps will help you understand the educational process discussed in this guide.

*As of the writing of this Guide, State regulations have not been developed. Contact PEN (800-522-5827) for more information about the status of these regulations.*

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*PARENT EDUCATION NETWORK 333 EAST 7TH AVENUE YORK, PA 17404 800-522-5827 V/TTY*

# **EARLY INTERVENTION FOR INFANTS & TODDLERS: BIRTH TO THE THIRD BIRTHDAY**

## **EARLY INTERVENTION? WHAT FOR?**

Most delays in a child's development are discovered before the age a child typically goes to school. Early discovery of delays in development allows parents to make early decisions about who will help and how and where that help can be found. In these early years, a child's brain is most ready to learn such basic skills as eating, communicating, understanding how toys and objects work, moving around in the world by crawling or walking, dressing, and getting along with others. Other, more complicated skills, are later built on these basic ones. That is why **intervention**, or help, is available at the earliest possible time in Pennsylvania. It is an ongoing process. **The role of early intervention is to assist you in finding the information and resources that you need, representing a full range of philosophies and options.**

## **THE EVALUATION PROCESS**

If your child is **younger than three years old** and you want to receive early intervention services, **a referral must be made by you for an evaluation to your county Mental Health/ Mental Retardation (MH/MR) office.** This office is funded by the PA Department of Public Welfare. It is the **entry point to early intervention for all children**, no matter what the reason for referral or the type of delay or disability that is suspected. Some MH/MR offices have a special division and name for their early intervention program. Find the number in the blue pages of your phone book or call **Parent Education Network at (800) 522-5827 (V/TTY).** It is a good idea to follow up your call with a letter stating that you called for an evaluation. **Keep a copy of your dated letter.**

A **SERVICE COORDINATOR** will usually be your first contact. This person's job is to coordinate your child's evaluation, assist you and others in designing a plan for your child and being a support to you in getting what your child and family needs to help your child develop. You have the right to ask the early intervention supervisor at MH/MR for a different service coordinator if dissatisfied.

**You must give your written permission before any screening or evaluation can be done.** Sometimes a screening is done first. This is a brief overview of your child's abilities, usually done by one professional. The purpose of the screening should be to help decide what to do in the upcoming evaluation. **After the screening, your service coordinator may recommend that an evaluation is *not* necessary. Know that your child has a right to an evaluation, which is more in-depth than a screening, no matter what the results of the screening are.**

Your local MH/MR office will probably have a contract with professionals in the local area to do evaluations. The evaluation must be in-depth and completed within **45 calendar days** of your referral.

A team of people must complete the evaluation. The team includes, at a minimum, parents, an MH/MR service coordinator and professionals who are qualified and understand your child's special needs.

You should ask who will be performing the evaluation and what tests will be used. If you feel that these team members are not qualified to evaluate your child's strengths and needs or if you feel that there should be additional members on the team, put a request in writing to your service coordinator.

**Parents have a right to understand all written forms, plans and notices. All forms must be interpreted or written in the native language of the parent.**

### **ALL EVALUATIONS IN THE EARLY INTERVENTION SYSTEM ARE FREE.**

#### **THE EARLY INTERVENTION EVALUATION FOR CHILDREN BIRTH TO AGE 3 MUST INCLUDE ASSESSMENT OF:**

- ✓ **Physical skills** (including motor skills such as rolling or crawling, walking, grasping toys, stacking blocks, signing as well as vision and hearing);
- ✓ **Communication skills** (how mouth muscles are used for eating or talking, how well the child talks or signs, how your child understands other people);
- ✓ **Cognitive or thinking skills** (how your child understands how toys work, pays attention and explores the environment);
- ✓ **Social or emotional development** (how your child relates to others);
- ✓ **Adaptive or self-help skills** (eating, drinking, toileting).

**IT IS REQUIRED AND IMPORTANT THAT ALL FIVE OF THESE AREAS OF DEVELOPMENT ARE EVALUATED.**

The purpose of the evaluation is to find out what your child has already learned and to let you know your child's "developmental age" in each one of these areas.

If you want an evaluation for your child that is independent from the MH/MR agency, you have the right to obtain such an evaluation at your own expense. If you are dissatisfied with the evaluation through MH/MR and wish to obtain an independent evaluation, send a written request to MH/MR. If it is agreed that MH/MR did not have the appropriate personnel or that the testing was inappropriate, the MH/MR agency will pay for that independent evaluation. If you are refused payment, try to discuss your reasons further with MH/MR. You may also use conflict resolution procedures found later in this section.

This evaluation is the foundation for the rest of the early intervention process, so it is important that you understand the evaluation results! Your child will be evaluated every year after that, if he or she remains eligible for early intervention services.

### ELIGIBILITY

Children are eligible for early intervention services if they have a delay of 25% or more of their chronological age in at least one area of development. Children are also eligible if they have a diagnosed condition which will probably result in a delay in development.

### THE IFSP TEAM

The next step in the process is for a team to have a meeting and write a plan that outlines what successes your child should have as a result of early intervention and the services that are needed for success to occur. This plan is called an **Individualized Family Service Plan or IFSP**. The IFSP team consists of **parent(s), service coordinator and at least one person involved in doing the evaluation**. Persons who will provide services to the child may also be included. There may be other participants if invited by you or the MH/MR agency.

### INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)

You are an important, equal member of the IFSP team! You bring a perspective that no other team member has! Share your knowledge about how your child has learned various skills and what you would like to see your child learn over the next year.

The Individualized Family Service Plan or IFSP is a legal document required by federal and state special education laws. It is important, therefore, that you know what must be written on an IFSP.

FEDERAL LAW REQUIRES THAT THE IFSP MUST CONTAIN:

- ✓ Present Levels of Development in physical

skills (motor, vision, hearing), communication skills, cognitive or thinking skills, social and emotional development and adaptive or self-help skills. These should be based on the results of testing;

- ✓ **Statement of Family Resources, Priorities and Concerns** relating to strengthening the development of the child;
- ✓ **Outcomes** expected to be achieved for the child and family because of early intervention;
- ✓ **Criteria** or how progress is defined;
- ✓ **Procedures** or how progress is measured;
- ✓ **Timelines** or when outcomes should be achieved;
- ✓ **Early Intervention Services** that will be given to meet the child's needs;
- ✓ **Frequency, Duration and Method of Service Delivery** or how many minutes, how many times per week of each service and if early intervention services will be given individually or in a group;
- ✓ **Beginning and Ending Dates of service**, which should be a full calendar year;
- ✓ **A Statement of Natural Environments** where the child will be served, including justification if services are not provided in the natural environment;
- ✓ **Transition Steps** to be taken when the child is ready to exit the program;
- ✓ **Name of Service Coordinator**;
- ✓ **Signatures of Consent** to implement the IFSP.

Because all IFSP team members have different and important perspectives, **the IFSP must be written at a meeting of those team members**. It cannot be written before the meeting and given to you. It is necessary, therefore, for all members to come to the meeting with ideas about what outcomes should be achieved. Some parents find it helpful to bring notes to the meeting to help them in writing the IFSP. The list provided in the appendix can assist you in exploring what you would like your child to achieve.

### CARRYING OUT THE PLAN

The final part of the early intervention process is deciding, based on the outcomes for your child that the team has just agreed to:

- **Where** this IFSP should be carried out (e.g., in your home, in a center with other children, in a childcare facility, in a therapist's office),
- **Who** will carry out the IFSP (e.g., a therapist, nursery school teacher),
- **What services** will be needed so that the outcomes can be achieved.
- **How much** of that service will need to be given so your child will achieve the outcomes on the IFSP (e.g., one



hour, once a week or three 30 minute individual sessions per week).

## SERVICES

There are a variety of early intervention services that can be provided to your child, *if they are written on your child's IFSP*. These should be discussed and chosen based on your child's individual needs, not because of funding, staff available or what other children receive. The following are **examples** of services that might be of particular benefit to your infant or toddler:

**Assistive technology** - selecting, fitting, maintaining, repairing assistive listening and communication devices.

**Audiology** - determining the range, nature and degree of hearing loss.

**Family training** - classes in behavior management, sign language, disability issues, etc.

**Medical services** - provided by a physician to determine developmental status.

**Nursing** - assessment of health status.

**Occupational therapy** - identification and intervention in the area of functional needs and fine motor skills.

**Psychological services** - administering psychological tests; explaining information about thinking skills and behavior.

**Physical therapy** - evaluation and service provision in the area of gross motor skills.

**Service coordination** - assisting parents in getting all services listed on the IFSP; helping parents find professionals knowledgeable about your child's disability; making referrals to appropriate professionals.

**Special instruction** - parent/infant group; using a specially designed curriculum; teaching parents how to do activities at home; training childcare staff.

**Speech-language pathology** - identifying the child's particular strengths and needs in any area of communication or feeding skills; providing communication services to the child; involving the family in language training.

**Transportation** - helping with any travel costs that are necessary to enable your child to receive early intervention services.

**Vision services** - evaluating vision; referral for medical services; orientation and mobility training.

**These and other services can only be provided if they are determined by the IFSP team to be necessary and are written into your IFSP.**

### ***OTHER IMPORTANT ASPECTS OF THE IFSP***

1. **All early intervention services are free.** You can give permission for your private insurance to be billed. You are under no obligation, however, to use your private insurance if you will incur any cost, such as a decrease in lifetime coverage or a reduction of coverage or other benefits, increase in premiums or paying the cost of a deductible. Parents may also choose to enroll in Pennsylvania's Medical Assistance program called ACCESS. Qualification for the ACCESS program is based on

your child's disability and the income of your child, **not on your income**. If you enroll, the early intervention system can bill Medical Assistance for early intervention services. **Services cannot be denied if you refuse to allow your private insurance to be billed or refuse to enroll in the ACCESS program. The type of services your child receives should not be dependent on the source of funding.**

2. You have a **right to be informed of options for service** and you should discuss with other team members the types, places and ways of getting services that make the most sense for you and your family.

3. The **evaluation and writing of the IFSP** must be completed within **45 calendar days of your referral**. Services should start as soon as possible after your signature of agreement.

4. As your child continues to receive early intervention services, a **reevaluation and new IFSP** will be completed every year. Parents or staff may call the IFSP team together at any time, if there is need for a change in goals or outcomes, location, type or amount of services. Changes cannot be made without your written agreement.

5. It is important that the **IFSP is specific enough** that you can understand what will be happening, who is responsible, how much and what types of services your child will receive, where these services will take place and how progress will be measured

6. The natural environment means a setting that is natural or normal for the child's age peers who have no disabilities. Services are to be given in the **natural setting to the maximum extent appropriate**. This means that when the IFSP team discusses where services are to be given, they must consider a variety of places, including your home, a community setting such as a childcare facility with children without disabilities or a center-based program. What guides the IFSP team decision about placements should be where the outcomes on the IFSP can be carried out appropriately for your child.

If services are given in a setting that does not meet the definition of "natural", a statement will be placed on the IFSP telling why services are being given in another place. Remember that your child may receive some services in one place and other services somewhere else.

7. Whatever method of service is used, you should be sure that your **service provider is a qualified or licensed professional able to carry out the outcomes on the IFSP**.

8. As a parent, you are your child's best teacher and you need to be involved in implementing the IFSP as much as you desire or are able. Your involvement is very important. You are not responsible, however, for carrying out the IFSP outcomes/objectives. That is the responsibility of the early intervention system.

**YOUR IFSP IS VERY IMPORTANT. UNDERSTAND WHAT IT MEANS AND REFER TO IT FREQUENTLY AS A GUIDELINE FOR WHAT SHOULD BE HAPPENING IN**

## YOUR CHILD'S EARLY INTERVENTION PROGRAM.

If you feel at any time during this process (the evaluation, writing of the plan or even after services have been started) that your child will not benefit from early intervention, you may simply withdraw your child from some or all early intervention services. Put your wishes in writing to the service coordinator.

Your local MH/MR is responsible for the entire early intervention process from evaluation, to gathering a team to write the IFSP, to providing services, even if those services are provided by another agency. If you find that something written on the IFSP is not happening, is happening in a different way or you want to make a change, inform your service coordinator. If you are not satisfied with the service coordinator's response, you can request that the early intervention supervisor at your local MH/MR assists you in resolution of your dispute. It is always good to put a dated request in writing, keeping a copy for yourself. **Your child's IFSP must be reviewed every six months whether you ask for a review or not.**

## WHAT ABOUT A COMMUNITY CHILDCARE?

It has been mentioned previously that children from birth to age 3 who are eligible for early intervention services have a right to services given in a "natural environment". One such environment might be a community childcare. If parents and other members of the IFSP team agree that this is the appropriate place where the IFSP goals and outcomes will be achieved, the time spent in that childcare devoted to working on those goals and outcomes must be paid for by the MH/MR agency.

It is hoped that many childcare agencies welcome children with disabilities. Others may need the supports paid for by the MH/MR agency, which must be written on the IFSP.

**The MH/MR agency has the responsibility for providing what the child needs only in developmental areas found to be delayed.** Your child may be in a childcare facility for a longer period of time than is necessary to work on early intervention outcomes according to the IFSP. This might occur because of a family member's work schedule, for example. The MH/MR agency would not be responsible for payment during that part of your child's stay in a childcare facility.

The **Americans with Disabilities Act (ADA)** prohibits public and private childcare agencies from denying services to any child based on the disability unless it can be shown that making "accommodations" would not be "reasonable". Consideration must be given to issues such as the welfare of all children, cost of the accommodation (such as a ramp or an interpreter, etc.) If you feel that your child is being discriminated against because of a disability, you can file a complaint with the Office of Civil Rights, using the address found later in this guide.

## CONFLICT RESOLUTION for Early Intervention - Birth to 3

You may use informal or formal methods of disagreement. Using informal methods to solve problems (communication, negotiation, compromise) is often the best way to resolve problems and such methods can strengthen the relationship that parents have with service providers. Sometimes, however, those methods simply do no result in resolution of the problem and parents need to use more formal processes of disagreement.

**COMPLAINT** - If you have a dispute about the evaluation, program, services or timelines that were not followed, a formal complaint can be registered with the **Regional Office of MH/MR**, either over the phone or in writing. You can ask your service coordinator to give you the name, address and phone number of the person to whom the letter should be addressed.

Include in your written complaint your name, address and phone number, your child's name and date of birth and a description of what happened and why you are not satisfied. An investigation of your complaint by interviews, review of reports and observations must be completed within **30 calendar days**. A written report will be sent to you. If a violation is found, corrective action must take place within the next **30 calendar days**. Keep a copy of your written complaint.

**MEDIATION** - You also have the option of asking for mediation, a free service in Pennsylvania, that assists parents and county MH/MR agencies to solve problems. Because mediation is voluntary, both sides must agree to meet. A mediation session can be scheduled by calling the **Special Education Mediation Service** at **800-992-4334 (V)** or through the PA Relay Service at **800-654-5984 (TTY)**. This office will contact your county MH/MR agency and ask for their participation.

If MH/MR does not agree to participate, mediation cannot occur. If they agree, the mediation is scheduled usually within **2 weeks**. A specially trained mediator will meet with you and the representatives from MH/MR to hear both sides of the issue(s) and then will assist both parties in trying to reach an agreement. No attorneys are permitted at mediation sessions. Agreements are binding if they are written on the IFSP.

**DUE PROCESS HEARING** - A request for a due process hearing must be made to your county MH/MR Administrator. This request can be made by phone or in writing. The MH/MR Administrator must have a request form signed by you within **2 working days** and send it to the **Department of Education's Right to Education Office** in Harrisburg within **3 working days**. A hearing should be held and a decision made within **30 calendar days**. The decision of the hearing officer can be appealed to an Appeals Panel at the state level. If this decision is not satisfactory to you or to MH/MR, the case can be filed in state or federal court.

**A due process hearing is a formal, legal procedure.** A trained

hearing officer will be assigned to hear your case. This person should be impartial. You must decide if you want the hearing closed (meaning only those invited by you can attend) or open to the public. A stenographer will keep an exact record of everything said at the hearing and a copy will be given to you and the MH/MR agency.

Verbal and/or written information proving facts and opinions is given at the hearing by parents and the MH/MR agency. Each side can ask questions of the other side. Witnesses can also be asked to provide verbal and/or written testimony. If parents or MH/MR want a witness to testify and the witness refuses, the hearing officer can order the testimony. All persons testifying must take an oath. All written documents used at the due process hearing must be submitted to the other side at least **5 days** before the hearing starts.

A due process hearing costs time, energy and, frequently, money. If a due process hearing is necessary, you need to start planning right away. Parents have the right to bring an advocate or attorney to the hearing. If you want an advocate or attorney, try to find one who is familiar with early intervention law. You will need time to meet with that person so that the issues can be explained and strategies can be mapped out.

The IDEA says that if you “prevail” or win most or all of your case, you may be reimbursed by the MH/MR agency for some or all cost related to the hearing, such as attorney fees or charges for hiring witnesses. The offer by a MH/MR agency to pay these fees must be accepted within 10 days of their offer. Parent reimbursement may be reduced if they cause an undue delay in the hearing or in the final resolution or if parents withhold information from the MH/MR agency.

Once you make a written request for a due process hearing, your child has a right to stay in the current placement with the same program until an agreement is reached. This is called “**stay put**” or “**pendency**”. Therefore, if a proposed change in your child’s services is the source of your disagreement, you will view this “stay put” as favorable because your child’s program will remain the same. If, however, your disagreement is because your child is being denied a service, then the “stay put” rule may not be positive for your child. In all cases, it is important to think about the consequences of “stay put” in your decision about requesting a due process hearing.

*You might disagree with the proposed services or placement at the time your child is to transition to the preschool early intervention system. If you request a due process hearing, your child would remain in the current early intervention (birth to age 3) program, until the hearing is held and a decision is made.*

**DISCRIMINATION COMPLAINT** - Any agency open to the public must comply with the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act. Should you believe that you or your child has been discriminated against because of disability, you may file a complaint with the **Office for Civil Rights (OCR)**, U.S. Department of Education, Region III, Wanamaker Building, Suite 515, 100 Penn

**Square East, Philadelphia, PA 19107 (215-656-8541)(V)**. In a letter, explain the situation and talk about why you believe that your child was discriminated against. Include copies of documents (IFSP, letters, etc.) that might prove your point. Give your full name, address, phone/TTY number. If the complaint is about your child, also give your child’s name, date of birth and early intervention program. An investigation will take place and a report will be sent to you and MH/MR. The complaint must be filed within 180 days of the alleged violation.

### TRANSITION AT AGE THREE

At least 90 days and up to 6 months before your child turns three years old, you will be invited to a transition meeting. This meeting is held because **on your child’s third birthday, the responsibility for early intervention changes from the PA Department of Public Welfare to the PA Department of Education**. While this change does not necessarily mean a change in your child’s placement, it will mean more paper work. The meeting should have representatives from your MH/MR, the agency responsible for special education preschool programs in your area (MAWA agency) and parent(s). Your child’s progress should be reviewed, a determination made about whether a new evaluation is needed and a recommendation about what services your child will continue to need. **The result of this meeting should be an Individualized Education Program (IEP), developed by the date of your child’s third birthday.**

## GETTING READY FOR THE IFSP MEETING

- ✓ Make a list of the things you want to discuss.
- ✓ Bring records, notes that would be helpful.
- ✓ Know what is in your child's agency/school file. If not, ask to see it.
- ✓ Know that you may bring anyone with you to the meeting (friend, relative, advocate, private therapist, etc.) to be a support, provide information or to take notes.
- ✓ Do the goals and objectives/outcomes address every area of delay found in the evaluation and in the present levels of development section of the IFSP?
- ✓ If words such as "improve" and "increase" are used in the objectives, do you know what skills your child is starting with in that particular subject area (baseline)? For example, if your child's IFSP outcome states that your child will "increase his expressive vocabulary", do you know what number of words he/she presently uses?
- ✓ Review your past IFSP, circling objectives which have not been met. Should they remain on the IFSP? Should the methods of instruction or criteria be changed?
- ✓ Place a check beside outcomes that have been completed. Ask about the next step.
- ✓ Think of your child in various situations. What are your child's particular strengths and needs in these situations?
- ✓ Think of what is motivating for your child. Can this reinforcement be used in the program?
- ✓ What aids, accommodations, services, equipment are needed?
- ✓ How can home-program communication be achieved (e.g., phone calls, notes, progress reports, communication book)?
- ✓ What amount, place or type of service would be appropriate for your child based on your child's needs and your family's desires?

## GLOSSARY OF ABBREVIATIONS

- CER - Comprehensive Evaluation Report
- DPW - Department of Public Welfare
- IDEA - Individuals with Disabilities Education Act
- IFSP - Individualized Family Service Plan
- MAWA - Mutually Agreed Upon Written Arrangement
- MH/MR - Mental Health/Mental Retardation Agency
- MDE - Multidisciplinary Evaluation
- MDT - Multidisciplinary Team



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