

~ You are invited ~

*Va-LEND is planting the seeds for
increasing family involvement in all of our activities.*

*We would like you to join us
for conversation and lunch on*

***Saturday, May 16,
from 10 am to 3 pm***

*at Lewis Ginter Botanical Garden
Kelly Education Center- Azalea Room
1800 Lakeside Avenue
Richmond, VA 23228*

*A stipend for childcare (\$160) will be
provided to the first 20 family
members who register.*

*Before and after the meeting, there
will be free access for you to enjoy
the gardens.*

*Please **RSVP** by Friday, May 1, to
Tracye Woodfin at 804-828-0073 or twoodfin@vcu.edu.*



Planting the Seeds for Increasing Family Involvement in Va-LEND

May 16, 2015

AGENDA FOR A DAY OF GARDENING

- 10:00** **Welcome and Introductions** (Beth Bader)
- 10:15** **Designing the Garden** (Tracy White)
- An overview of Va-LEND and its activities
- 10:45** **Preparing the Soil** (Tracy White, Shannon Hayworth, Monique Tinsley)
- Finding your voice in Va-LEND - how other family members have used what they have learned through Va-LEND activities
- 11:30** **Planting the Seeds** (Elaine Ogburn, Mauretta Copeland, Shannon Haworth)
- Current opportunities for family members within Va-LEND and the wider “world” of LEND
- 12 Noon** **Lunch** - and a stroll in the Garden
- 1:00** **Pulling the Weeds**
- Exploring issues and barriers that affect participation (Table Talk)
- Group 1 - facilitated by Tracy and Monique
Group 2 - facilitated by Shannon
Group 3 - facilitated by Elaine
Group 4 - facilitated by Mauretta
- 1:45** **Fertilizing the Plants**
- Coming up with possible solutions to the barriers (Table Talk)
- 2:30** **Break**
- 2:45** **Harvesting What We Have Sown** (Beth and *The Seed Team*)
- Overview of day's discussions
 - Using your voice with Va-LEND
 - Evaluation
- 3:00** **Adjourn**
- Go and enjoy Lewis Ginter Gardens until closing at 5:00 pm

*Virginia Leadership Education
in Neurodevelopmental
Disabilities
(Va-LEND)*



Partnership for People
with Disabilities

Linking people. Changing lives.



VCU

VIRGINIA COMMONWEALTH UNIVERSITY

Make it real.

wp.vcu.edu/virginialend



The purpose of the
Va-LEND Program is
to prepare the next
generation of leaders
in the field of
childhood
neurodevelopmental
disabilities.

The program provides a 12-24
month curriculum of:

- academic courses,
- leadership and research data seminars,
- clinical- and community-based experience,
- a family mentorship experience,
- and planned grassroots- and systems-level policy activities.

The curriculum emphasizes all
aspects of neurodevelopmental
and related disabilities, the social
and family environments, the
interdisciplinary approach,
leadership, and research.

Va-LEND is funded by a grant from the Maternal and Child Health Bureau to provide an interdisciplinary education program that prepares health professionals for leadership and advocacy roles.

The program was developed in collaboration with VCU Department of Pediatrics and the Title V Program, Virginia Department of Health. Va-LEND is part of the Partnership for People with Disabilities at VCU.

This program targets a high-risk population of children and their families and addresses priority issues of reducing health disparities, providing access to care, and delivering quality care through advanced level training.

Lend Themes

Leadership

Interdisciplinary

Teamwork

Lifecourse

Interdisciplinary Practice

Working on Teams

Learning new perspectives.

*Experiencing how assessments are
conducted.*

Collaborating to solve problems.

Expanding your network.

What is MCHB?

Maternal & Child Health Bureau

Under DHHS, HRSA

Primary Funding, Title V Programs

Important Legislation: **Autism CARES**--
Collaboration, Accountability, Research,
Education and Support Act



MCHB targets women, children, and families

Emphasis on low income and
isolated populations.

Children with special health care needs
including developmental disabilities.

**There are 43 LEND
programs in the United
States.**

Specific LEND Activities:

Coursework:

Teamwork

Leadership Seminars

Childhood Neurodevelopmental
Disabilities

Data Workshops

Family Mentorship

Clinics

Va-LEND is seeking to increase family involvement in all aspects of our program.

Help us brainstorm today on how to best accomplish this.

May 16, 2015

Make it real.

Current Family Involvement Possibilities within Va-LEND

◆ Be a LEND Trainee

- ◆ Family Discipline trainee; or
- ◆ Professional trainee who has a family member with a developmental disability -- We need to find ways to recognize professional trainees who have family members with DD and find ways for them to share their family discipline expertise within the LEND curriculum.


◆ Be a Mentoring Family

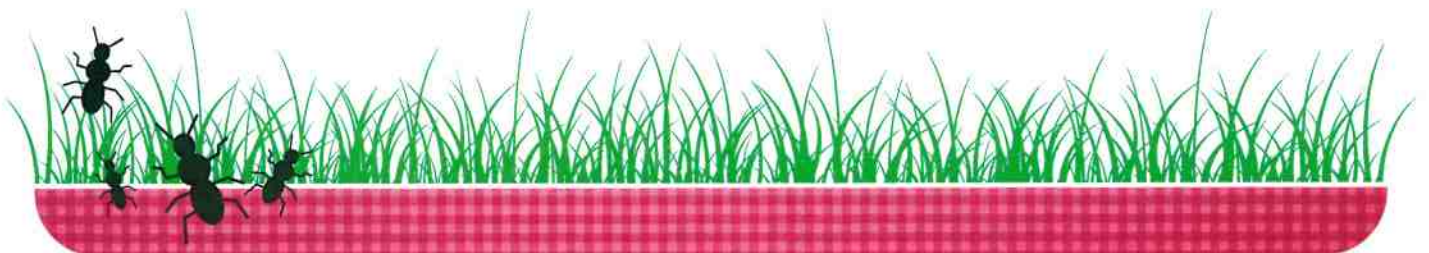
- ◆ Usually this is a family, but we have had one self-advocate serve as a trainee's mentor for a year, very successful for all involved.
- ◆ Host winter FME potluck (home must be fully accessible)

• Participate in Presentations to

- Sibling Panel
- Leadership Seminar
 - Family Leadership
 - Self-Advocates
- Childhood Neurodevelopmental Disabilities Class Sessions
- Teamwork Class
- Research Seminar



- 
- Present to classes outside of LEND with LEND faculty presenters
 - Participate in Va-LEND clinics specifically to share specific experience/expertise as a family member
 - Participate in the Disability Policy Seminar in Washington, DC as part of Va-LEND contingent
 - Participate in Va-LEND site reviews
 - Serve on committees to:
 - Review trainee applications
 - Revise Va-LEND curriculum
 - Review drafts of family discipline publications in which Va-LEND faculty are co-authors
 - Apply for grant funds
 - Plan for use of funds once granted
 - Plan for inclusion of self-advocates as trainees
 - Participate in Va-LEND Book Adventure
 - Attend Va-LEND poster fair
 - Participate in trainee research studies



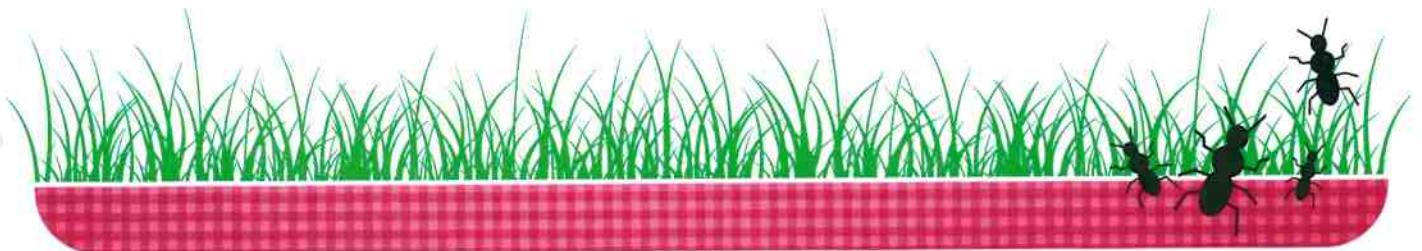
Publicity for LEND

- ◆ Awareness of LEND (and UCEDDs) outside of each specific network and immediate geographic area is typically low among parents and providers alike. The partnership that exists in VA between the Family 2 Family organization, Partnership, and Va-LEND is fairly atypical across the US, but is one of its biggest assets in VA. It would be wonderful to nourish this relationship to help LEND reach beyond the Richmond area alone. This would go a long way to enhancing the diversity of trainees (parents and other disciplines), as well as the awareness of providers regarding the LEND network.

"Leadership (can be) as simple as educating or energizing those around you, one person at a time." Dennis LaMountain

Other Opportunities:

- ◆ Help recruit new trainees and build awareness of LEND throughout the state: Share with your service providers about what LEND is, how LEND has impacted your family's life, and how LEND graduates contribute to interdisciplinary, family-centered care throughout Virginia and beyond (Va-LEND can provide bullet points for your short "elevator speech").



Discussion Points for Pulling the Weeds Session

Previously, Va-LEND sent out a survey to a number of Family Mentors seeking their input into barriers and issues that could have an impact on their participation as trainees, guest speakers, and family mentors. Using this information as a basis for discussion, we want each group to further tease out reasons that prevent family members participating in Va-LEND activities. Each of the 4 groups will discuss the following questions. The facilitator will ask someone to write down each issue discussed and a short summary on same color post-it notes, but identifying the issue/barrier by the number below. The post-it notes will then be placed on the group's wall paper under ISSUES, grouping same numbers together.

- 1) The number one issue/barrier that was identified in the survey was **TIME COMMITMENT**, but we need more information as to what this means. For example, is it the time that classes take place in the afternoon?, the length and number of courses for trainees?, the time it takes to get to campus, park and return home in addition to the activity?, family life is so hectic that adding one more commitment is impossible?, or
- 2) It's a given that **CHILDCARE** is a barrier/issue, but what about obtaining care for your children and adults would make it difficult to participate in Va-LEND activities?
- 3) Another issue identified was **FINANCIAL**. Even though as a trainee, all tuition costs are covered and there is a stipend to cover books, why is being a trainee a financial strain? When asked to participate in a Va-LEND activity, are there costs that play a part in your being able to participate?
- 4) If Va-LEND training is opened to individuals who do not hold **UNDERGRADUATE DEGREES**, do you believe that family members would apply to become trainees?
- 5) Do you think that family members feel a degree of **INTIMIDATION** in taking courses with trainees who are professionals (or soon to be professionals)? What about speaking in front of classes of professionals?
- 6) What **OTHER ISSUES/BARRIERS** can you identify?

Discussion Points for Fertilizing the Plants Session

- Take a look at the barriers that your group identified, or what other groups have identified.
- Prioritize your top barriers from among those discussed in the WEEDING session:
 1. **TIME COMMITMENT**
 2. **CHILDCARE**
 3. **FINANCIAL**
 4. **UNDERGRADUATE DEGREE**
 4. **INTIMIDATION**
 5. **OTHER**
- Everyone spend a few minutes alone writing down possible solutions to the first barrier that was chosen and jot them down on the notepad. Then repeat this for the second and third priority barriers. The table facilitator will keep track of the barriers that have been chosen.
- For the first barrier, everyone at the table identify one possible solution and put it on a post-it note. If someone has named something that you have thought of, you can pass. Then continue going around the room, with each person identifying another solution, until all possible solutions have been identified and post-it notes made for that barrier.
- Participants at the table can discuss the solutions after everyone has had a chance to present all of their possibilities. Choose the solutions with which there seems to be most agreement and put a star on that post-it note.
- All post-it notes are then put on the wall sheet under SOLUTIONS, grouping them together on the sheet. When putting all of the post-it notes on the wall sheet, write down the number and name of the barrier close to each group of post-it notes.
- Do the same process with the second barrier.
- And then the third.
- If you have time, do the process with the other barriers.