

Family Orientation Manual

Family Mentorship Experience 2006-2007

Va-LEND Program

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Family Orientation

Va-LEND Family Mentorship Experience

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The Family Mentorship Experience is a program in which families like yours help train professionals who work with children with disabilities and their families. These professionals may be physical therapists, occupational therapists, speech therapists, pediatricians, nurses, psychologists, social workers, nutritionists, audiologists, special education teachers, or professionals in other related fields. The trainees chosen for this program are being prepared to be leaders in their fields.

The Family Mentorship Experience is a part of the Virginia Leadership Education in Neurodevelopmental Disabilities Program (Va-LEND), a program of the Partnership for People with Disabilities, which is affiliated with the VCU School of Education. The Va-LEND Program trains professionals to work in interdisciplinary, family-centered ways.

Each family will have a trainee assigned to them. Your job will be to show the trainee what it is like, in your own personal experience, to have a child with a disability or special health care needs. We hope that you will share your feelings and experiences, including the good times and bad times, so that they can see “the whole picture” of what it is like to be a family with a child with a disability. The trainee will always respect your family’s confidentiality and will not share information that may identify your family to others.

Objectives for Trainees:

Professionals who serve the families of children with disabilities generally do not get to see these families in “real life” settings, such as the home, playground, birthday party, grocery store, restaurant, and so on. The Family Mentorship Experience is your chance to show one professional (your trainee) the “bigger picture” of your family’s life, in order to help the trainee with the following objectives:

1. To be sensitive to how families live with a disability in order to consider the family and its routine when developing treatment plans for future families.
2. To appreciate family strengths and recognize the family as the expert in order to promote parent-professional partnerships.
3. To recognize the similarities to families who do not have a member with a disability in order to see families who have a member with a disability as part of the larger community.
4. To appreciate the variety in families.
5. To develop leadership in promoting systems change among professional colleagues regarding family-centered care.

Overview of Time Commitment

1. FME Picnic, Saturday, September 23, 2006 from 4:00-6:00 at Huguenot Park.
2. Five visits with your trainee during the school year (the picnic counts as one).
3. One phone conversation or email exchange monthly (initiated by your trainee).
4. A few phone calls from me (Elaine Ogburn) throughout the year.
5. Completion of evaluation form at end of year.

Details of the Family Mentorship Experience Commitment

1. Family Mentorship Picnic on Saturday, September 23, 2006 from 4:00 to 6:00 at Huguenot Park, Shelter #1.

This will be an opportunity for you to meet your trainee as well as other mentoring families and some of the Va-LEND faculty members. It will be an indoor picnic, with a short orientation for families (during which trainees will be with the children), and time for the children to play on the outdoor playground. Families and trainees alike have enjoyed this event in the past!

NOTE: Please bring your calendar or schedule book with you, so that you and your trainee can get a head-start on scheduling your next visit.

2. Five face-to-face visits during the school year, including the September 23 picnic.

If you or your trainee cannot come to the picnic, your trainee will contact you to schedule your first visit. Each visit can be a home visit or another activity that you think would help your trainee see what your family's life with a child with a disability is like. See page 4 for more ideas about the kinds of visits that will be good learning opportunities for your trainee.

NOTE: You or another adult must be with your child and the trainee at all times during these visits. Also, trainees are not permitted to do childcare or babysitting for mentoring families during the family mentorship experience year. Trainees are also prohibited from providing transportation for their mentoring families or others during the FME.

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3. One phone conversation or email exchange each month with your trainee.

The trainee needs to stay in touch with your family in-between visits, to keep up with what has been happening in your family since the last visit. (As you know, sometimes a lot can happen in a short period of time!). Your trainee will ask you about the best ways and times to contact you by phone and/or email.

It is the trainee's responsibility to initiate the contact with you. However, if your trainee emails you or phones and leaves a message for you, we ask that you please reply to the email or return the call as soon as you conveniently can. Your trainee should do the same for you.

Families in the past have found it helpful to look ahead at their schedules when the trainee contacts them each month, and suggest possible opportunities for the trainee's next visit.

4. Follow your trainee until the end of his/her program.

This group of trainees is scheduled to begin their Family Mentorship Experience in September 2006 and complete the FME in April 2007. We ask that you stay with the program until then if at all possible. If something unforeseen happens which makes it too difficult for your family to continue in the program, please let me know. If necessary, I will reassign your trainee to another family.

5. Please remember to show your trainee the whole picture of your family's life.

Please share with your trainee not only the joys and "up" times in your family's life, but also the "down" times and the struggles or uncertainties that you have faced in the past or may be facing presently. Sometimes families feel they need to keep their "happy face" on with the trainee – but that limits what the trainee can learn from you. It's extremely valuable for your trainee to see and experience with you the stressful times so that he or she can gain a better appreciation of what families sometimes go through. This will help your trainee be a more sensitive and caring professional when working with other families in the future!

Roles of Family and Trainee

- You are the expert in your own child. You have a wealth of experience as a family, and there is much that the trainee can learn from getting to know your family you that he or she may never have the chance to learn in the normal course of professional practice.
- In the Family Mentorship Experience, YOU are the teacher, or mentor.
- The trainees are the learners. They are not acting in their professional capacity as therapists, nurses, psychologists, etc. They are there to learn from YOU.
- Please do not ask your trainee for professional services such as therapy! However, you may feel free to ask your trainee for an informal opinion, resource leads, or other information related to the trainee's field of training and experience.

In Order To Best Educate Your Trainee, Please Take Some Time To Think About The Following Questions:

1. **What would you like a professional to know about your family and your family's life? Be as specific as you can.** Depending on your child's age and disability, you may want to cover during the year such topics as:
 - when and how you found out about your child's disability
 - what services you have used or are using now for your child
 - scheduling and coordinating of medical care, therapies, child care, etc.
 - ways that you have found professionals to be helpful and not so helpful
 - the joys and challenges of everyday life
 - the frustrations and challenges of everyday life
 - ways that having a child with a disability has affected:
 - relationships within the family and with friends and beyond
 - your other children, if you have others
 - how you use your time; your money; your energy
 - your ability to plan ahead
 - your leisure time
 - your ability, or your need, to work
 - your feelings about the future
 - where you draw your own strength for being strong for your child
 - whatever else you would like this trainee to learn from you and your family.

2. **What do you want your trainee to experience or see with you?**
 - If meals are an adventure, invite your trainee to join you and your family for one.
 - If your child's morning or evening routine is always a challenge for your family, invite your trainee to spend that stretch of time with you one day (for example, supertime/bathtime/bedtime).
 - We encourage our trainees to attend an ISFP or IEP meeting with their mentoring family if possible.
 - Other suggestions might include opportunities such as:
 - observing your child in school
 - attending a therapy or other medical session
 - playing with your child and other children on the playground
 - watching your child in a recreation class or on a sports team
 - attending your child's birthday party
 - going with your family to your house of worship
 - shopping for groceries or holiday gifts
 - going to McDonald's or Chuck E. Cheese.

These are just examples. Consider what would most help YOUR trainee get to know YOUR family.

Checklist for First Visit or Call

- **Exchange home phone numbers and any alternative contacts if appropriate** (work number? cell phone? pager? e-mail?). Find out the best ways to reach each other.
- **Share good and bad times to call.** For example, “Do not call between 7:00 & 8:15 because that is when I am trying to get Katherine in bed and it is a complicated process.”
- **Negotiate timing and frequency of contacts.** We require 5 visits during the school year and a monthly phone conversation or email exchange. You are welcome to have additional contacts with your trainee if you both so desire. Your trainee is not, however, permitted to baby-sit or provide childcare for your family during the period of the family mentorship experience.
- **Share any “household rules” that your trainee needs to know about in your home.** For example, “Be careful when you come in because Johnny likes to slip out the door and run away from the house, and he may run into the street!”
- **Discuss parking and safety issues, if appropriate.** For example, “Do not park in numbered parking spaces because they are for the apartment residents only.”
- **First home visit:** Introduce your trainee to everyone in your family, if possible. If you are a two-parent family, it is important that both parents be involved in the family mentorship experience with your trainee to the extent possible. For the first home visit, you may want to talk with your trainee alone to give some family history and details of your child’s disability and related issues, and then have the trainee spend some time with your child(ren). The trainee should be sensitive to the importance of not discussing such things as diagnostic labels, adoption, and so on in front of your child(ren).
- **Set the date, time, and place of your next visit. Write it on your calendar!** It may also be very helpful to go ahead and plan the remaining visits in general terms – for example, attend child’s IEP meeting, come to child’s birthday party, go to pumpkin patch in October, visit when grandparents are in town, etc.
- **Now you’re on your way with the Family Mentorship Experience!**

Confidentiality:

It is important for you to be very open with the trainee so he or she can truly see what it is like to have a child with a disability. Trainees have been instructed to always maintain your confidentiality so that you can be comfortable sharing your life with them. They will be writing in a journal and sharing some of their insights and experiences with the other trainees and faculty in the Va-LEND Program. They are required to write and speak in a respectful manner which protects your confidentiality, and they are never to discuss their mentoring family in a public place or with people who are not in the Va-LEND program.

In speaking or writing about their experiences with their mentoring families, trainees are to use the first name only of children, and only initials or words such as “Mom,” “Dad,” or “Grandma” for adults. They may not give any information such as your place of employment or the name of your child’s school.

Even though many of our families and trainees will all meet each other at the September picnic, after that event our trainees will follow the above guidelines for confidentiality in writing or talking about their mentoring families at all times.

Evaluation

Trainees receive grade points for this experience. We evaluate the success of the program using:

- Journal kept by trainee with observations and reflections on the family mentorship experience. This is a private journal kept by the trainee for his or her own growth as a professional. The journal is read only by the trainee’s faculty advisor and myself for the purpose of giving the trainee feedback on his or her use of the Family Mentorship Experience opportunity.
- Web-based and in-person discussion among trainees and faculty regarding trainees’ experiences in the family mentorship experience (observing full confidentiality regarding families). These are opportunities for our trainees to learn from one another and thus have exposure to the life experiences of families beyond their own mentoring family.
- Occasional phone calls to families from myself, Elaine Ogburn, Family Mentorship faculty member.
- Evaluation of the program by families at the end of the year, via a questionnaire
- Evaluation of the program by trainees at the end of the year

Ongoing Support:

- My name is Elaine Ogburn, and my official title is Family Specialist with the Va-LEND Program. I am also the proud parent of a wonderful daughter who has a disability. My responsibility is to make sure the Family Mentorship Experience goes smoothly for all of our families and trainees. I will call you periodically to ask how the experience is going for your family, and you are always welcome to call or email me if you have questions or concerns at any time during the year. I will be calling you in early October, once you and your trainee have met one another, to learn your first impressions of the trainee and of the Family Mentorship Experience.
- My home phone number is (804) 320-4514. I work mostly out of my home, so that is the best place to reach me. I also have e-mail: esogburn@vcu.edu. Feel free to contact me either way! My work with Va-LEND is part-part-time, and my usual work day is Tuesday. However, I am here to help the Family Mentorship Experience go smoothly for all families and all trainees, so do not hesitate to contact me at any time.
- I will occasionally email you with information on resources, trainings, and advocacy opportunities for families of children with disabilities, if you would like to receive such information.
- I look forward to working with you this year, and all of us in the Va-LEND Program hope that you will find the Family Mentorship Experience an interesting and rewarding experience for you and your family. Thank you for volunteering for this program and helping to build better, more family-centered systems for health-care and education for our children!

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