

We Are Hands & Voices And Guide By Your Side

***Empowering Parents
to
Influence & Lead***



**HANDS &
VOICES™**



H&V Mission Statement



Hands & Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology.

We're a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access, social and educational outcomes for their children. Our outreach activities, trainings, parent/professional collaboration, and advocacy efforts are focused on enabling Deaf and Hard-of-Hearing children to reach their highest potential.

Hands & Voices...



- ***We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.***
- ***We believe that there is no one communication choice that will work for all children who are deaf or hard of hearing. We think families need access to good information that's free from a sponsoring agenda or ideology.***

Hands & Voices...

what makes us tick



- ***We believe that “What works for your child is what makes the choice right.” ©***
- ***We believe our children have a fundamental human right to communication, regardless of their mode or method of communication.***

Hands & Voices...

what makes us tick



- ***We get meaningfully involved in early hearing detection and intervention programs, educational advocacy, and other systems to improve them from an end-user perspective. – through highly trained, knowledgeable parents***
- ***We exist to help our children/students reach their highest potential.***

Hands & Voices...

what makes us tick



- ***We believe Parent-to-Parent Support is a cornerstone for families finding their way, “when you come to a place where the streets are not marked” – Dr. Seuss***
- ***We promote the life experiences and talents of adults who are Deaf and Hard of Hearing to help families ensure success for their own children who are d/hh***

Hands & Voices supports and represents...



- Kids with mild, moderate, severe, profound, unilateral, conductive, auditory neuropathy, congenital, sensorineural, acquired, deaf +, and age progressive hearing loss or deafness
- Kids who speak, kids who sign, kids who do both, kids who cue, kids who are aided or not aided, and/or kids who have cochlear implants
- The families of these children and the professionals who work with them in all capacities

Why do families need Hands & Voices?



95% of all deaf children are born to hearing families (Mitchell & Karchmer, 2004)

90% of these families have no background in deafness or connection to the deaf community. (Center for Demographic Studies, 1984)

Remember what it felt like?



“The days that followed my son’s identification of hearing loss were filled with the echo of my cries along with his. I remember feeling like something was wrong with me - or with everyone else. No one seemed to think it was a big deal. They would say, “Well, at least he's healthy.”

“Yes, YES - I know I should be grateful for that, but why wasn't anyone else upset that my son couldn't hear! Certainly, I grew to learn how much he could hear. But at the time "mild-moderate" had no meaning to me. **There was no history of hearing loss in either sides of the family. I had a healthy pregnancy. The "Why?" haunted me for a couple of years.**”

Sharing our Journeys and 'aha' moments with one another...



"Looking back I remember many knots in the pit of my stomach. But now those knots are forgotten because of the real joy that rearing our son has been. Our lives have truly been enriched. I suppose I reflect on the many mistakes we have made, but I also can see the good decisions we have made for our son. **The most critical element in our philosophy was that we decided very early that our son would always be allowed to set his own limits, that we would not, nor allow others to decide what he could do because of his deafness.**"

Observations about Changing Needs of Parents

- 10 years ago, families had to personally attend workshops to get information or to find support from other families
- Today, families have access to information without leaving their home
- Families are far more complicated and heavily scheduled
- Our charge is to make sure that parents get accurate, comprehensive information/support for all choices in as many ways as possible

source: Lindow Davies, C. MN H&V

What are the burning issues we hear about?

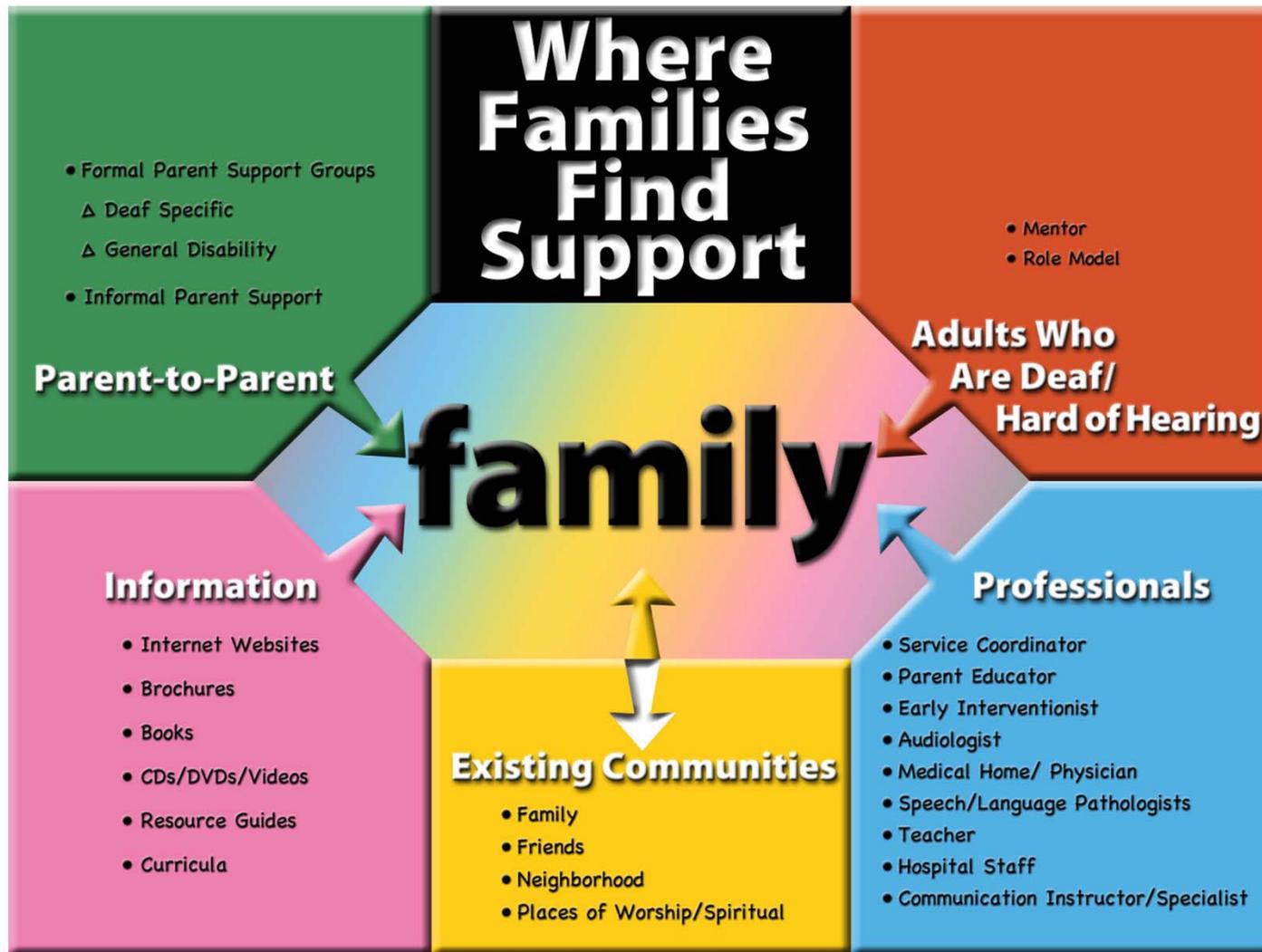


- “Help, I was told to get a follow up screen from the hospital, but there are no appointments available for 3 months.”
- “Help!, My early intervention provider is telling me if we don’t choose _____ as our communication option, our child will not succeed”
- “Help, they tell me my son is not eligible for special ed. Because he’s doing ‘too well’?”
- “Help, they’ve assigned a new interpreter to my daughter who uses ASL, and the terp uses SEE?”
- “Help, my school just assigned an SLP who has never worked with deaf kids, and my child just got a CI”

What are the burning issues we hear about?



- “Help, the school told me my daughter has to go the center based program...can’t go to the center based program...has to go to the school for the deaf...never told me about the school for the deaf, has to go to the neighborhood school due to LRE...”
- “Help, I’ve been assigned a service coordinator in Part C who knows nothing about deafness.”
- “Help, my child has never learned any self-advocacy tools to along in the ‘real world’.”
- “Help, my child can’t find a job.”
- “Help, my child is getting good grades but is really lonely and has no friends”
- “Help, my child is being bullied.”



The History of Hands & Voices



- Tired of the war...
- A group of parents/professional in CO in 1992
- Created support for families with kids birth – high school...
- Autonomy at each chapter level while maintaining a vision for a shared enterprise
- Requests for educational advocacy support started rolling in...
PARENTS NEED(ED) TRAINING
- Now a national presence... 40 approved or provision chapters (including to 2 approved International and 3 provisional)/ 9 start ups (including 2 international)

The H&V Organization: Secrets of our success



- Credibility: Parents for parents
- Use-ability: Offering different forums for support (phone, newsletter, workshops, meetings, conferences, social events, etc...)
- Applicability: Choosing topics “where the rubber meets the road”
- Dependability: Consistency
- Realistically: Funding
- Replicability: TRAINED parents in every chapter

Hands & Voices Branded Activities:



- Guide By Your Side *embodies our strong values of direct peer connections and networking. It promotes self efficacy and hinders isolation by exploring our common bond, shared experiences, challenges, wisdom and insight.*
- Communication Considerations *series features national experts who've been invited to address DHH topics*
- Training Curriculums and On-Site Workshops *Parent & Professional*
- O.U.R. Children's Safety Project *Observe, Understand, and Respond*
- Annual Leadership Conference *Opportunity for ongoing training and development and sharing of the "wisdom among us"*

Hands & Voices Branded Activities:



- Social Events for Families

Picnics, Play dates, Mom's Night Inn, Dad's Night Out, Easter Egg Hunts, Holiday Parties, (with signing and speaking Santa), Literacy Night, Halloween Carving, Family Camping Trips, Spanish Speaking Fiesta with Pinata and traditional dancing, "Newly ID Picnics", Pen Pal Programs, Chucky Cheese Night out.....

- Research Partnerships with Universities and Agencies

- Parent Advocacy & Education Seminars

- Communicator Newspaper/Website/Resource Guides/Funding Toolkit/Videos/DVDs

Hands & Voices Branded Activities:



- Representation on Committees and Boards *locally & nationally*
- Thought-Leadership for Systems *focused & Effective on Deaf Ed. Reform, Deaf Child's Bill of Rights, Universal Newborn Hearing Systems, Early Intervention, Social/Emotional, Health, Hearing Aid & other Funding, Medical Home, Legislation, Systems Change, Communication Access*
- And More!

HANDS & VOICES CHAPTER COUNT



32 US and 2 International Chapters APPROVED

Colorado (flagship), Arkansas, Arizona, Delaware, Florida, Idaho, Illinois, Indiana, Iowa, Georgia, Kentucky, Louisiana, Maine, Michigan, Minnesota, Nebraska, New Mexico, Nevada, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming, British Columbia, and Kenya

10 US Provisional Chapter and Start -ups California, Connecticut, Hawaii, Military H&V, New Hampshire, New York, Missouri, South Carolina, Kansas, New Jersey

3 International Provisional Chapters Ontario H&V, CA, Kamay at Boces/Philippines, Pacific Hands & Voices (Guam, Saipain/CNMI et al)

Possible International Start –ups Australia, Nigeria, Italia

H&V Influencing Systems...



Just a few examples from our chapters...

- West Virginia
 - An energetic start-up that's already fundraising and building support with local stakeholders that's resulted in support to register three parents at our H&V 2010 Leadership Conference.

- Wisconsin
 - Hearing Aid/Cochlear Implant Legislation
 - Annual Statewide Family Conference

- Colorado
 - CO H&V and CO AGBell partnered for three years & finally won: Hearing Aid Legislation signed into law June 2008
 - Newly Created Booklet "Beyond the IEP"

- Florida
 - One of our newest start-ups is already on-line with a website, regular meetings and they rep'd H&V at the AGBell Conference in Orlando where we received in-kind exhibitor space thanks to AGBell!

- Minnesota
 - H&V GBYS is point of first contact in EHDI systems, funded from legislative pipeline

...every day, all over the country, we're heading out the door to represent H&V on committees, task forces, boards, coalitions....

And much More...

How do trained, motivated parents get Involved?



- *Parent led, centered, involved, directed...*
For their own child
- *Parent-to-Parent...*
For each other
- *Parent participation through advocacy...*
In the System

Not just involved... ...but leading the way



- **A person who guides others in action or opinion; a person of eminent position and influence is a leader.**
From the Oxford English Dictionary 5th Edition
- **Leadership** - “Bringing People to a place where they wouldn’t go on their own”

From Hands & Voices:

- **A parent leader is capable of effectively representing a consigned H&V agenda to impact/improve systems that serve children and families.**

Who can H&V parent Leaders *represent*?



- Their own family experience
- Looks beyond their own personal experiences to represent other family stories/experiences
 - Networks with other families; utilizes surveys of parent experience; often linked with parent organizations
- Other families you have met, read about, understand, know, have gotten input from

Utilizing Parents' Own Skill Sets



- **Leadership or visionary Level:**
 - (vision, risk, influence, value)
- **Managerial level:**
 - (communicate, coordinate, translate)
- **Task Level:**
 - (professional, technical, clerical, support)
 - ✦ Citation: 2002 CO nonprofit Leadership and Management Program



Hands & Voices Parent Training

We Are Hands & Voices . Supporting Families Without Bias. **Is This a “Deaf Thing?”** . **A Parents Wishlist for Professionals** . **Special Education Law & DHH Students** . **Advanced Advocacy for DHH** . **Beginning With the End in Mind** . **What Do I Say When...** . **The Art of Story** . **Communication Conflict Management** . **SIBLINGS** . **Encountering Emotions** . **Communication Considerations & Decision Making** . **Methods, Modes & Matches** . **Parents As Allies** . **Deaf Cultural Sensitivity & Etiquette** . **Spanish Speaking Family Support** . **Parents at the Podium** . **DHH CASE LAW** . **The Turbo IEP** . **What Parents Need to Know About Recommended Practices in Deaf Ed** . **The Deaf/HH Child’s Bill of Rights** . **Headin’ Em Off at the Impasse** . **A is for Access: How to Provide Full & Effective Communication Access for DHH Students** . **Parents from Hell & Other Advocacy Myths**, **Chapter Management**, **FUNDRAISING**, *and more!*

Creating a **SYSTEM** of Formalized Parent Involvement



- Mandating parent involvement through position papers/state guidelines/policies and practices
- Utilizing organizations
- Paid parent positions provide meaningful contribution
- Professional trainings accessible to Parent Leaders
- Parents who train other Parents
 - “Not about us without us”

Parent Leadership Applications

- Mentoring families with newly identified D/HH babies
- Advocating for individual student or full systemic improvement
- Providing thought leadership to program development and implementation
- Serving as parent consultants to programs and agencies
- Training professionals on sensitivity and awareness of family issues
- Providing end-user quality control oversight to services and systems



The Power of Parents



- 1 Parent = A fruitcake
- 2 parents = A fruitcake and a friend
- 3 parents = Troublemakers
- 5 parents = “Let’s have a meeting”
- 10 parents = “We’d better listen”
- 25 parents = “Our dear friends”
- 50 parents = A powerful organization

From the Parent Leadership Associates www.plassociates.org

Hands & Voices presents...





GUIDE BY
YOUR SIDE

- A program based on direct feedback from families sharing their opinions on what is most helpful to them: **direct support from experienced, trained parents of deaf/hh children.**
- Modeled after H&V unbiased support philosophy and replicable in early intervention systems.



From the Beginning - GBYS Genesis to Revelations



- **Desire to Formalize what we have always done – *parent –to-parent support***
- **Hands & Voices – Takes on the Guide By Your Side Program and replicates nationally**
- **Vision, creation, policy, guidance, operations, values, procedures...**

RESOURCES

□ **We have...**

- GBYS head quarter advisory and oversight committee
- GBYS Operations Manual and FAQ
- GBYS Website Section
- GBYS Yahoo Group
- Each other
- The Book of Choice

● **NEW:**

- GBYS “Guide’s Guide”
- Policy Clarifications
 - Indicators of Chapter and GBYS program cohesion
- Staff positions at the head quarter level

GBYS Programs

18 GBYS Implemented Programs

- Arizona: Jeanne Hollabaugh
- Colorado : Janet DesGeorges, Sara Kennedy
- British Columbia, Canada: Teresa Kazemir
- Delaware: Julie Johnson
- Illinois: Carrie Balian
- Indiana: Lisa Kovacs
- Iowa: Susan Hagerty
- Kentucky: Susan Francke
- Louisiana – Mariah Ranko
- Maine: Darlene Freeman
- Michigan: Denise Farrand
- Minnesota: Candace Lindow Davies
- Pennsylvania: Anne Gaspich
- Oregon: Helen Cotton-Leiser

- Texas: Debbie Kopp
- Washington: Christine Griffin
- Wisconsin: Laurie Nelson
- Virginia: Bailey Vincent Clark

8 GBYS START-Ups (Has shown interest)

- Georgia
- Arkansas
- Idaho
- New Mexico
- North Dakota
- Ohio
- Utah
- Nevada

Guide By Your Side™

is a Hands & Voices program that embodies our strong values for direct peer connections and networking.

It promotes self efficacy and hinders isolation by exploring our common bond, shared experiences, challenges, wisdom and insight.



What do GBYS Guides do?

Guides Do...

- . Know how to share their personal story concisely & appropriately
- . Provide unbiased, non-judgmental emotional support
- . Go with the family's agenda
- . Share resources and information in a comprehensive, equitable manner
- . Maintain ethical standards and actively develop their knowledge-base to help families make informed decisions.

Guides Don't...

- . Sway a family's opinion through bias
- . Manipulate a family towards a decision
- . Air their personal issues & put themselves in the spotlight
- . Provide intervention or professional services
- . Give medical advice or share medical/clinical opinions about services or providers

Hands & Voices Guiding Principles
are constant, but
GBYS custom applications
are a fixture of the program!



Program Elements



Your state GBYS Program may consist of one or more of the following elements:

Parents as “Follow-Up” Support

- Reduce the risk of loss to follow up by connecting Parent Guides to families with babies who do not pass the newborn hearing screening.

Parents as Point-of-First Contact

- Provide timely parent-to-parent support at the time of confirmation of hearing loss.
- Offer specific support and resource dissemination about deafness/hearing loss

Parent support during and after EHDI

- Assure continuity to families by providing support throughout a child’s life, especially at times of transitions.

Support families through the early intervention years by combining an experienced parent’s insight with knowledge of early intervention and educational systems. GBYS programs can also support families with older children and teenagers.

Program Elements...



Parents as Change Agents

- Influence and improve the systems
- Representation and collaboration

GBYS D/HH Guides

- Allows parents to possibly “see the future” for their child
- Provides children with an opportunity to identify with an adult
- Allows families to hear real life experiences from a person with hearing loss
- Exposure to D/HH adults can provide families and D/HH children/youth with invaluable perspectives that come from personal experience.
- GBYS does not “proscribe” what a DHH Guide does for/with a family...that directive comes from the family—based on what they want from a Guide.

Guiding Principles



- **Parent leadership**
- **Collaboration within state**
- **H&V Values ...Nonbiased/full range of options, parent leadership, and more**
- **Cultural representation and sensitivity**
- **Supporting families unique needs**
- **Cohesion with GBYS programs nationwide**
- **All Guides are paid**
- **Ongoing training and support for Coordinators and Guides**

GBYS Program Goals



Goal 1: provide parents with the opportunity to **establish a supportive relationship** with an experienced parent of a child who is d/hh soon after they learn of their child's hearing loss.



Photo by Widex

GBYS Program Goals



Goal 2: Provide an understanding of the unique needs of infants who are deaf or hard of hearing.

Goal 3: Provide unbiased information regarding communication options.

Goal 4: Link families to resources locally, regionally, and statewide

Goal 5: Ensure that families are linked to their county Birth to 3 Program or local school district



GBYS Program Goals



Goal 6: Ensure that families are connected to other parent to parent resources

Goal 7: Ensure that families have an opportunity to create context for their own child's life by connecting to Adult Role Models who are Deaf/Hard of Hearing.

Goal 8: Ensure that families' voices are heard in the systems that are serving them.

What Do We Look for in Guides?



- **Firsthand knowledge of joys and challenges of raising a D/HH child or growing up as a Deaf or Hard of Hearing**
- **Sensitivity to the range of emotional responses**
- **Positive resolution about their own life and professional relationships**
- **Open and honest communication style**
- **Interpersonal skills which empower**
- **Sense of humor**
- **Information about the system and resources specific to the family of the D/HH child**
- **Ability to communicate how to meet the unique needs of a child who is deaf or hard of hearing including communication tips and strategies**
- **Unbiased information about modes or methods of communication**
- **Formalized GBYS training from and on-going affiliation with Hands & Voices**
- **Multiple year commitment**

"Our Guide was outstanding in every aspect. She made us aware of programs and gave us support to pursue them. "

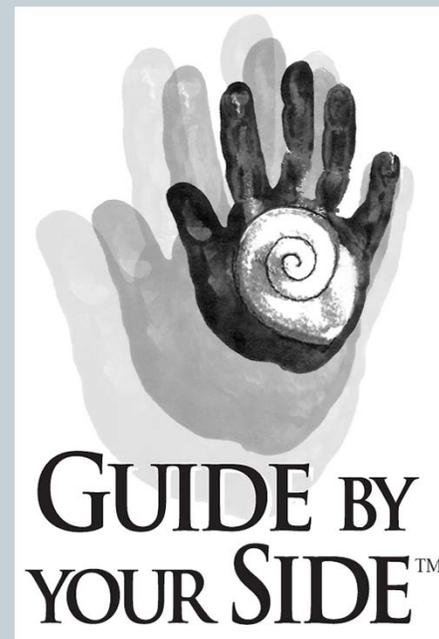
"She was the boost we needed to find resources for our daughter. Thank you for offering the GBYS Program."



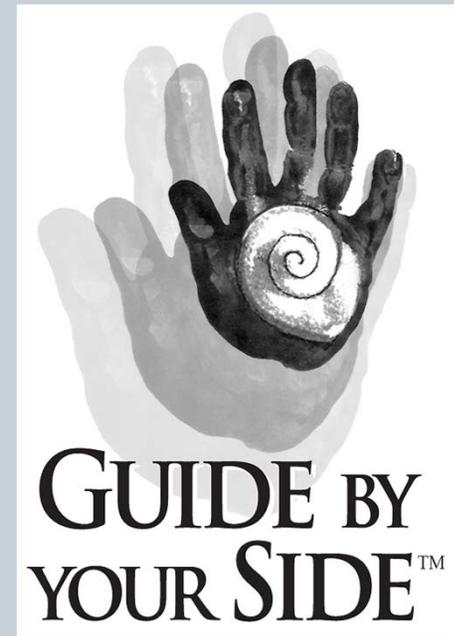
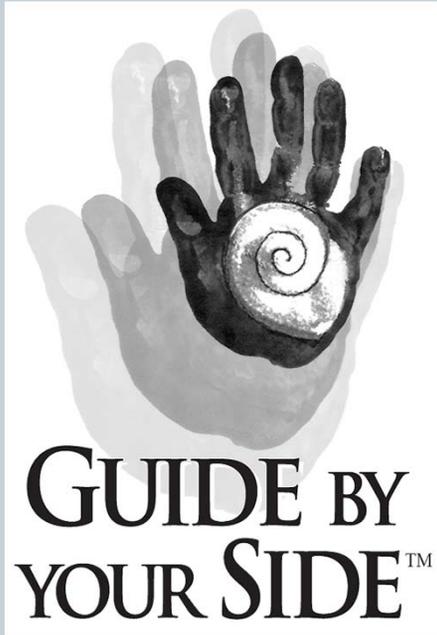
“The Guide talked to us like hearing loss was normal.

I want to be like that.

I just knew after talking with the Guide that everything was going to be okay.”



Thank you!



Hands & Voices
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www.handsandvoices.org