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Voicing Diversity: Creating Space to Listen in the Healthcare System

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Voicing Diversity: Creating Space to Listen in the Healthcare System

By

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Abstract

Throughout the United States over 20 million people do not speak English as their primary language. As part of legislation and The Joint Commission, health care organizations are required to provide interpreter and translation services to individuals with limited English proficiency (LEP). Through the provision of language services health care professionals can provide quality care that is patient centered and culturally sensitive to the needs of families. As communities continue to be transformed and become multicultural so too the healthcare system needs to transform, growing resources that empower and educate patients helping them navigate the healthcare system.

Dedication

In loving memory of my mother Carolyn M. Foster who loved her patients and family well. And in recognition to those whose story and journey inspired my research and continued call in life to create space to listen, your voice matters.

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Introduction

Sitting in a child development class, the professor posed the question, “What lens are you looking through?” In other words, what experiences in life have transformed the way in which you interact with the world around you? As I took a seat on the train that night, I realized I chose to sit next to a person based on how they made me feel. Whether it was their outfit, their demeanor, or even their smell, I inadvertently had placed them above or below me on a human scale. I had judged them without knowing their story, and perhaps at the heart of my choice was fear and ignorance clouding my lens. While interning in a pediatric healthcare setting, a new question emerged through observation and research: how do I create opportunities for individuals to tell their story?

Child Life Specialists (CCLS) are devoted to providing holistic care by serving and engaging with pediatric patients and families of all backgrounds. They value the importance of partnering with the healthcare team to create a child-friendly, healing environment to minimize fears, encourage normalization, and promote optimal development. The CCLS utilizes knowledge of family systems and child development to provide children with therapeutic and medical play opportunities, procedural preparation and support, medical education, and emotional support to guide and empower.

In New York City, child life specialists work with people from diverse cultures

encountering a multitude of languages. Creating a space to hear a patient or family member means also giving them a voice in their language. Children's literature, signs, and documentation only in English restricts a patient from participating in their own healthcare and sends a message that their voice does not matter. This paper explores the historical background of non-English speakers in New York, hospital and state regulations for language provision, and the dilemmas encountered when assessing patient and family needs. Research will help support the rationale for a meet and greet language resource for child life professionals in multiple languages highlighting the importance of patient and family centered care.

Historical Background

New York City because of its central location and deep harbors has been an initial point of entrance for diverse populations of migrants seeking new opportunities. From as early as 1664 when the Dutch colonists sought to create a New Amsterdam, waves of immigrants such as French, Irish, German, and Jewish groups have transformed and diversified the city that is today (Binder, F. & Reimers, D, 1996). With each new influx of immigrants, residents often have shown discord toward the immigrant population ranging "from nostalgia to benign indifference," more often reactions of contempt and fear have arisen to the front headlines (Igoa, 1995, p.vii). The most recent immigrants have been restricted by racial discrimination, bigotry, and intense prejudices.

> When immigrant children leave the country that was their home--a familiar language, culture, community, and social system--they experience a variety of

> emotional and cognitive adjustments to the reality of life in a new country. (Igoa, 1995, p. xi)

As a result, culture shock can often ensue with unfamiliar signs and symbols of a new culture. Survival instincts are set in motion and are more acute with each additional unidentifiable marker. This can in turn increase the likelihood of a child experiencing intense emotions (Igoa, 1995). Within society there is often the assumption that a child will adapt easily, however when a child is silenced because of an inability to speak in their native language, isolation, regression, and loss of identity can occur.

Developmental psychologist Vygotsky theorized that, "social experience shapes the way of thinking and interpreting the world available to individuals," (Berk, L., and Winsler, A.,1995, p.12). Further, "he regarded language as a critical bridge between the sociocultural world and individual mental functioning," and "the most significant milestone in children's cognitive development," (1995, p.12). Through individual accounts and research Otto Santa Ana in his book *Tongue-Tied the Lives of Multilingual Children in Public Education* brought to light the disservice given to immigrant children within the education system. Upon initial entry to school, non-native English speaking children over the years have been taught to drop their native language and speak English. It was further suggested that their native language should be spoken at home classifying it as a private language. As a result, cognitive development and individual mental functioning is stifled. This type of ideology and monolingualism stems from European colonialism it creates a scale of civilized versus primitive, superior versus inferior, educated versus non-educated and ultimately causes segregation and oppression, (Santa

Ana, 2004). It could be assumed that English is classified as a 'White Privilege' or 'Middle-Class Privilege.' Sonia Nieto a professor in the School of Education at the University of Massachusetts in Amherst highlighted a journal entry in her multicultural education series:

> We have plenty of warm friendly teachers who tell the kids nicely to forget their Spanish and ask mommy and daddy to speak to them in English at home; who give them easier tasks so they won't feel badly when the work becomes difficult; who never learn about what life is like at home or what they eat or what music they like or what stories they have been told or what their history is. Instead, we smile and give them a hug and tell them to eat our food and listen to our stories and dance to our music. We teach them to read with our words and wonder why it is hard for them. We ask them to sit quietly and we'll tell them what's important and what they must know to "get ready for the next grade." And we never ask them who they are and where they want to go. (Nieto, S., 1999, p. 86)

In the United States, it was not until 1968 over ten years after Brown vs. Board of Education that Title VII of the Elementary and Secondary Education Act also known as the Bilingual Education Act was set into motion. Title VII promoted ESL and the training and education to support bilingual curriculum. Bilingualism and biliteracy require the individual to recognize morphology, phonology, syntax, semantics, and pragmatics, (Luz Reyes, M., 2011). It requires intellect and mastery, and should not be attached with classifications such as inferior or uneducated. In 2002, the No Child Left Behind Act, ended the Bilingual Education Act, "reversing thirty-four years of U.S. language policy

in public schools."

> Languages do not exist independently from the people, families and communities that use them. In other words, language and ethnocultural identity and existence are inextricably linked…when people lose their native language to English; they do not become Anglos and obtain social acceptance. They lose the language as a tool for accessing the help their families and communities can give them. (Soto, L., 2002, p. 53)

Families coming to the United States seeking refuge and asylum, usually come with very little belongings, often having lost everything in their home countries. Language becomes a way to hold onto identity and culture.

State and Government Language Provision Policies

In accordance with the Civil Rights Act of 1964, Title VI section 601 states, "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Failure to provide interpretations services is considered discrimination and does not provide equal access to healthcare. In 2000, President Clinton authorized the Executive Order 13166 *Improving Access to Services for Persons with Limited English Proficiency*. Under this legislation, organizations are required to evaluate systems ensuring that those with LEP have equal access to systems. Because of this legislation, the New York Department of Health as part of a Statewide Access Language Policy created a Language

Access Plan for LEP Individuals to protect individuals within the state and to promote healthy living.

In determining the needs of the state, data was gained from several different sources such as the U.S. Census Community Bureau, school data systems, Office of Motor Vehicles, Social Service Agencies, and the Migration Policy Institute. From the data obtained in 2015, there were 1,230,302 Spanish speaking individuals with LEP, 329,482 Chinese speaking individuals with LEP, and 130,961 Russian speaking individuals with LEP throughout the state of New York, (NYSDH, 2015). Once individuals are identified, it is required that all organizations provide patient rights to language provision both vocally and in written form. Secondly, competency of interpretation and translation services is reviewed. Through this process interpreters are reviewed based upon their training, certification, and their ability to speak, read, and write in a language other than English. When translating documents, forms are first identified as being vital such as consent forms or intake forms and then reviewed for "plain language compliance prior to translation," (NYSDH, 2015). In all cases, proper training should be ensured as well as compliancy to HIPAA confidentiality standards.

Hospital Language Provision Policies

As observed, in conjunction with state and governmental protocols and patient and family centered care, hospitals are developing best practice standards to meet language needs. Listed throughout the hospital are patient's rights to have free access to language services in several languages, such as, Spanish, Traditional Chinese, and

Arabic. It is the role of the healthcare professional to ask the preferred language, and once known to record in patient's Electronic Medical Record (EMR). The preferred language should be used for each encounter at the healthcare facility. If patient is scheduled for an appointment, language services should be established and scheduled prior to visit. As hospitals provide language needs, often specific distinctions are made for translating and interpreting services. Translation is specific to written documentation. Sight translation is reading of medical documentation when documentation is unavailable in a patient's preferred language such as content forms. Interpreting is verbal communication, this can be done through over-the-phone interpretation, video remote interpretation, and direct in person service. It is permitted by some hospitals for bilingual staff members to speak with preferred language. Friends and minors should not be used as interpreters, unless in case of emergency (NYP Quality & Safety, 2016).

Hospitals often communicate a policy of "providing affective communication," (NYP Policy and Procedure, 2016). Providing language communication is not only for limited English proficiency but for those who are deaf or hard of hearing, visually impaired, or speech impaired. The goal for most hospitals is to meet the demographic needs of the community, which requires the necessity for continual evaluation of language services. For services to be affective there needs to be consistency and specific implementation guidelines for all staff members, (NYP Policy and Procedure, 2016). Trainings and education for staff members on how to effectively communicate with individuals with limited English proficiency will help to create culture sensitivity as well as affective use of language provision services. In all cases the first goal should be in

person interpretation secondary to over the phone interpretation. The interpreter should be a known trained certified professional contracted by the hospital. All written documentation should in turn be vetted through the department of language and interpreter services to avoid error.

Translation and Interpreting Dilemmas

As healthcare organizations attempt to "provide affective communication," often challenges arise that cause adverse effects in quality of care (NYP Policy and Procedure, 2016). As observed and vocalized by several staff members is the need for increased interpreter services. In most cases because of budgetary costs, in-person interpreters are limited. While the goal is first to provide in-person interpretation, this often does not occur. Predominantly an in-person interpreter was scheduled only for pre-known appointments and in the case of family meetings when more than one medical provider was scheduled to be present. While the hospital was researching affective use of video interpretation, systems were limited and required pre-scheduling for use. As in most hospitals, interpreters are shared by several different departments or contracted outside of the hospital. As a result, information pertinent to the well-being of a child was often delayed in communication to the family.

In most cases, medical personal used over-the-phone interpretation to help assess patient needs, verify patient history, and relay information. Often during over-the-phone interpretation, it was a challenge to hear the interpreter amidst other background noise. In several encounters and observations, it was noted that phone communication was often

disconnected because of low service. As a result, communication varied in the amount of information shared by both caregiver and provider in correlation with the needs of the child.

In a study done by the Robert Wood Johnson Foundation in correlation with a research program *Speaking Together*, it was found that the quality of care was directly linked with the quality of interpreter and translation services provided, (RWJF, 2007). Patients with limited services often had decreased understanding of diagnosis and treatments in relation to English speaking patients. With limited knowledge, research showed increase of non-compliancy towards medications and follow-up visits. Conclusively, research revealed the need for interpreter education, uniform standards of implementing services, and training for medical staff working with interpreters.

Untrained interpreters may be unfamiliar with medical language and the variations of treatments among hospital departments. Untrained interpreters will often impose their own views of healthcare and summarize communication, (RWJF, 2007). As observed through work in the refugee population, a patient may decline services due to inability to understand interpreter dialect, such as, having the wrong language interpreter. The patient would rather be polite and not show their confusion than relay the error on the part of healthcare team. This was seen when an Iraqi Arabic interpreter was contracted for a Sudanese Arabic patient. As illustrated by the Bronfenbrenner social development model, if language reflects culture it is influenced by an individual, family, community, state, and country. Therefore, there are variations of one language, such as, phrases, definitions of words, and intonation, such as when talking with an individual

from Boston, Massachusetts versus talking with an individual from Montgomery, Alabama or individuals from London, England and Sydney, Australia. With ineffective interpreting standards, a hospital can be made liable for patient safety. The varied emotions and experiences that can arise when a child has an injury or is diagnosed with an illness mixed with an unfamiliar environment and a family may "feel lost amidst the chaos," (Lee, 2014). Dr. Thomas Lee suggests taking the time to understand and connect with a family can help bring change within a hospital's environment and staff as well at the experience of the patient and family.

Benefits of Quality Language Provision

When organizations affectively promote change for culturally sensitive practice through supporting individuals with limited English proficiency, it has positive effect on the development of the child and their long-term relationship with the healthcare system. Families who receive quality language provision are more likely to understand diagnosis and show compliancy during treatment. Families are more likely to be involved in the health of their child and more able to make better choices for the safety of their child and their family unit. One study in the Massachusetts division of health revealed quality language provision to be financially viable, (Jacobs, Shepard, Suaya, & Stone, 2004). Costs of service were attributed to interpreter services and year-long health expenses. Within the second year, costs were decreased and research revealed patients and families increased participation in primary and preventive care, (Jacobs, Shepard, Suaya, & Stone, 2004). This was associated with prescription drug compliance, physician visit compliance, and increase in patient satisfaction. It has been found within the school

system when educators promoted value and respect for their student's language and culture and celebrated diversity, it enhanced communication and increased student self-esteem, (Santa Ana, 2004). This filtered into respect for the family which transformed caregiver involvement in the education of their child and involvement in the community. Therefore, how do child life specialists encourage native languages and culture and create a space to listen?

Child Life Specialist Role

The role of the child life professional has changed over the years from creating normalcy with therapeutic play to helping provide holistic care for the whole family. The mission of the child life specialist established by the CLC is "to reduce the negative impact of stressful or traumatic life events and situations that affect the development, health, and well-being of infants, children, youth and families," (Official Documents of the CLC, 2002, p.1). A child life specialist should "embrace the value of play as a healing modality to enhance the optimal growth and development of infants, children and youth through assessment, intervention, prevention, advocacy, and education." (Official Documents of the CLC, 2002, p.1) Considering the theories laid out by child psychologists and the mission of the organization, child life specialists provide learning opportunities for understanding procedures, help to instill coping mechanisms for processing pain and anxiety, and work as an advocate for both the child and caregivers.

The child life specialist through age appropriate activities such as medical play or other expressive therapies has a unique opportunity to build relationships creating an atmosphere of trust and respect. This opens the door for both the child and family to

receive help and to validate their feelings. Through communication and play modalities the specialist can assist the child and family to acclimate to the hospital setting, understand any clinical procedures and protocols during their stay, assess pre-existing anxiety or fear in relation to the health care setting, and identify current coping mechanisms. (Gaynard, et. al, 1990) Further, a child life specialist helps to advocate for both hospital and child by working to keep the lines of communication open between hospital and caregiver and to help provide the quality care for the child and family unit. (Webb, 2009) Advocacy can be in the form of ensuring equal access to healthcare through language provision.

When preparing medical education and expressive therapies, child life specialists should be mindful of the child's learning style and educate through the patient's lens and not the CCLS's own cultural view. Art and music can reflect the patient's culture helping to normalize the hospital setting. Further, feeling charts, communication boards, and activities can be provided in multiple languages to help empower the patient and family.

Child Life Language Interventions

To improve the quality of language provision, I created a Meet and Greet Language Assistant book as a tool to establish communication when interpreting services are delayed or unavailable. The book follows the steps of assessment for a child life specialist from initial greeting, introduction of child life services, and questions to get to know the patient and family. The book can be adapted by child life professionals specific

to each case encounter and should be used alongside a caregiver. This then fosters inclusion of caregiver role and helps assist children who are non-verbal or unable to read.

In accordance with the data from New York Statewide Access Language Policy, Spanish and Traditional Chinese were chosen as first languages for document translation. As part of research, I worked with both a certified language company for translation of Traditional Chinese and bilingual students for Spanish translation. In preparing the book, I was mindful to use "plain language." "Plain language" stems from a 1998 *Memorandum on Plain Language in Government Writing* issued by President Clinton, (USDHHS, n.d.). The term "Health literacy" was termed by the 2000 National Library of Medicine, (USDHHS, n.d.). "Plain language" and 'Health literacy" are terms identified as ensuring that all individuals have equal access to understanding public policy and healthcare options, (USDHHS, n.d.).

In New York City, the three major Chinese newspapers are all in Traditional Chinese versus Simplified Chinese. Therefore, Traditional Chinese was chosen to reach a broader audience of readers amidst the community, (see Appendix A). When working with both a translation organization and bilingual interpreters, both clarified language preferences, often providing variations of sentence structure as alternative options. Throughout, I strove to choose language that was clear, plain, and developmentally appropriate for ages two to twenty-one.

When asking questions, such as, 'who is with today' or 'who lives with you,' I tried to be sensitive to different family structures and cultures, (see Appendix B.) When asking questions about school activities and home activities, I included a variety with

developmental variations, activities specific to temperaments and was mindful of the multiple intelligence learner, (see both Appendix A and B for examples). All illustrations throughout are my personal original designs. Throughout the book, I tried to be diverse with images that are relevant to the current interests of children. The overall goal is not to replace an in-person interpreter, but serve as a tool for supporting individuals with limited English proficiency. In the future, I hope to provide additional translations, such as, Arabic, Russian, and Hebrew. Additionally, the goal will be to have the book accessible via the Internet with sound functions to help vocalize translation to assist those who are non-literate. Overall, the tone of the book is to create an atmosphere in which patients and families feel heard and valued thus sending a message their story matters.

Along with the Meet and Greet Language Assistant book, I created a website entitled Voicing Diversity, (see Appendix C). The website encourages child life professionals to diversify play materials, enrich children's literature through variations of language, and provide culturally sensitive material when creating therapeutic interventions, (see Appendix C, resource pages). The website provides resources and information specific to language and diversity. It highlights several different organizations and current events as way to educate and inform, and promote the importance of an individual's story, (see Appendix C, Storytelling and Events). The goal will be to continually update the website with current information throughout my professional career as a child life specialist.

Conclusion

As healthcare organizations continue to promote patient and family centered care,

necessary language provisions should be in place to aid the quality of centered care. Creating funded jobs for interpreters to become part of the medical team would decrease the amount of time a patient is left waiting for an interpreter. This would lower emergency room costs and aid in reducing medical confusion of patients and families. Providing literature, documentation, and interpretation in multiple languages, acknowledges the multicultural needs of the community. It creates a space for patients to be affectively heard.

> Shifting how we think about language and how we use it necessarily alters how we know what we know...I suggest that we may learn from spaces of silence as well as spaces of speech, that in the patient act of listening to another tongue…we may disrupt that cultural imperialism that suggests one is worthy of being heard only if one speaks in standard English. (Santa, A. 2004, p.251)

Creating a space to listen means letting native tongues and cultures sing. Listening, requires one to stop, to position one's own body and mind in an attitude to receive. Listening, requires one to take witness of what is being unsaid through body language, tone of voice, and rhythm of syntax of the story teller. Listening, requires acknowledging their story without interjecting one's own. Listening, may call one to understand truths, to recognize beauty, and as a result call one to action.

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Appendix A

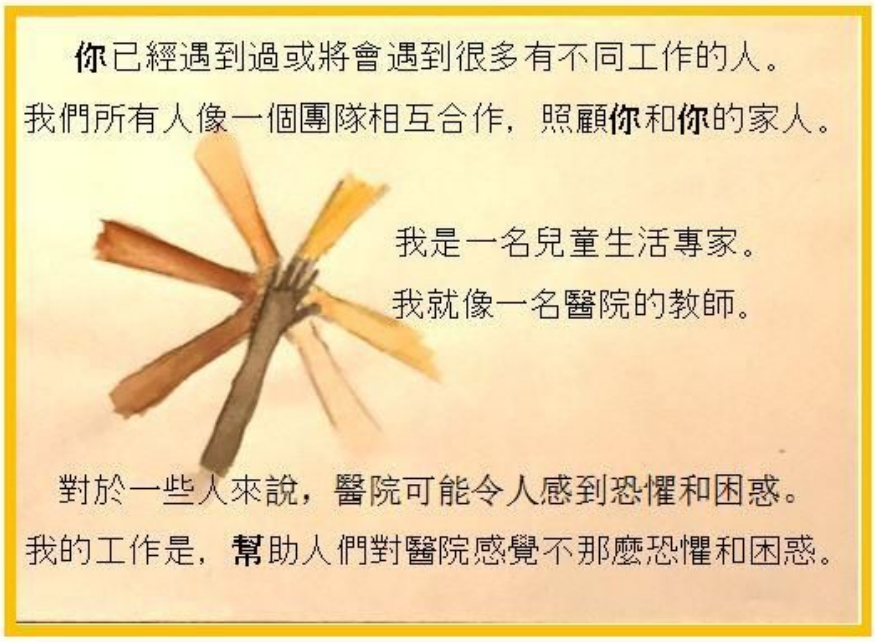
You have met or will meet a lot of people with different jobs.

Like a team, we all work together to take care of you and your family.

I am a Child Life Specialist.
I am like a teacher for the hospital.

For some people, the hospital can feel scary and confusing.

My job is to help make the hospital feel not so scary and confusing.



file:///C:/Users/margelizfost/Documents/Child%20Life%20Language%20Assistant%20Traditional%20Chinese.pdf

Appendix B

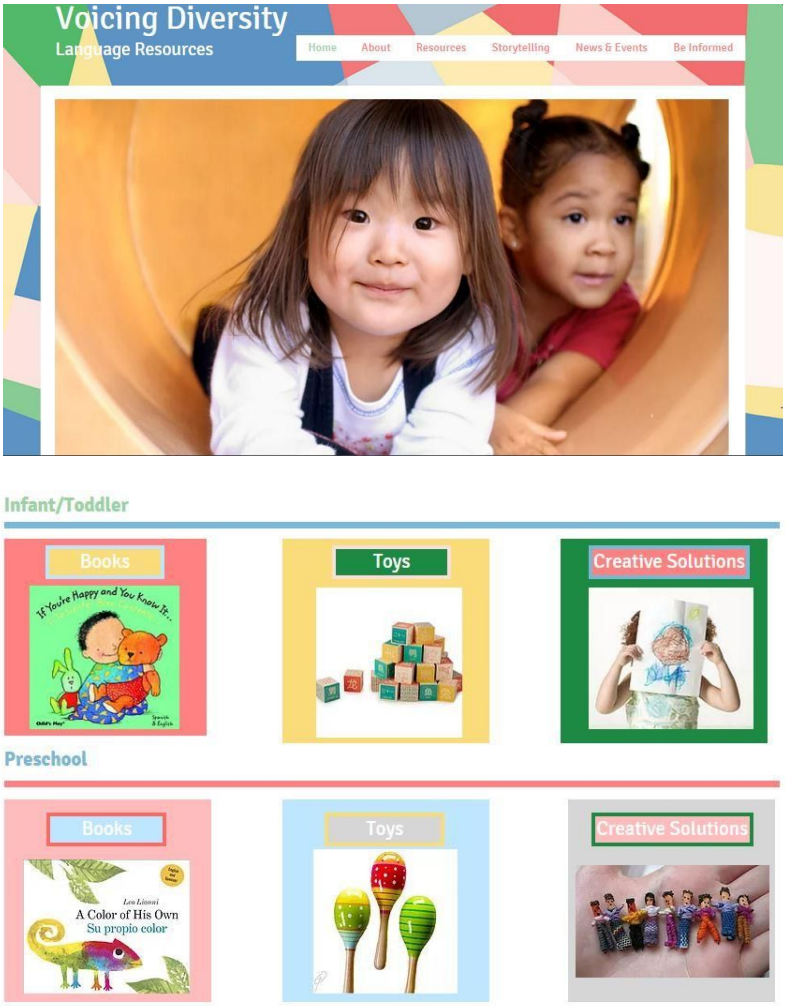
Who lives at home with you?

Father	Mother
Grandpa	Grandma
Brother	Sister
Uncle	Aunt
Foster Father	Foster Mother
Friend	Cousin
Pet	

file:///C:/Users/margelizfost/Documents/Child%20Life%20Language%20Assistant%20Spanish.pdf

Appendix C

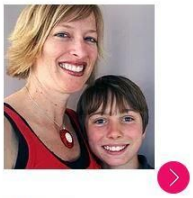
www.mfoster431.wix.com/voicingdiversity



TedTalks

Chimamanda Ngozi Adichie
The danger of a single story
Our lives, our cultures, are composed of many overlapping stories. Novelist Chimamanda Adichie tells the story of how she found her authentic cultural voice — and warns that if we hear only a single story about another person or country, we risk a critical misunderstanding. -TedTalk

StoryCorps



Jennifer and Grant Coursey
How do you think you've changed?
StoryCorps' mission is to preserve and share humanity's stories in order to build connections between people and create a more just and compassionate world. We do this to remind one another of our shared humanity, to strengthen and build the connections between people, to teach the value of listening, and to weave into the fabric of our culture the understanding that everyone's story matters. At the same time, we are creating an invaluable archive for future generations. -StoryCorp

Create Your Story

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my storybook

susan Kapuscinski gaylord
makingbooks.com

kids activities Blog

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SCHOLASTIC STORY STARTERS