

Participant's Name:

Date:

LINKING HANDS PROGRAM

Before we begin your orientation for the Linking Hands Project, we would like you to take a few minutes to answer some questions. We are interested in any previous experience you may have had with a disability awareness program, whether in a medical school, college, or even in your earlier education. These questions are followed by a pre-assessment.

Have you ever participated in a disabilities awareness program before?

Yes _____ No _____

If yes:

Did that program include a home visit? Yes _____ No _____

Please explain the nature of the disability awareness program, what year were you involved and where was it held.

Looking back at the program, what did you gain from it?

PRE-ASSESSMENT

Following are a series of statements which address the topic of working with children who have special health care needs and their families. For each statement please circle the number which indicates the degree to which you agree, from 1 for "Totally Disagree" to 5 for "Agree Strongly".

	Totally Disagree					Agree Strongly
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	
1. Parents of children with special health care needs are generally unhappy.	1	2	3	4	5	
2. It is very important to help children who use medical technology to get the support they need to stay in a regular classroom.	1	2	3	4	5	
3. As a professional, it is frustrating to work with a child with a disability.	1	2	3	4	5	
4. Families which include children with special health care needs are able to have a satisfying, enjoyable and rewarding family life.	1	2	3	4	5	
5. Parents of children with special health care needs tend to be angry at the health care system and health care providers.	1	2	3	4	5	
6. For professionals it is rewarding to work with families who have children with chronic illness or disabilities.	1	2	3	4	5	
7. Including children with disabilities and/or chronic illness in regular classrooms doesn't really work.	1	2	3	4	5	
8. Parents of children with special health care needs are no more demanding than any other parents.	1	2	3	4	5	
9. As a professional, it is difficult to bond with a child who is low functioning.	1	2	3	4	5	

In thinking about your home visit to a family with a child with special health care needs, there are a number of possible benefits you might expect to receive. We have listed these below. We would like you to indicate how important each one of these objectives is to **you** using a scale of 1 to 5 where 1 means "Not at All Important" and 5 means "Very Important."

	Not at All Important		Very Important		
	1	2	3	4	5
1. Seeing the child out of the clinical setting.	1	2	3	4	5
2. An opportunity to ask questions of families with children with special health care needs.	1	2	3	4	5
3. Insight into issues of access to medical services.	1	2	3	4	5
4. Improved recognition of home health management issues.	1	2	3	4	5
5. Practical emphasis on/understanding of special needs/disabilities.	1	2	3	4	5
6. Observing child as part of the family unit in their regular routine.	1	2	3	4	5
7. Opportunity to experience and learn from the parents as teachers.	1	2	3	4	5
8. Opportunity to <i>interact</i> with the family unit.	1	2	3	4	5
9. To experience the positive environment families create for their child and the rest of the family.	1	2	3	4	5
10. To become familiar with resources and programs helpful to families.	1	2	3	4	5
11. Recognition of parents as those with most knowledge of their child.	1	2	3	4	5
12. Opportunity to examine personal beliefs and ideas about families with children with special health care needs.	1	2	3	4	5
13. Re-thinking the importance of communication skills and approaches when talking to families.	1	2	3	4	5

LINKING HANDS PROJECT

GUIDELINES FOR PARTICIPANTS

- Families participating in the Linking Hands Project have received an orientation to prepare them for a visit. In this orientation, they learned the goals of the program and reviewed suggested activities for the visit.
- Prior to their visit, Linking Hands participants will receive an email which will include the name, address and phone number of the family they will be visiting. They will also receive a very brief diagnosis of the child as provided by the parents, as well as directions on how to reach the family's home. Families are very generous to share their time so we expect scheduled visits to occur accordingly.
- Arrangements have already been made with the family for the date and time of the visit. Families understand that participants have very full schedules and that there is virtually no flexibility with this designated home visit time. However, it is also very important that you respect the family's schedule by being on time for your visit.
- Participants should contact the family to confirm the home visit as soon as possible. **Be sure to give the family a way to reach you.** A cell phone number is recommended in case an emergency arises. If you are unable to attend your visit for some reason, you should notify Angela Lombardo, Linking Hands Coordinator, 617-355-6369 pager #1795 ASAP.
- Families know the visit is to last for two hours and this is what they are planning for. On the day of the visit, if both you and the family are comfortable with extending the length of the visit, that is fine. However, participants and families are expected to spend a full two hours.
- Linking Hands participants are not to evaluate or assess the family or to provide any professional services. Their visits are solely for the purpose of learning from the family about their life experiences and issues related to parenting a child with special needs. We ask that during your visit, you are mindful of using People First Language while talking about the child and their special needs.
- After your visit with the family, we suggest you take the time to write a brief thank you note. The success of this program is based in large part on the generosity and commitment of the participating families. Please take the time to let them know how much you appreciated their sharing their family with you.

LINKING HANDS PROGRAM
LEND TRAINEE INFORMATION SHEET

Please answer the questions below so we can coordinate your home visit appropriately!

Name: _____

Email Address: _____

Phone Number: _____

Best way to reach you in an emergency!

How will you get to this visit?

Only by car? _____ Only by T? _____ Can do car or T _____

List some dates/times you are available to do a home visit. Please note that most children are in school so afternoon times would be best.

Date (2/15, 2/20)	Day of Week (all Mondays)	Time Frames (3-5)

Are there any concerns you have regarding this visit?

Please fill out this sheet and return to Angela Lombardo's mailbox at 1295 Boylston no later than February 1st. Feel free to email Angela Lombardo with any questions!
angela.lombardo@childrens.harvard.edu

Linking Hands Reflection Paper

Respond to the questions below based on the two goals or objectives chosen.

1. List your goals or objectives for your Linking Hands home visit
2. Briefly describe your visit
3. Who or what made an impression on you and why?
4. What lessons did you take away from the family home visit?
5. Identify one or two resources (i.e. website, article, book, or resource) that relates on some way to any of the following: family home visits, parent support, family centered care, the parent experience, parent professional collaborations, cultural competence, or sibling issues.

Reflection Papers will be collected at the follow up meeting that will be held in November. Exact date will be provided to you shortly!

LEND – LINKING HANDS

Outcomes

Family Mentorship provides an opportunity for trainees to learn:

- All families have strengths
- A family is the sum of all of its members, including those in the extended family
- Families are diverse: each family is different and no two children with the same type of disabilities is alike
- Children and youth with disabilities and their families live most of their lives on their own turf in their home and community, outside of clinical settings
- Families generally want to collaborate and partner with health care professionals
- Family participation is a contribution from the families that better prepares trainees to work with families post-LEND
- Family centered care is built upon family-professional collaboration

Family Mentorship provides the opportunity for families to do the following:

- Gain personal satisfaction by contributing their expertise to the education and preparation of future service providers
- Tell their story in a learning environment outside of a clinical setting
- Demonstrate that services or recommendations that may appear critically important from a professional perspective can decrease in importance when viewed within the context of the family's daily routine
- State their choices and priorities in a safe environment and be listened to
- Build collaborative partnerships with future professionals

(Adapted from #6 NM)

Promising Practices in Family Mentorship,
A Guidebook for MCHB-LEND Training Programs

To ensure INCLUSION, FREEDOM, AND RESPECT

for all, we must use

PEOPLE FIRST LANGUAGE

by Kathie Snow

WHO ARE THE SO-CALLED “HANDICAPPED” OR “DISABLED”?

According to stereotypical perceptions, they are:

- People who *suffer* from the *tragedy of birth defects*.
- *Paraplegic heroes* who *struggle* to become *normal* again.
- *Victims* who *fight* to *overcome* their *challenges*.

Categorically, they are called *retarded, autistic, blind, deaf, learning disabled, etc., etc., etc.—ad nauseum!*

WHO ARE THEY, REALLY?

Moms and Dads • Sons and Daughters
Employees and Employers • Friends and Neighbors
Students and Teachers • Leaders and Followers
Scientists, Doctors, Actors, Presidents, and More
They are people. *They are people, first.*

People with disabilities constitute our nation's largest minority group (one of five Americans has a disability). It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, ethnicities, and socioeconomic levels are represented. Yet people who have been diagnosed with disabilities are all different from one another. The only thing they have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person can join at any time!* You can join at birth or later, through an accident, illness, or the aging process. If and when it happens to *you*, will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described? And how will you want to be treated?

—THE POWER OF LANGUAGE AND LABELS—

Words are powerful. Old, inaccurate descriptors, along with the inappropriate use of medical diagnoses, perpetuate negative stereotypes and reinforce an

incredibly powerful attitudinal barrier. *And this invisible, but potent, attitudinal barrier—not the diagnosis itself—is the greatest obstacle facing individuals with disabilities.* When we make the diagnosis the most important thing about a person, we devalue and disrespect him/her as an individual. Do *you* want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Sadly, disability diagnoses may be used to define a person's value and potential, and low expectations and a dismal future are often the predicted norm. Once we know a person's diagnosis, we (mistakenly) think *we know something important about him*, and this information is then used to decide how/where the person will be educated, what type of job he will/won't have, where/how he'll live, and more, including what “services” he needs. And those “special” services frequently result in the social isolation and physical segregation of millions of children and adults in special ed classrooms, congregate living quarters, day programs, sheltered work environments, special (segregated) recreational activities, and more. (Are other people isolated, segregated, and devalued because of *their* diagnoses?) With the diagnosis in hand, we work on people's bodies and brains, while paying scant attention to their hearts and minds. Far too often, the misuse of a diagnosis can lead to harm, instead of help—and can ruin people's lives.

*The difference between the right word
and the almost right word is the
difference between lightning
and the lightning bug.*

Mark Twain

—INACCURATE DESCRIPTORS—

“Handicapped” is an archaic term (it's no longer used in any federal legislation) that evokes negative images of pity, fear, and more. The origin of the word is from an Old English bartering game, in which the loser was left with his “hand in his cap” and was thought to be at a disadvantage. A *legendary* origin of the “H-word” refers to a person with a disability begging with his “cap in his hand.” This antiquated, derogatory term perpetuates the stereotypical perception that people with disabilities make up one homogenous group of

pitiful, needy people! Other people who share a certain characteristic are not all alike; similarly, individuals who happen to have disabilities are not alike. *In fact, people with disabilities are more like people without disabilities than different!*

"Handicapped" is often used to describe modified parking spaces, hotel rooms, restrooms, etc. But these usually provide *access* for people with physical or mobility needs—and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the inaccuracy and misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is "accessible.")

"Disabled" is also not appropriate. Traffic reporters frequently say, "disabled vehicle." They once said, "stalled car." Sports reporters say, "the disabled list." They once said, "injured reserve." Other uses of this word today mean "broken/non-functioning." *People with disabilities are not broken!*

If a new toaster doesn't work, we say it's "defective" or "damaged" and return it. Shall we return babies with "birth defects" or adults with "brain damage"? The accurate and respectful descriptors are "congenital disability" or "brain injury."

Many parents say, "I have a child with special needs." This term generates *pity*, as demonstrated by the usual response: "Oh, I'm *so sorry*," accompanied by a sad look or a sympathetic pat on the arm. (*Gag!*) A person's needs aren't "special" to him—they're ordinary! *I've never met an adult with a disability who wanted to be called "special."* Let's learn from those with real experience, and *stop inflicting this pity-laden descriptor on others.*

"Suffers from," "afflicted with," "victim of," and similar descriptors are inaccurate, inappropriate, and archaic. A person simply "has" a condition, period!

WHAT IS A DISABILITY?

Is there a universally-accepted definition of disability? No! First and foremost, a disability descriptor is a medical diagnosis, which becomes a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs, depending on which service system is accessed. The "disability criteria" for early intervention is different from early childhood, which is different from vocational-rehabilitation, which is different from special education, which is different from worker's compensation, and so on. Thus, "disability" is a *social construct*, created to identify those who may be entitled to services or legal protections because of *certain characteristics* related to a medical diagnosis.

—DISABILITY IS NOT THE "PROBLEM"—

Because society tends to view disability as a "problem," this seems to be the #1 word used about people with disabilities. People *without* disabilities, however, don't spend a lot of time talking about *their* problems. They know this would promote an inaccurate perception of themselves, and it would also be counter-productive to creating a positive image. A person who wears glasses, for example, doesn't say, "I have a *problem* seeing." She says, "I wear [or need] glasses."

What is routinely called a "problem" actually reflects a *need*. Thus, Susan doesn't "have a problem walking," she "needs/uses a wheelchair." Ryan doesn't "have behavior problems," he "needs behavior supports." *Do you want to be known by your "problems" or by the multitude of positive characteristics which make you the unique individual you are?* When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there's the "something wrong" descriptor, as in, "We knew there was *something wrong* when..." What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what's "wrong" with you? Let's stop using this word about people!

THE REAL PROBLEMS ARE ATTITUDINAL AND ENVIRONMENTAL BARRIERS!

A change in attitude can change everything. If educators believed children with disabilities are boys and girls with the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have millions of children being *segregated and undereducated* in special ed classrooms.

If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn't have an estimated (*and shameful*) 75 percent unemployment rate of people with disabilities. If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as "customers," instead of "clients/consumers/recipients," perhaps it would begin to meet a person's *real* needs (like inclusion, friendships, etc.) instead of trying to remediate his "problems."

**If thought corrupts language,
language can also corrupt thought.**

George Orwell

And if individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of society, we might focus on what's really important: living a *Real Life in the Real World*, enjoying ordinary opportunities and experiences and dreaming big dreams (like people without disabilities), instead of living a *Special Life in Disability World*, where low expectations, isolation, segregation, poverty, and hopelessness are the norm.

—A NEW PARADIGM—

"DISABILITY IS A NATURAL PART OF THE HUMAN EXPERIENCE..."

U.S. Developmental Disabilities/Bill of Rights Act

Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. Are *you* defined by your gender, ethnicity, religion, age, sexual orientation, or other trait? No! So how can we define others by a characteristic which is called a "disability"?

Yes, *disability is natural*, and it can be *redefined* as "a body part that works differently." A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. Yet the body parts of people *without* disabilities are also different. It's the *way* these differences affect a person (or how a person is *perceived*) which creates the eligibility for services, entitlements, or legal protections.

In addition, a disability is often a *consequence of the environment*. Why are many children not diagnosed until they enter public school? Is it because physicians are ignorant or parents are "in denial"? Or is it because as toddlers, they were in environments which supported the way they learned? Then in public school, if a child's learning style doesn't mesh with an educator's teaching style, he's said to have a "disability." Why do we blame the child, label him, and segregate him in a special ed classroom? Why don't we modify the regular curriculum (per special ed law) to meet his learning needs?

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? No! *Disability is not a constant state*. The *diagnosis* may be constant, but whether the condition represents a "disability" is more a *consequence of the environment* than what a person's body or mind can/cannot do. We don't need to change people with disabilities through therapies or interventions. We need to change the *environment*, by providing assistive technology devices, supports, and accommodations to ensure a person's success!

USING PEOPLE FIRST LANGUAGE IS CRUCIAL!

People First Language puts the person before the disability, and describes what a person *has*, not who a person *is*.

Are you "myopic" or do you wear glasses?
Are you "cancerous" or do you have cancer?
Is a person "handicapped/disabled"
or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that sets them apart and devalues them.

Boys and girls with disabilities are *children, first*. The only labels they need are their names! Parents must not talk about their children using the medical terms used by professionals. Educators must not use terms like "sped kids," "LD students," "inclusion students," or other stigmatizing descriptors. Children in school are *students* and some *receive special ed services*.

Men and women with disabilities are *adults, first*. The only labels they need are their names! They must not talk about themselves using professional lingo. Service providers must not use terms like "MR client," "quads," and other diagnostic terms.

The use of disability descriptors is appropriate *only* in the service system (at those ubiquitous "I" team meetings) and in medical or legal settings. Medical diagnoses have no place—and they should be irrelevant—within families, among friends, and in the community.

We often use a diagnosis to convey information, as when a parent says, "My child has Down syndrome," hoping others will realize her child needs certain accommodations or supports. But the outcome of sharing the diagnosis can be less than desirable! A diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that...*"). In these circumstances, *and when it's appropriate*, we can simply describe the person's *needs* in a respectful, dignified manner, and *omit the diagnosis*.

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And too many of us talk about people with disabilities *in front of them, as if they're not there*. We must stop this demeaning practice!

The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

William James

My son, Benjamin, is 19 years old. His interests, strengths, and dreams are more important than his diagnosis! He loves politics, burned fish sticks, classic rock, and movies—and he's great at mimicking actors and politicians! He's earned two karate belts, performed in children's theater productions, and recently won a national award for his *Thumbs Down to Pity* film. Benj is attending college and wants to be a film critic. He has blonde hair, blue eyes, cerebral palsy, and a service dog, Riley. His diagnosis is just one of many characteristics of his whole persona. *He is not his disability, and his potential cannot be predicted by his diagnosis.*

When I meet new people, I don't disclose that I'll never be a prima ballerina. I focus on my strengths, not on what I cannot do. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple, *but vitally important*, matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want him to know what a great young man he is*—I must use positive and accurate descriptors that portray him as a valuable, respected, and wonderful person, instead of as a collection of "deficits," "problems," or "challenges."

A person's self-image is strongly tied to the words used to describe her. For generations, people with

disabilities have been described by negative, stereotypical words which have created harmful, mythical perceptions. We must stop believing (and perpetuating) the myths—the *lies*—of labels. We must believe children and adults who have been diagnosed with conditions called "disabilities" are unique individuals with unlimited potential, like everyone else!

The Civil Rights and Women's Movements prompted changes in language and attitudes. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, "We are *not* our disabilities." It's not about "political correctness," but good manners and respect. Some reject People First Language, saying it's unimportant; others say they *prefer* descriptors like "special needs." But the feelings and preferences of people *without* disabilities are irrelevant. What *is* relevant? The *feelings* of the people we're talking *about* and the *perceptions* of them which we create with our words!

We can create a new paradigm of disability. In the process, we'll change ourselves and our world—as well as the lives of millions of children and adults.

Isn't it time to make this change?

If not now, when? If not you, who?

People First Language is right.

Just do it—NOW!

EXAMPLES OF PEOPLE FIRST LANGUAGE

SAY:	INSTEAD OF:
People with disabilities	The handicapped or disabled.
Paul has a cognitive disability (diagnosis).	He's mentally retarded.
Kate has autism (or a diagnosis of...)	She's autistic.
Ryan has Down syndrome (or a diagnosis of...)	He's Down's; a Down's person; mongoloid.
Sara has a learning disability (diagnosis).	She's learning disabled.
Bob has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
Mary is of short stature/Mary's a little person.	She's a dwarf/midget.
Tom has a mental health condition	He's emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair	She's confined to/is wheelchair bound.
Steve receives special ed services	He's in special ed; he's a sped student.
Tonya has a developmental delay	She's developmentally delayed.
Children without disabilities	Normal/healthy/typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer.	Client, consumer, recipient, etc.
Congenital disability	Birth defect.
Brain injury	Brain damaged.
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses	She has a problem with. . . /She has special needs.

Keep thinking—there are many other descriptors we need to change!

You may copy & share this 4-page document as a handout; please tell me how/when you use it (kathie@disabilityisnatural.com).

Do not violate copyright law: *request permission before reprinting in any publication newsletter, web site, list serve, etc.*