

Summary Report 2012 Family Leadership Training Survey

Family Members: N=25
DB Project Staff: N=8

DEMOGRAPHICS OF SURVEY PARTICIPANTS

HOW MANY FAMILY LEADERS HAVE BEEN TRAINED IN YOUR STATE?

Total in 8 states: 266 family leaders trained

CHECK ALL DEMOGRAPHICS THAT PERTAIN TO YOUR FAMILY LEADERSHIP PARTICIPANTS.

The majority of the family leadership training participants were mothers from two parent households.

<u>Type of Participants</u>	<u>% of Projects Reporting Participants in this Category</u>
Two parent households	100% of projects
Mothers	100%
Single parents	87.5% of projects
Non-English speaking, primary language:	63% Spanish
Fathers	75%
Grandparents	50%
Foster Parents	50%
Brothers/sisters	25%
Aunts/Uncles	12.5%

WHAT GEOGRAPHIC SETTING BEST DESCRIBES WHERE YOU LIVE?

The participants were fairly evenly spread across geographic settings. The majority (40%) were from suburban areas close to a city of 50,000 or more.

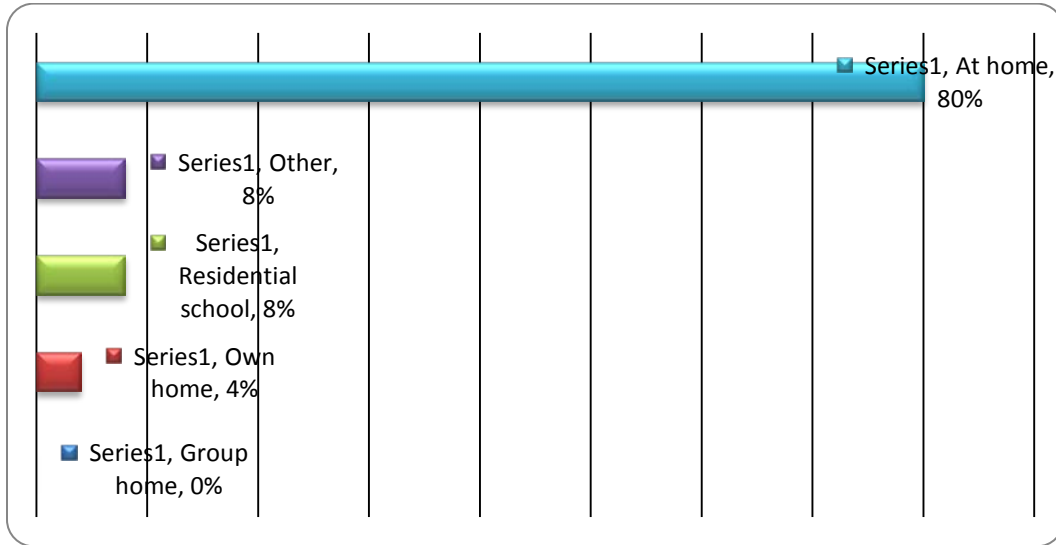
Suburban area (on the outskirts of a city of 50,000 or more)	40%
Urban area (within a city of 50,000 or more)	32%
Rural area	28%

HOW OLD IS YOUR CHILD WHO IS DEAF-BLIND?

Age range: 4 – 31
Average age: 14 years old

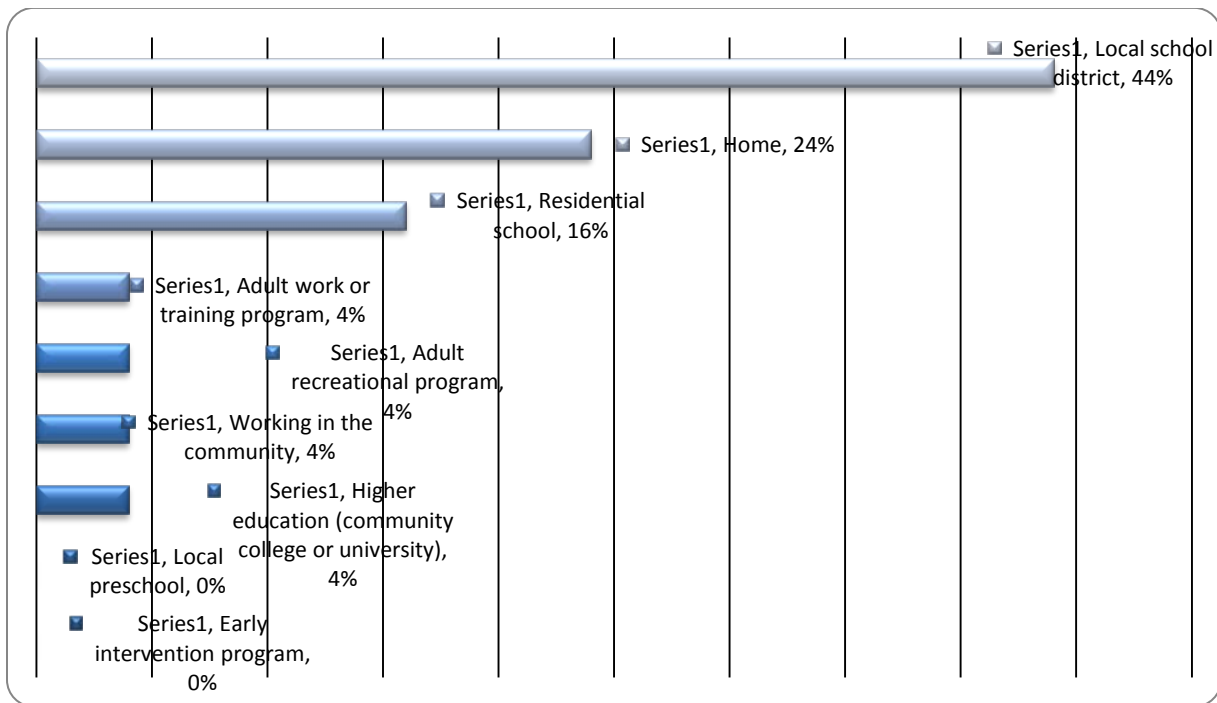
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WHERE DOES YOUR CHILD LIVE MOST OF THE TIME?



WHAT TYPE OF SETTING IS YOUR CHILD IN MOST OF THE TIME?

Forty-four percent of the participant's reported that their child spends most of their time in his/her local school district. An additional 24% (N=6) said their child spends most of their time in the home. Four participants had children 21 and over. Although it wasn't asked, it can be assumed that perhaps four of the six that are primarily in the home have aged out of the Part B school system.



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QUESTIONS RELATED TO THE ONSITE TRAINING ACTIVITIES

IN YOUR OPINION, HOW IMPORTANT ARE THE FOLLOWING TRAINING TOPICS FOR EMERGING FAMILY LEADERS?

The survey participants were asked to rate the importance of these topics on a scale of 1 – 5, with 1 being “Not Important” and 5 being “Critically Important.” The following results identify the percentage of respondents who rated the item a 4 or 5 on the five-point scale. The second number indicates the average score on the 5-point scale for that topic.

TOPIC	FAMILY LEADERS	DEAF-BLIND PROJECT
Understanding Deaf-Blindness (For example: Understanding the federal program for deaf-blindness; the deaf-blind census; impact of deaf-blindness on learning, families and quality of life; resources on deaf-blindness)	92% Avg 4.48	100% Avg 4.625
Understanding Systems and Opportunities for Family Leadership (For example: Leadership within community, social, educational, medical, legislative and adult service systems; ways to make change occur)	92% Avg 4.44	87% Avg 4.375
Understanding Leadership (For example: Defining and understanding family leadership; characteristics of family leaders; discovering your own leadership qualities, passions and interests)	92% Avg 4.36	100% Avg 4.625
Maintaining your Personal Life Balance (For example: Relaxation and regeneration activities; strategies to keep your life in balance; ways to take care of yourself)	92% Avg 4.36	100% Avg 4.75
Partnership and Collaboration Skills (For example: Accessing resources; building collaboration; teaming skills; group dynamics and development)	91.7% Avg 4.41	100% Avg 4.75
Your Communication Skills (For example: Communication and active listening; conflict negotiation; supporting other families)	88% Avg 4.44	100% Avg 5
Advocacy Skills (For example: How to telling your story; public speaking strategies, writing skills for letters, newspaper stories, articles)	84% Avg 4.36	100% Avg 4.75
Connecting with Families: How to Build Relationships and Involvement (For example: Activities to introduce and connect families; how to identify the needs of families; activities to include the whole family)	84% Avg 4.28	100% Avg 4.25
Training Skills (For example: Understanding learning styles; adult learning strategies; how to develop and deliver a presentation)	72% Avg 3.96	100% Avg 4.375
Loss and the Grieving Process (For example: Impact of loss on families; how to relate to people in crisis)	70.9% Avg 4.0	62.5% Avg 4.0
Cultural Competence Skills (For example: Understanding and respecting beliefs, attitudes, values; strategies to identify underserved populations; outreach strategies for culturally diverse families)	68% Avg 3.92	100% Avg 4.625
Other Important Topics mentioned: <ul style="list-style-type: none"> ○ Advances in technologies ○ Listening, not always having to feel the need to share the story of you but listen to others ○ The important of siblings in this journey ○ ASL and Braille ○ Understanding of the Special Education Laws and rights as it pertains to students with Deafblindness ○ How to maintain Child's medical records; How to create a Child's Portfolio; Personal & Family PATH; ○ The topic of possibly the need to implement a technique such as "Body Breaks" in a child's classroom setting. ○ "Capturing your kids story", because it's as important as their medical records. Gives your child a sense of place in this world. ○ Coming to agreement 		

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- o Creating a personal and family PATH; Person Centered Planning; Keeping Medical Records; Child's Portfolio; Simulation on DB
- o We've recently added a new strand on effective parent leadership paradigm shifts that is proving to be a cornerstone for communication, partnership, collaboration and advocacy skills refinement.
- o Interest-Based Problem Solving training is also being identified by the family leaders as critical.

WERE THESE TOPICS TAUGHT AT THE APPROPRIATE LEVEL FOR YOU (THE PARTICIPANTS) TO GAIN ENOUGH KNOWLEDGE TO USE THE INFORMATION?

The survey participants were asked to rate the appropriateness of the level of teaching for these topics on a scale of 1 – 3, with 1 being "Not enough information given," 2 being "Too much information given" and 3 being "Right amount of information given." The following results identify the percentage of respondents who rated the item on the three-point scale. Most respondents felt the topics were covered at an appropriate level, however, there were a few notable differences between the category of respondents. For instance, Thirty-two percent of the family leaders felt the topic of "Maintaining your Personal Live Balance" was not covered with enough information, but 0% of the state deaf-blind projects agreed with that statement. Conversely, 25% of the deaf-blind project respondents felt that the topic of "Understanding Deaf-Blindness" received too little information, but only 8% of the family leaders agreed with this. Very few responded that too much information was given on any of the topics.

TOPIC	Level 1 Not enough info	Level 2 Too much info	Level 3 Right amount of info	Topic not Taught
Understanding Deaf-Blindness (For example: Understanding the federal program for deaf-blindness; the deaf-blind census; impact of deaf-blindness on learning, families and quality of life; resources on deaf-blindness)	FL - 8% DBP - 25%	FL - 4% DBP - 12.5%	FL - 80% DBP - 62.5%	FL - 8% DBP - 0%
Understanding Systems and Opportunities for Family Leadership (For example: Leadership within community, social, educational, medical, legislative and adult service systems; ways to make change occur)	FL - 20% DBP - 12.5%	FL - 8% DBP - 12.5%	FL - 60% DBP - 75%	FL - 12% DBP - 0%
Understanding Leadership (For example: Defining and understanding family leadership; characteristics of family leaders; discovering your own leadership qualities, passions and interests)	FL - 16% DBP - 12.5%	FL - 8% DBP - 0%	FL - 68% DBP - 87.5%	FL - 8% DBP - 0%
Your Communication Skills (For example: Communication and active listening; conflict negotiation; supporting other families)	FL - 4% DBP - 12.5%	FL - 4% DBP - 0%	FL - 84% DBP - 87.5%	FL - 8% DBP - 0%
Partnership and Collaboration Skills (For example: Accessing resources; building collaboration; teaming skills; group dynamics and development)	FL - 20% DBP - 12.5%	FL - 4% DBP - 0%	FL - 72% DBP - 87.5%	FL - 4% DBP - 0%
Advocacy Skills (For example: How to telling your story; public speaking strategies, writing skills for letters, newspaper stories, articles)	FL - 12% DBP - 25%	FL - 0% DBP - 0%	FL - 80% DBP - 75%	FL - 8% DBP - 0%
Maintaining your Personal Life Balance (For example: Relaxation and regeneration activities; strategies to keep your life in balance; ways to take care of yourself)	FL - 32% DBP - 0%	FL - 0% DBP - 0%	FL - 60% DBP - 75%	FL - 8% DBP - 25%
Training Skills (For example: Understanding learning styles; adult learning strategies; how to develop and deliver a presentation)	FL - 20% DBP - 50%	FL - 0% DBP - 0%	FL - 68% DBP - 50%	FL - 12% DBP - 0%
Loss and the Grieving Process (For example: Impact of loss on families; how to relate to people in crisis)	FL - 48% DBP - 25%	FL - 0% DBP - 0%	FL - 36% DBP - 37.5%	FL - 16% DBP - 37.5%
Connecting with Families: How to Build Relationships and Involvement (For example: Activities to introduce and connect families; how to identify the needs of families; activities to include the whole family)	FL - 28% DBP - 37.5%	FL - 4% DBP - 0%	FL - 64% DBP - 62.5%	FL - 4% DBP - 25%

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TOPIC	Level 1 Not enough info	Level 2 Too much info	Level 3 Right amount of info	Topic not Taught
Cultural Competence Skills (For example: Understanding and respecting beliefs, attitudes, values; strategies to identify underserved populations; outreach strategies for culturally diverse families)	FL - 26% DBP - 25%	FL - 0% DBP - 0%	FL - 65% DBP - 50%	FL - 9% DBP - 25%

HOW EFFECTIVE WERE THE FOLLOWING TRAINING STRATEGIES IN HELPING TO INCREASE YOUR (THE PARTICIPANTS') KNOWLEDGE AND SKILLS AS AN EMERGING FAMILY LEADER?

The survey participants were asked to rate the effectiveness of the training strategies used in the family leadership training series on a scale of 1 – 5, with 1 being “Not effective” and 5 being “Very effective.” The following results identify the percentage of respondents who rated the item a 4 or 5 on the five-point scale. Participants who indicated that a particular strategy was NOT USED, were not included in the following results.

TRAINING STRATEGY	FAMILY LEADERS	STATE DEAF-BLIND PROJECT
Watching someone demonstrate a skill	66.6%	100%
Small Group activities	65%	87.5%
Role playing to practice a new skill	64%	100%
Practicing a skill with someone guiding or watching you and giving feedback	64%	87.5%
Listening to a presentation	60%	25%
Large group activities/discussions with all family leaders participating	60%	100%
Working 1-on-1 with your buddy	63%	75%
Individual activities with each participant working alone	39%	25%
Watching videos	41%	62.5%
Other effective strategies used in training: Assigning each member of the training team to coach individual participants throughout the training series. Contact primarily made outside of formal training times.		

HOW EFFECTIVE WERE THE SUPPORT AND DISTANCE TRAINING STRATEGIES USED BETWEEN ONSITE TRAINING WEEKENDS IN HELPING YOU TO INCREASE YOUR KNOWLEDGE AND SKILLS AND KEEP YOUR MOMENTUM GOING?

The survey participants were asked to rate the effectiveness of the distance training and support strategies used in the family leadership training series on a scale of 1 – 5, with 1 being “Not effective” and 5 being “Very effective.” The following results identify the percentage of respondents who rated the item a 4 or 5 on the five-point scale. The second percentage indicates the percentage of respondents who said

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this strategy was NOT USED in the training. Only respondents who indicated that this strategy was used in the training are included in the first percentage. For instance: 40% of the family leaders said they did not have face-to-face meetings with a mentor. However, of the remaining 60% of respondents, 87% rated this strategy as a 4-5 on a five point scale of effectiveness.

DISTANCE TRAINING & SUPPORT STRATEGY	FAMILY LEADERS Rated 4-5	STATE DEAF-BLIND PROJECT Rated 4-5
Face-to-face meetings with a mentor from the deaf-blind project or NCDB	87% 40% DNA	71% 12.5% DNA
Phone calls from a mentor from the deaf-blind project or NCDB	74% 24% DNA	50% 12.5% DNA
Emails from a mentor from the deaf-blind project or NCDB	67% 16% DNA	75% 0% DNA
Distance support (emails, phone, Facebook) from another training participant	70% 8% DNA	75% 0% DNA
Group discussions via phone conference calls	59% 32% DNA	67% 25% DNA
Group discussions via video conference calls	54% 48% DNA	50% 50% DNA
Homework assignments (examples: reading articles, watching videos)	38% 12% DNA	14% 12.5% DNA
Keeping a leadership journal	37.5% 36% DNA	100% 87.5% DNA
<ul style="list-style-type: none"> • Collaboration with other families in a similar situation. • Implementing my notes from my leadership journal to my own personal Blog page. • Mentorship among parents was effective. • Maintaining communication after the training with one specific buddy; had small meetings in different locations throughout the state. 		

DID YOU PLAN A PERSONAL LEADERSHIP GOAL AS PART OF YOUR FAMILY LEADERSHIP TRAINING?

	<u>FAMILY LEADERS</u>	<u>STATE DEAF-BLIND PROJECT</u>
Yes	84%	87.5%
No	16%	12.5%

DID WORKING ON YOUR PERSONAL LEADERSHIP GOAL INCREASE YOUR SKILLS AS AN EMERGING FAMILY LEADER?

	<u>FAMILY LEADERS</u>	<u>STATE DEAF-BLIND PROJECT</u>
Yes	95.2%	87.5%
No	4.8%	12.5%

PLEASE EXPLAIN WHY YOU ANSWERED YES OR NO:

- Having an identified goal helped to focus
- I encourage families to learn about the system, resources and advocate for their childrens

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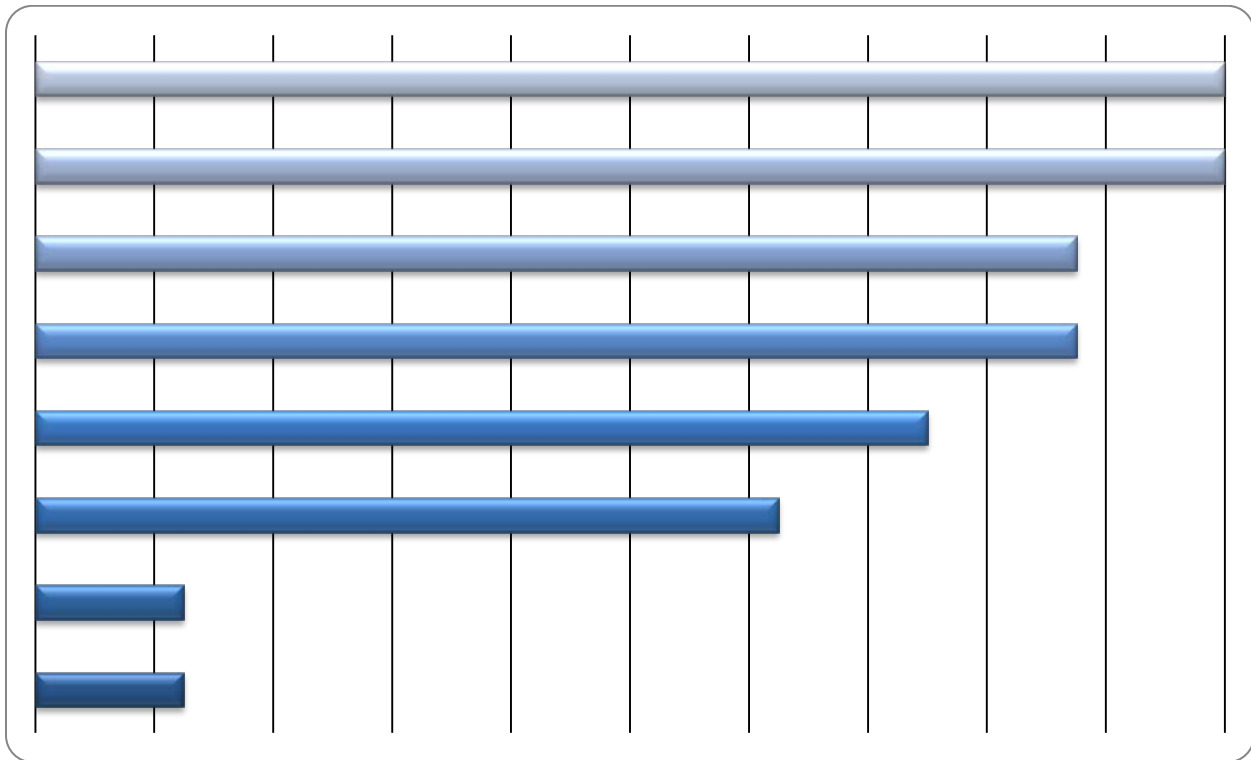
- I gave me a defined goal to reach and steps to take to reach it
- I picked a topic that I liked that would be able to grow as a person more.
- It gave me more confidence to believe I can
- It helped me prepare for some of the challenges we faced.
- Legislative Issues
- worked a lot on boundaries
- I'm the kind of person that needs a reason to do something, having a leadership goal made me move to action. Also having guidance from the family specialist helped me have courage even when I was afraid to step out as a leader.
- Yes, because I could apply the material I was learning at the training to the real life goal I am working on. My skills as a family leader improved.
- Quite honestly, it was more than 2 years ago, and i can't remember what the goal was or how I approached it. I am so sorry that I can't be more helpful!
- Because it helped me to focus on the task at hand and it helped me to identify the tools and resources that would help me to achieve my goal.
- My leadership training help me to gain the skills to work in the field as an employment support specialist for the deafblind and other disabilities.
- I learned more about where I fit in with my style with others and how to move more effectively in and out of groups in order to get my goals accomplished. I also found feedback very valuable. It helped me gain reassurance and gave me a wonderful insight into myself.
- I put my writing to use. I started writing in my leadership journal. Later, I began blogging and writing more. Also, I recently learned I am one of the finalists for the Paying It Forward Awards for Texas Parent to Parent. I had to write a 1 page essay about a professional who has provided support to my family. It was a joy to write and nominate someone for this award, and I am very honored to be one of the finalists. It has given me hope that my words do matter to someone and that I can ultimately use my words and writing to help other special needs families.
- Yes- because I had to contact out of state help and when they sent the wrong handouts- I had to be persistent in contacting them again to send the correct one. Therefore- I worked on communicating more affectively and also had some practice in perseverance.
- I've assumed leadership roles in the field of disability since my son was an infant, and have been planning a personal path since my son was 2 ½ years old and my school district recommended he be sent to a residential placement out of state (that wasn't going to happen). I was a founding member of Parents of Blind Children-NJ and have been on the board of this organization for more than 20 years. I was the president or vice president of our Home & School Association for 12 years, and was a Tiger and Cub Scout leader for an all Deaf troop for 7 years. For the past 10 years, I regularly present (8x/year) a program to third-year medical students at the University of Medicine & Dentistry of NJ regarding the needs of children with developmental disabilities, the impact of having a child with a disability on the family, and how doctors can support such families; this role also includes recruiting and training the families who participate in this seminar. I served as co-chair of the NJ Commission for the Blind's Deaf-Blind Unit Consumer Advisory Board from 2002-2006. Before my son was born, my job was to develop and instruct sales training and teller training programs regularly attended by more than 500 employees at a NJ savings bank; when I resigned from that job (to have my son), was an Assistant Vice President and Sales Manager. I am the editor of The Sounding Board, the bi-annual publication of the NFB of NJ, and co-editor of In Touch, the magazine of Parents of Blind Children-NJ. I have written articles, presented at many seminars, and been a guest lecturer at numerous college classes over the past 20 years.
- The leadership goal was to create a Parent Leadership Training in Spanish changing the curriculum and the time frame of the workshops to accommodate the needs of the families. Also the format of the training and the in between meting follow up was modified to adjust to their needs.

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DID WORKING ON YOUR PERSONAL LEADERSHIP GOAL INCREASE YOUR CONFIDENCE AS AN EMERGING FAMILY LEADER?

Yes 90.5%
 No 9.5%

WHICH OF THE FOLLOWING SUPPORTS DID THE PARTICIPANTS RECEIVE AS THEY WORKED ON THEIR PERSONAL LEADERSHIP GOALS? (CHECK ALL THAT APPLY)



HOW IMPORTANT WAS IT TO RECEIVE SUPPORT DURING THE FOLLOWING STEPS OF YOUR PERSONAL LEADERSHIP GOAL?

The survey participants were asked to rate how important it was to them to receive support during the development and implementation of a personal leadership goal. The rating scale was 1 – 5, with 1 being “Not important” and 5 being “Critically important.” The following results identify the percentage of respondents who rated the item a 4 or 5 on the five-point scale.

Steps in Personal Leadership Goal	
Help to identify your leadership goal	95%
Help in overcoming challenges while working on your goal	95%
Ongoing support from NCDB or the state DB project to implement your goal	90%
Help to plan the action steps to reach your goal	89.4%
Celebrating your successes in achieving your goal	75%

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Ongoing support from other training participants to implement your goal	63.1%
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HOW EFFECTIVE WERE THESE TYPES OF SUPPORT STRATEGIES AS YOU (THE PARTICIPANTS) WORKED ON YOUR PERSONAL LEADERSHIP GOAL?

The survey participants were asked to rate the effectiveness of the several types of supports used as they worked on their personal leadership goals. The rating scale was 1 – 5, with 1 being “Not effective” and 5 being “Very effective.” The following results identify the percentage of respondents who rated the item a 4 or 5 on the five-point scale. The second percentage indicates the percentage of respondents who said this strategy was NOT USED in the training. Only respondents who indicated that this strategy was used in the training are included in the first percentage.

SUPPORT STRATEGY	FAMILY LEADERS	STATE DEAF-BLIND PROJECT
Face-to-face meetings with a mentor from the deaf-blind project or NCDB	69% 20% DNA	62.5% 0% DNA
Phone calls from a mentor from the deaf-blind project or NCDB	65% 15% DNA	71% 12.5% DNA
Emails from a mentor from the deaf-blind project or NCDB	47% 10.5% DNA	87.5% 0% DNA
Face-to-face meetings with another training participant	79% 30% DNA	33% 25% DNA
Distance support (emails, phone, Facebook) from another training participant	44% 10% DNA	43% 0% DNA
Group phone or video conference calls with all of the training participants	50% 36.8% DNA	50% 25% DNA

OTHER EFFECTIVE SUPPORT STRATEGIES USED AS YOU WORKED ON YOUR PERSONAL LEADERSHIP GOAL (PLEASE DESCRIBE):

- Support from my spouse.
- Listening skills
- Trainings, reading materials, and hands on.
- I felt supported when I would send out a simple text, email or facebook post about my writing. It made me feel great to have a friend's support.
- Emerging new ideas to motivate families to participate on a face to face meeting, for ex. the Conditional Cash Transfer.
- Keep minutes of meetings
- Willing to meet at family homes or other locations
- Flexible because of child's health

WHAT CHALLENGES DID YOU FACE WHILE PARTICIPATING IN THE FAMILY LEADERSHIP TRAINING SERIES? (CHOOSE ALL THAT APPLY)

Response	Rural	Suburban	Urban	Total
The time needed to put what I learned into practice	28.6%	40%	75%	48%

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The time needed to attend the face to face training	14.3%	60%	50%	44%
Someone to watch my children at home	14.3%	40%	50%	36%
Costs to attend the face to face training (expenses that were not reimbursed)	14.3%	20%	37.5%	24%
Difficulty in traveling to the face to face training	0%	20%	20%	16%
Childcare expenses	14.3%	20%	12.5%	16%
Support from my family to attend the face to face training	0%	0%	25%	8%
Didn't have the technology needed at home (computer, Internet, webcam)	0%	20%	0%	8%
Didn't learn enough to develop and implement a leadership goal	0%	10%	12.5%	8%

TOP THREE CHALLENGES REPORTED BY BOTH THE PARTICIPANTS AND THE STATE DEAF-BLIND PROJECT STAFF ARE HIGHLIGHTED BELOW.

Challenge	FAMILY LEADER	STATE DEAF-BLIND PROJECT
The time needed to put what I learned into practice	52.2%	75%
The time needed to attend the face to face training	47.8%	75%
Someone to watch my children at home	39.1%	87.5%
Costs to attend the face to face training (expenses that were not reimbursed)	26.1%	25%
Difficulty in traveling to the face to face training	17.4%	50%
Childcare expenses	17.4%	62.5%
Other (please describe):	17.4%	
Support from my family to attend the face to face training	8.7%	25%
Didn't have the technology needed at home (computer, Internet, webcam)	8.7%	12.5%
Didn't learn enough to develop and implement a leadership goal	8.7%	12.5%
Other Challenges: <ul style="list-style-type: none"> Finding a volunteer opportunity in our community that will work with both my child and I. I am still searching for a good fit. I had and still have no idea what the goal of the training was / what kind of leadership role the DB project wanted me to take needing to stay with a sick child Language & Cultural barriers Not having the technology skills (surprising amount of participants early on whose typing skills and ability to access the Internet hindered their activities). This is improving. Illness of their child--that happened to two of our families (one in hospital and one with illness) 		

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**WHAT MADE YOUR EXPERIENCE WITH FAMILY LEADERSHIP TRAINING MOST SUCCESSFUL?
 (CHOOSE ALL THAT APPLY)**

	FAMILY LEADERS	STATE DEAF-BLIND PROJECT
Ongoing support of the deaf-blind project	83.3%	100%
My interest and passion for making a difference in services	79.2%	87.5%
My previous knowledge and experience (with services, resources, etc)	70.8%	87.5%
Ongoing support of the other participants	62.5%	75%
Support from my family/friends to participate in the training	58.3%	75%
Financial support to attend face to face training	50%	87.5%
Other Responses: <ul style="list-style-type: none"> • Ongoing research to implement resources, information • Continuing to build friendships with the other parents - we were all in the same boat • Support from PTI, Advocacy Center, P to P, Independent Living Center, Parent Network • The continued support of the family leadership and the families involved in the PA Deaf blind Project • If it would have been "just" a course in how to be a family leader I wouldn't have done it, I went to be with other parents who understood my life AND honestly to get a break from my family for a while. • Convenient location with accessible transportation available 1 • The initial contact where they learned they were nominated seemed to be a pivotal point in them realizing they were family leaders. 		

HOW HAVE YOU USED YOUR LEADERSHIP SKILLS? WHICH OF THESE STATEMENTS DESCRIBES HOW YOU VIEW YOURSELF NOW THAT YOU ARE A TRAINED FAMILY LEADER? (CHECK ALL THAT APPLY). The state projects report that the participants of the family leadership training have accomplished 100% of these activities.

Use of Leadership Skills	Responded YES
I am more confident asking questions and speaking up for my child in meetings related to his/her education (e.g., early intervention program, school, day program)	86.4%
I am more confident asking questions and speaking up for my child with other professionals (e.g., doctors, local or state agency representatives)	77.3%
I have shared my story with one or more people to try to impact services for my child and/or other individuals with deaf-blindness	77.3%
I have been successful in changing something for my child at school or in the community.	68.2%
I have helped another training participant find resources or solve a problem.	63.6%
I have helped other families in our state find resources or solve a problem.	63.6%
I have attended additional training offered by parent organizations in my state.	54.5%
I have called or written a state or national politician about an important issue related to my child, our family, and individuals with deaf-blindness.	40.9%
I have contacted new families and shared information about the deaf-blind project	36.4%
I have helped raised funds to assist children with deaf-blindness.	31.8%
Other (please describe): <ul style="list-style-type: none"> • Board Member of Deafblind Family group • I am ready to venture onto my next 1/2 marathon race for The MAGIC Foundation. Details on the next big group race are soon to come 	

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PLEASE TELL US MORE ABOUT HOW YOU'VE USED YOUR TRAINING – WE NEED TO HEAR YOUR STORIES TO INSPIRE EVEN MORE PARENTS TO BECOME FAMILY LEADERS! NO ACTION IS TOO SMALL TO MOTIVATE OTHERS!

- I new very little about special education rights and procedures before our trainings.
- This training helped me realize there are others with the same struggles and joys that I do. It shows nobody is alone and everyone can help.
- I find it easier now to talk to parents, professionals, etc. when it comes to my child, deaf-blindness, ONH-Optic Nerve Hypoplasia. From listening to other parents stories, it is inspiring and motivates me to keep telling my story about my child. I'm trying every way I know how to have my voice heard: blogging, essay writing, belonging to support groups, talking to other families. I'm not afraid to ask questions to get the best care out there for my child. (doctors or therapy)...Every child deserves the Corvette model...this Mom is saying "no" to the "push mowers" out there.
- I started a support group for exceptional families in Oak Harbor. It is still going every month. I have handed the reins over to other parents who are now running it. I coordinated lunch meetings with local child resources (FRC, Navy School liaison, autism project director, Navy Peds social worker).
- I have been successful in getting my town to include four deaf-blind children in a recreational program offered to other children in town.
- I felt very confident going to our State Capitol and talking to legislators and staff about why cutting Medicaid, in any way, was bad for people and families. It also gave me a stronger purpose for why I need to do this work. Other families in my situation have children in school or are at a critical point in their child's health and can't do the work I am somewhat able to do. I am a carrier of the stories. I am a storyteller and my hope is that the stories I tell move people towards change and why change might not be the right answer either. Let me do the work now for others so that when my time is done, you might lead by my example.
- I have used my training and skills to help other parents approach their schools with more confidence. I have much more confidence in my son's ARD meetings and have the knowlege that I need to better equip him with the resources that he will use the rest of his life.
- I think that it is important for families that have gone through the trainings and the process for some time to perhaps be paired up with families that are newer to the system and might be overwhelmed and inundated with questions and concerns.
- Well as a parent I try to put all together to understand help my daughter with her need, and implement at home what ever I learn but as an advocate I help other who are in disvantage to lear how they can improve their child life and understand educational need and how ask for services.
- I guess until I took this survey and realized how much I have done because of the training I didn't realize what a big impact the leadership training had on me. Like I commented earlier, I took advantage of the training primarily because it offered me a "most expenses paid" get away from my family where I wouldn't have guilt about leaving because I was learning how to be a better mom for my child. I wanted to see other families like mine. I went for the break and socializing but I truly did learn so much. I'm so proud of the DB 101 classes I did and wish I had the time and energy to do more in other areas where children with deaf-blindness live, not just my child. I have advocated for my child's educational needs more assertively and effectively since the trainings as well. Even though that's not being a leader to others, the help in advocating for my own child is HUGE for our family. After the training I felt like I had a place and right to attend meetings and speak up and not "just" the mom they had to notify. Also I do know more now and have been able to offer information to other families with children who have special needs. Not many families are like ours, but the knowledge is helpful so I'm happy to share.
- I have done the following since the training, but not because of the training: I have shared my story I have been successful at implementing change I have contacted state officials regarding an issue connected to deafblindness I have helped raise funds I have helped a co-trainee find resources, solve a problem I have continued to teach my son to self-advocate and stand up for the supports he needs, whether that be in a medical, educational or community setting
- My husband and I tell our story to 2 college classes each year- I am now able to incorporate some of the skills I've learned into that experience and be more educated about the impact db has on a child and their family.

RED QUESTIONS & RESPONSES = Family Leaders

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BLACK QUESTIONS & RESPONSES = Asked of both Family Leaders and DB project staff

- I am now employed the Blind and Vision Rehabilitation Services of Pittsburgh as an Employment Support Specialist. I work with individuals in the community obtain successful employment and to maintain their jobs. I love my job and the work it entails in helping individuals with disabilities in the community and in school.
- Parents are more motivated to get members of their own family to learn new skills as well as being ambassadors on deafblindness talking to other families and sharing what they are learning and inviting them to get more involved. The amount of resources that the families take home with them is significant and they feel good sharing them with others.

QUESTIONS ASKED ONLY OF THE DEAF-BLIND PROJECTS

Challenge	Percent %
Continuing to support participants after the training is over	100%
The financial cost of the training	75%
Finding the right participants for the training	75%
The time needed to mentor each participant between face to face trainings	75%
The amount of time it takes to put on the training	62.5%
Communicating with participants after the training to determine results	50%
Finding enough participants for training	37.5%
Participants dropping out in the middle of the series	37.5%
Other #1 (please describe):	25%
Other #2 (please describe):	12.5%
Not enough support from NCDB during the face to face trainings	0%
Not enough support from NCDB to provide distance support between the face to face trainings	0%

PLEASE IDENTIFY THE TOP THREE CHALLENGES YOUR PROJECT FACED IN DELIVERING FAMILY LEADERSHIP TRAINING.

Challenge	Total Score	Overall Rank
The time needed to mentor each participant between face to face trainings	11	1
Finding the right participants for the training	9	2
Continuing to support participants after the training is over	9	3
The amount of time it takes to put on the training	8	4

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The financial cost of the training	6	5
Finding enough participants for training	4	6
Communicating with participants after the training to determine results	1	7
Other #2 (as described in question above)	0	8
Other #1 (as described in question above)	0	9
Participants dropping out in the middle of the series	0	10
Not enough support from NCDB during the face to face trainings	0	11
Not enough support from NCDB to provide distance support between the face to face trainings	0	12

DID YOU MAKE ANY REVISIONS TO THE FAMILY LEADERSHIP TRAINING MATERIALS PROVIDED BY NCDB? (PLEASE DESCRIBE)

- Yes, I shorten the amount of time of the training, but used some of the same materials.
- We adapted the original NCDB materials into a new version including material from Texas and other issues pertinent to our state.
- We were involved in the development of some materials, but used some from our PTI as well as NCDB. Other state initiatives (e.g., Maryland) also helped in development of materials.

WHAT OTHER ORGANIZATIONS OR AGENCIES DID YOU COLLABORATE WITH TO PROVIDE YOUR FAMILY LEADERSHIP TRAINING. (CHECK ALL THAT APPLY)

Organization	Count	Percent %
State Parent Training and Information Center	6	75%
State Parent to Parent Organization	6	75%
Developmental Disabilities agency	6	75%
Vocational Rehabilitation agency	5	62.5%
Community Organizations (please describe):	3	37.5%
Other (please describe): Advocacy Center 1 Family Organizations 1 Consultant at local catholic schools and Parent		

PLEASE PROVIDE DETAILS OF WHAT WORKED IN THE COLLABORATION (E.G., SHARED COSTS, PRESENTERS, TRAINING SPACE, ETC.):

- Presenters
- Presenters at trainings.
- shared presenters and information; shared costs
- Since we did the training in different parts of the State we used our "partners" training space and the skills from their own team to present in different issues, according to session and content

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- We found it helpful to offer local personal family leadership trainings with at least a two-year commitment (i.e., offer two separate classes). The first year, we shared costs. This included using a hotel for our training space to promote all the participants staying together for each weekend. Our project took the primary responsibility of presenting and preparing training materials the first year with the expressed goal of our partners having a year to observe before being asked to share responsibility the second year.
- NCDB played an essential role in developing and implementing the training. Sharing costs and presenters was critical, as well as the expertise of Kathy McNulty, John Reiman, and others.

PLEASE PROVIDE DETAILS OF WHAT DIDN'T WORKED IN THE COLLABORATION (E.G., SHARED COSTS, PRESENTERS, TRAINING SPACE, ETC.):

- Collaboration made it work.
- It all worked fine.
- Surprisingly, it was almost impossible to get the partners to attend the entire training series (we too often heard, "I don't work on weekends" even though they knew that was the ideal time for families. As part of that seemed to be a lack of commitment and vision. Obviously, these challenges impacted our success in getting them to present. And when they did, they tended to pull out a canned presentation that was "off mark" from the training goals.
- One of the locations did not have available public transportation for the participants and that was a small obstacle

PLEASE TELL US ANYTHING ELSE YOU WOULD LIKE ABOUT YOUR FAMILY LEADERSHIP TRAINING. WE NEED TO HEAR YOUR STORIES TO INSPIRE EVEN MORE PROJECTS TO OFFER FAMILY LEADERSHIP TRAINING!

- While we are not formally continuing family leadership training, the family leaders continue to advocate for the needs of individuals who are deaf-blind.
- Small clarification on the response to providing DB specific information in the training. When the training was exclusively for family leaders who had DB children, the level this was addressed seemed to fit the leaders' needs. It has been much harder to do so now that we've expanded it for both VI and DB family leaders. We continue to work towards making sure DB specific information is adequately covered, including recruiting new members to the core family leadership training team. I remain convinced that while the training is no longer for DB family leaders, the expansion was the right choice for our state. Success stories??? Aren't you tired of me constantly sharing my enthusiasm for all the family leaders are doing within our state??? Family Leaders now comprise the majority of our family organization boards as well as serve on state level advisory committees and boards, work for disability programs and services (The Arc, state voc agency). The family leaders have been responsible for legislation being passed to expand DB services within our state and a few have even been involved in national legislative issues. Family Leaders continue to use the art of story telling to touch the hearts and influence the heads of decision makers at all levels (local schools, communities, regionally, statewide and nationally). They have remained a strong and active community that their partners respect and include in systems change initiatives. I remain convinced that the training itself is not the key but more so, the recognition they received that they were emerging family leaders and then the community they built to boost their confidence they would be successful leaders that made the real difference. 'Nuff said, huh?
- Following our experience with the second group of potential family leaders, we decided that conducting these trainings regionally made a great deal of sense. (With the first group, we tried to bring together a variety of family members from different parts of the state. Some were not appropriate candidates; the group never quite worked.)
- We are learning we need to adjust the length of the training sessions according to different groups. - Our participants enjoyed activities that involved movement and practice of skills. - Technology is sometimes a barrier because not everyone has the proper equipment available and we have do contact over the phone - The Conditional Cash Transfer is a win/win situation for the training

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- So many wonderful things from this training: 1) parent did not know each other in the beginning, now they are major supporter of each other and db project; 2) increase # of parents on my db adv. committee--added 3-4 more; 3) each parent's presentation of their story "elevator talk" was outstanding. I just wish I had videotaped each presentation....too busy enjoying it (smile).!! 4) Facebook page developed and we use it; 5) follow-up meeting occurred and now developing PR materials and used some from other states; 6) one parent signed up for online course on interveners though Utah State; 7) This group will also be presenting at my state db summer inst in July 2012.