



Hospitalized children using computer technology for self-expression

Winter 2001

Anuja Dharkar  
Heather Laird  
Tacy Trowbridge

# Table of Contents

<b>Abstract</b> .....	4
<b>I. Site Description</b> .....	5
A. Hospital.....	5
B. School .....	5
C. Technology .....	6
D. Child Life Philosophy.....	7
E. Recreation Room .....	7
F. STARBRIGHT.....	7
<b>II. Needs Assessment</b> .....	8
<b>III. Curriculum Rationale</b> .....	9
<b>IV. Curriculum</b> .....	11
A. Description .....	11
B. Goals .....	11
Primary goals.....	12
Secondary goals.....	12
<b>V. Facilitator Guide</b> .....	13
A. Goals.....	13
B. Introduction.....	13
C. Brainstorming .....	13
D. Audience.....	13
E. Culture and Diversity .....	14
F. Safety and the Internet .....	15
G. Dealing with Emotional Issues.....	15
H. Teaching Strategies .....	16
I. Helping People use Computers .....	16
J. Allies.....	17
K. The Gallery.....	17
L. Useful Equipment .....	18
<b>VI. Activities</b> .....	19
A. Digital Art: Create a Collage.....	20
B. Intrepid Explorers Wanted.....	31
C. Documentary 101: Sharing Your Life.....	33
<b>VII. Assessment</b> .....	36
A. Child Rubric .....	37
B. Activity Rubric .....	38
C. Your Opinions .....	39
D. Activity Assessment .....	40

E. Digital Voices Assessment .....	41
<b>VIII. Appendix.....</b>	<b>42</b>
A. Resources.....	42
Hospital Programs .....	42
Hospital Allies.....	42
Job Description for the Technology Intern.....	45
Technology Standards for Children .....	46
Websites .....	47
Gallery Flier .....	48
B. Contributors .....	49
C. Process .....	50
D. Additional Information.....	54
Interview with Dr. Brie Williams.....	54
Interview with Lisa Karpanty.....	54
Hospital Map .....	56
Meeting with Cammy Sunde and Thayer Gershon .....	57
LPCH Hospital School Program .....	59
Email with Jordana Huchital .....	60
STARBRIGHT Information.....	62

## **Abstract**

*Digital Voices* is an innovative, student-centered curriculum for patients at the Lucile Packard Children's Hospital that encourages self-expression, while developing technology skills in the process. In order to serve an especially diverse and variable population, this is an extremely flexible, non-linear curriculum designed for an informal learning environment and can easily be tailored for a range of ages, group sizes, and abilities. The curriculum is comprised of self-standing activities led by a facilitator and supplemented by computer tutorials and peer mentoring. If participants choose to share their work, finished products will be displayed in an online gallery that can be viewed by children's friends, families and classmates.

# **I. Site Description**

## **A. Hospital**

Lucile Packard Children's Hospital at Stanford University Medical Center is a 240-bed hospital run by 1,648 employees, 762 staff physicians, and more than 2,830 volunteers. Every year 14,788 inpatients and 82,278 outpatients come to the hospital from all around the world.<sup>1</sup> The hospital and its staff demonstrate a clear commitment to both make the hospital a comforting place for children to receive medical care and to help them recover. In addition to doctors and nurses, there are child life specialists, recreational therapists, teachers, and volunteers who all work to help children heal and return to the outside world. The building was designed and decorated with children and healing in mind. It encircles a central courtyard with 27 gardens and outdoor play areas, including a roof garden to maintain a connection with the outdoors and nature. Children's art decorates the walls, the halls are well lit and carpeted, and animal topiaries grace the entrance.

Lucile Packard Children's Hospital offers treatment for childhood cancers, blood disorders, cystic fibrosis, bone marrow transplants, organ transplants and orthopedic conditions. There is a specific unit for patients with medical conditions like bulimia that have psychiatric components. The hospital also serves the local community for general pediatric medical needs. Some of the patients who are in the process of transitioning out of the hospital live at the local Ronald McDonald house or with their families at home.

In line with trends in adult healthcare, there has been a strong move towards more outpatient care because of the insurance system in the United States. Depending on their insurance coverage, children tend to leave the hospital sooner and are readmitted more often. This has changed the role of teachers and staff in supporting the needs of these children.

Patients are children of all ages, from all over the world and with all kinds of medical conditions. Some do not speak English as a first language, if at all. They may stay for months or just a few days depending on their insurance and medical condition. It is not unusual for children to be in and out of the hospital for years. According to their teachers and child life specialist, all of these different children need to learn and grow. The school, the recreation room and a range of Child Life programs work to address children's social, emotional and intellectual needs.

## **B. School**

Since 1924, the hospital has collaborated with the Palo Alto Unified School District to provide educational services for patients. Throughout the school year, the district employs three teachers, three instructional aids and a secretary to implement an individualized program from Kindergarten to 12<sup>th</sup> grade. These teachers work with different age groups: primary, intermediate and secondary for two hours in the morning and an hour and a half in the afternoon and offer bedside teaching if patients cannot

---

<sup>1</sup> Lucile Packard Children's Hospital website. <http://www.packardchildrenshospital.org>.

attend classes. Most days, each section has four to eight students attending and an additional four to eight students are seen bedside. These teachers adapt their curriculum to the length of the child's stay in the hospital, their academic abilities, and other individual circumstances. Most of the work tends to be individual as the community of students changes from day to day in terms of who is in the hospital and able to attend class. Computers are available in the classrooms and as part of the bedside program and are used for word processing, educational programs and some recreational programs.

Teachers describe challenges in this setting:

- Today, children with serious illnesses need more attention paid to their education because they are living longer and potentially richer lives.
- Reentry to their home schools is becoming a larger issue.
- Schools feel pressure to meet standards and to score well in high-stakes testing and do not always want to risk adapting to the needs of a sick student.
- Hospital teachers cannot create formal Individualized Education Plans and only offer recommendations to home schools unless the Palo Alto School District plans to pay for these services.
- Patients must be advocates for themselves in their healthcare and reentry into schools.
- Parental and patient expectations are not always realistic and do not take into account that students cannot be expected to maintain the same level of commitment and achievement as they did prior to their hospitalization.
- Young people with eating disorders are hospitalized for longer periods of time; some receive their entire high school education at the hospital.
- There is evidence of cognitive impairment due to eating disorders.
- Only psychiatric patients are required to attend school as part of their therapy.
- The non-psychiatric patients are not required to attend school but are encouraged by the teachers because they believe it is beneficial for all children to know that people are concerned about their education and re-entry.
- Maintaining a familiar routine can be important and reassuring for children in the midst of disruptive and often unpredictable changes.

### **C. Technology**

The use of technology can support learning in this environment in many ways. Computers are well suited for individual work and offer flexibility in terms of location and timing. Email and the Web offer opportunities for closer communication between patients and their home schools and can reduce the sense of isolation. Computer simulations can expand the kinds of instructional options available to teachers and students. There is a need for academic and recreational activity, both of which can be enhanced by computers.

Important considerations for technology use

- Communicating with the home school is easiest when the school already posts homework on the Web.
- The Internet connection does not always work in the high school and middle school classrooms.
- Some rooms have an Internet connection but not all.

- High school students check email on their own.
- All children have VCR's in their rooms and can have access to a bedside computer.
- Video is a familiar, motivating and effective medium for these children.
- Wireless networks would be wonderful but interfere with hospital equipment.
- Videoconferencing would be useful for high school students but potentially too distracting for younger students.
- Patients keep track of each other sometimes for years.
- CD-ROMs work well and can help in areas such as English language acquisition or science lab experiments, which are difficult to support in this setting.

#### **D. Child Life Philosophy**

The Lucile Packard Hospital has a strong Child Life Program to support the needs of children and their families. They describe this program as aiming

“to reduce the impact of stressful or traumatic events and situations which affect the development, health and well-being of infants, children, youth and families. We embrace the value of play as a healing modality as we work to enhance the normal growth and development of infants, children and youth through assessment, intervention, prevention, advocacy, and education.”<sup>2</sup>

The Child Life professionals support a broad variety of programs and have designed age appropriate physical spaces such as the recreation room with these goals in mind.

#### **E. Recreation Room**

A newly renovated recreational therapy room is as a safe place where patients of all ages can relax, do crafts projects, play, watch movies, use computers, and interact with other children. No medical treatments that children might find frightening or painful ever happen here. Doctors and nurses tend to be very respectful of this need for a safe and comfortable place. Specific areas of the room are targeted towards different age groups with a craft table in the center, a play corner for younger kids, and the Forever Young room for teenagers. Steve Young sponsored this room which contains a large television, a table and chairs, several more comfortable chairs, fancy lighting on the ceiling and a glass wall of sports memorabilia.

#### **F. STARBRIGHT**

The Lucile Packard Hospital participates in the STARBRIGHT network, which offers patients access to a private network of children in hospitals around the country. Because children have access to information about health through STARBRIGHT, the hospital staff has decided an adult must always be present when a child participates.

For other programs at the children's hospital see the Resources section.

---

<sup>2</sup> Lucile Packard Children's Hospital website.

[http://www.packardchildrenshospital.org/services/other\\_services/childlife.html](http://www.packardchildrenshospital.org/services/other_services/childlife.html).

## II. Needs Assessment

Given the details of this hospital context, there were four major issues that defined *Digital Voices*:

- The need to promote patient self-expression and assertiveness particularly around health care.
- The limitations of the current recreation center
- The constraints of the school
- The results of STARBRIGHT research

Both the teachers and child life specialist at LPCH stressed the need to promote patient self-expression and assertiveness. They explained that home schools and communities were not educated about, and thus not attentive to the special needs of these children. For this reason, children need to learn to be more confident and assertive when dealing with issues concerning their learning and well-being.<sup>3</sup> *Digital Voices* addresses this need by promoting opportunities for communication, leadership and self-guided education.

February's activities in the recreation center were directed towards younger children. Many activities centered around crafts, while activities for older children were limited to movie/television watching, and video games<sup>4</sup>. *Digital Voices* focuses on constructive and creative activities that address the needs of both older and younger children and teaches new skills.

The LPCH school exists under many constraints such as individualized academic requirements, a variable population, and a wide age range. *Digital Voices* accommodates these school constraints by creating flexible, adaptable activities that function independently of each other. It also allows students a valuable opportunity to develop social skills as children can work together or serve as peer mentors.

Finally STARBRIGHT serves as a guide and model for *Digital Voices*. The Starbright Foundation has conducted extensive research and has found that their chat programs to connect children in hospitals assist with pain and anxiety management, improve self-esteem, and aid with feelings of individual empowerment and control.<sup>5</sup> *Digital Voices* strives to employ similar methods at addressing these children's needs.

---

<sup>3</sup> Interviews with Lisa Karpany, Cammy Sunde and Thayer Gershon (see Appendix)

<sup>4</sup> LPCH Recreation Room February Activity Calendar. Internal document.

<sup>5</sup> The STARBRIGHT Foundation. <http://www.starbright.org/projects/sbw/research.html>

### III. Curriculum Rationale

*Digital Voices* provides an opportunity for patients at the Lucile Packard Children's Hospital to create, explore and learn with the use of technology. Filling a niche between school and recreation, the curriculum aims to both encourage and develop self-expression, as well as to build technology skills.

Elements of several ideologies contribute to the theoretical framework of this curriculum. From Progressivism, particularly from Dewey, we use the concept of "child-centered" learning<sup>6</sup>. *Digital Voices* is constructed in a way that it *begins* with the child's abilities and interests. The curriculum recognizes that all children come in with different technology skills, and ways of learning. Following Dewey's philosophy, learning is seen as an active, dynamic process rather than something passive or static. The curriculum's focus on self-expression is an attempt to speak to the "whole child", to all aspects of the child's life, rather than compartmentalizing the intellectual from other areas of his/her life.

Similarly, Duckworth's idea of placing children in an environment where they develop understanding informs the central objectives of the curriculum<sup>7</sup>. Although there is the intention of helping children develop their technology skills, how they apply these skills is their choice. There is not a preconceived goal of where the children should be, or how they should apply these skills. Additionally, the curriculum's intent is to build technology skill by providing challenges and opportunities for child ownership of the lessons by letting the child apply them to other projects.

Encouraging self-expression is a key objective in this curriculum. The mediums for children to express themselves are intentionally varied in order to acknowledge different abilities and proclivities. Therefore, cognitive pluralism, specifically Gardner's work on multiple intelligences informs the ideology of the curriculum.

In terms of curriculum design, Wiggins' method of backward design influenced the process for creating this curriculum<sup>8</sup>. Essentially, the process of backward design can be divided into three distinct stages. First, identifying the desired results demands that the curriculum objectives be clarified prior to creating the curriculum. The next step involves determining the acceptable evidence, which entails that the assessment component of the curriculum is not planned after the curriculum is created, but instead, that issues concerning assessment will be thought of before the curriculum is created. Wiggins also adds that assessment "should be thought of in terms of a collection of evidence over time instead of an event." *Digital Voices* incorporates an ongoing assessment procedure that involves children, facilitator and staff members. This matter will be more fully discussed in the assessment section. Finally, the third step in Wiggins'

---

<sup>6</sup> Dewey, John. (1938). *Experience and Education*

<sup>7</sup> Meek, A. (1991). On Thinking About Teaching: A Conversation with Eleanor Duckworth. *Educational Leadership*.<sup>7</sup>

<sup>8</sup> Wiggins, G., & McTighe, J. (1998). *Understanding By Design*. Alexandria, VA; Association for Supervision and Curriculum Development.

process is to plan the learning experiences and activities. Thus, only after solidifying objectives and giving careful thought to the role and function of assessment were the activities for this curriculum created.

In attempting to bridge children's academic and recreational worlds at the hospital, *Digital Voices* strives to provide tools and a space for communicating self-expression while developing technology skills.

## IV. Curriculum

### A. Description

In light of the variable population the children's hospital supports, the curriculum needs to function within this environment. *Digital Voices* is flexible and non-linear in design to best serve various ages, experiences, talents and interests, as well as to accommodate for an environment whose members may be constantly changing due to a variety of circumstances. These lessons are designed for both groups of children and individuals depending on the population in the recreation area. There are various challenge levels or challenge activities either in or after lessons, so children who excel can be supported in their increasing skill. Challenge activities could range from incorporating more advanced technology to exploring more sophisticated forms of self-expression. One goal of the hospital is to provide children with a place and time during the day where their health status is not the primary focus. The *Digital Voices* curriculum also contributes to this goal.

Since it may be difficult to have a full time facilitator, the curriculum consists of discrete lessons that a technology volunteer could implement supported by stand-alone "wizards." These "wizards" are animated, interactive modules that help remind children about the skills they learned as well as provide younger and bedside patients with a means of practicing a piece of the lesson. For example, there are lessons and wizards on creating digital art, making a virtual tour, and creating a "day in the life" journal.

Children also have opportunities to take on leadership roles by acting as peer mentors when they have excelled at the technological task. Although the curriculum lessons are be mainly targeted to the older children in the hospital, there will be activities available for younger children to complete with the aid of a technical volunteer.

If children choose to publish their *Digital Voices* work in the gallery, they then have access to an opportunity to express themselves to an authentic audience. They may choose to send out email announcements when new work is posted or to use this space to create work that communicates directly with family, friends and classmates.

### B. Goals

The main goal of *Digital Voices* is to allow children to express themselves and learn technical skills in the process. Just as they spend time in a "safe zone" where they control their own activities, they also control their own learning. *Digital Voices* allows for children to take ownership of the activities, as their interests guide the lessons. Presently, children engage in two distinct types of activities at the hospital: school work or recreational activities. This curriculum will bridge those two types of activities. The lessons are fun and engaging but also teach technology skills and provide opportunities for self-expression. Since the recreation center already has craft activities, *Digital Voices* enhances the types of informal and "fun" activities available by proposing computer activities. *Digital Voices* also addresses National Educational Technology standards, and expands on the artistic side of self-expression by teaching technology skills. Therefore,

*Digital Voices* supports informal learning by serving the zone between "fun" and "learning."

**Primary goals**

- Build technical skills through the creation of work for an online gallery
- Encourage self-expression
- Create for a space between "fun" and "learning"

**Secondary goals**

- Encourage communication to the outside world
- Allow patients to mentor each other
- Ease the transition back to home and school
- Promote patient assertiveness by developing self-expression and communication skills.

## V. Facilitator Guide

### Contents

Goals.....	13
Introduction .....	13
Brainstorming.....	13
Audience.....	14
Culture and Diversity. ....	14
Safety and the Internet.....	14
Dealing with Emotional Issues.....	15
Teaching Strategies .....	16
Helping People use Computers .....	17
Allies .....	18
The Gallery.....	18
Useful Equipment.....	19
Resources.....	20

### A. Goals

- Provide resources to assist the facilitator. Address possible teaching strategies.
- Provide a range of activity ideas for children of varying ages, energy levels, interest in communication through technology, and mobility
- Plan assessment strategies to compile feedback from facilitators, patients, staff and Internet communities.
- Explore possible concerns and questions such as censorship, Internet safety and age appropriate activities.
- Encourage alliances with other hospital staff including nurses, speech therapists, child life practitioners, and teachers.
- Provide written guidelines for basic and ideal equipment

### B. Introduction

The most likely facilitator for *Digital Voices* is a technology intern, a volunteer high school or college student (see technology intern job description). However, these activities are designed for any volunteer or recreational therapist to use as appropriate. The facilitator's role involves working with children either one-on-one or in small groups. The facilitator can complete various activities included in this curriculum while helping children use their new skills to pursue their own interests. When teaching technology and using the Internet with children, there are important management issues to address. The following are methods of avoiding difficult situations involving children and the production of inappropriate material.

### C. Publishing to an Audience

It is helpful to discuss with children the implications and importance of publishing before an audience. A group discussion or an individual conversation with a child can draw out

issues to keep in mind. These questions may serve as a starting point for this important discussion.

- What is an audience?
- Who is your ideal audience?
- Who is the audience for *Digital Voices*?
- Why is it important to identify an audience?
- How narrow should an audience be?
- What are the traits of an adult audience like parents? Teachers? Doctors?
- What are the expectations of an audience of children?
- What sorts of response do you hope to receive from your audience?
- Would you want other people to see responses you may receive?

#### **D. Brainstorming**

Brainstorming can be useful in groups to generate creative and diverse ideas on a project. However, general management issues may arise such as respect for the ideas of others and respect for taking turns in the conversation. Many times it is helpful to come to a consensus with the group as to the rules that will govern the brainstorm, regardless of how obvious the rules may seem. Some sample rules are:

- Allow others to finish their comment before starting your comment  
If raising hands seems too formal, the use of an object, such as a marker, designated as the "talking stick" helps control interruptions. Only the person with the object can speak and once finished, passes the object to the next person who wishes to speak.
- No idea is a stupid idea  
Try suggesting constructive words when judging the ideas of others so that the discussion does not insult the person, but suggests valid reasons to favor one idea versus another.

#### **E. Culture and Diversity**

The patient population is very diverse in hospitals all over the world. Chronically ill children from many different cultures and different countries. This rich diversity provides an opportunity to learn more about one another and about different backgrounds. Use it as such. Becoming as familiar with the backgrounds of the children as possible is advisable. For example, if a child feels uncomfortable in English, encourage the child to use a native language, or use a visual medium for self-expression. There are an increasing number of websites in languages other than English. Help children locate them to use these in activities if they prefer. Learning about each child's cultural and linguistic background will help individualize activities and make them more effective.

## **F. Safety and the Internet**

Although the Internet is a useful tool, there are circumstances that could raise concern with its use. At any time if there is a question as to the appropriateness of a site or chatroom, the recreational and child life therapists should be consulted. These hospital staff members should also be consulted for the rules of using the Internet. They may wish that patients use the Internet only in the presence of a hospital staff member. Also it is important to respect the wishes of the family if they do not believe their children should be on the Internet. Aside from these outside interventions that may help children have a safe "journey" on the Internet, there are also laws that protect the rights of minors. It is important to tell the children they are not allowed to release their email addresses or post their full names on the Internet without written consent from their parents.

## **G. Dealing with Emotional Issues**

Children with chronic illnesses and their families face many difficulties as they cope with the emotional and physical stresses associated with their medical conditions. These include:

- Accepting and resisting limitations imposed by health condition
- Anxiety
- Anger
- Embarrassment
- Fear
- Feelings of inadequacy
- Guilt
- Inappropriate reactions from family, other children, teachers and professionals
- Lack of self-esteem
- Pain
- Sadness
- Sense of powerlessness
- Social isolation
- Stress

Encouraging self-expression will necessarily bring up emotional issues for children and their families. Digital Voices provides the opportunity for a healthy release and exploration of these feelings. At times, issues of anxiety, death, and grief will arise. These issues as well as matters concerning easing school re-entry should be discussed with Child Life specialists or hospital therapists. As trained professionals, they can offer assistance and guidance for these complicated issues.

## **H. Teaching Strategies**

The following teaching strategies grow out of the philosophy that guides this curriculum, as it begins with the child's abilities and interests.

### **Be flexible**

- Adjust the activities to meet the child's needs and goals. If a child wants to do something you did not plan, as long as it seems feasible and appropriate, help out!
- Technology projects cannot always go as planned so be prepared with a backup plan.

### **Keep your eyes on the big picture**

- Remember your goals and the child's goals.
- Don't get frustrated by setbacks or when things don't go as planned.
- Have fun and learn.

### **You don't have to know everything**

- You will be teaching an important lesson by admitting you don't know and trying to find out.
- Model good problem solving techniques.
- Continue to try to help

### **Ask for feedback**

- Talk to the child about the project before, during and after you work together.
- Encourage people to view the child's work and to give feedback.

### **Take advantage of help**

- Use allies
- Use peer mentors
- Conduct related research on the web

### **Be patient**

- Take questions seriously.
- Support the child as he/she learns.

## I. Helping People use Computers

adapted from a list by Phil Agre<sup>9</sup>

- Nobody is born knowing how to use technology.
- If it's not obvious to them, it's not obvious.
- A computer is a means to an end. The person you're helping probably cares mostly about the end. This is reasonable.
- The best way to learn is through apprenticeship – that is by doing some real task together with someone who has skills that you don't have.
- Your goal is not to solve their problem for them. Your goal is to help them become one notch more capable of solving their problem on their own.
- Most user interfaces are terrible. When people make mistakes, it is usually the fault of the interface. You've forgotten how many ways you've learned to adapt to bad interfaces. You've forgotten how many things you once assumed that the interface would be able to do for you.
- Knowledge lives best in communities, not in individuals. A computer user who's not part of a community of computer users is going to have a harder time of it than one who is.
- By the time they ask you for help, they've probably tried several different things. As a result, their computer might be in a strange state. That's not their fault.
- Never do something for someone they are capable of doing for themselves.
- If possible, don't take over the keyboard. Let them do the typing, even if it's slower that way and even if you have to point to each and every key they need to type.
- Be aware of how abstract your language is... keep adjusting your language downward towards concrete units until they start to get it, then slowly adjust back up towards greater abstraction so long as they are following you.
- Pay attention to the symbolism of the interaction. In particular, try not to tower over them. If possible, squat down so your eyes are just below the level of theirs.
- Find out what they are really trying to do. Is there another way to go about it?
- When they are confused by a false assumption about computer behavior, tell them their assumption was reasonable. Tell yourself it was reasonable. It was.

---

<sup>9</sup> Seymour Paper, The Connected Family: Bridging the Digital Generational Gap. 1996

## **J. Allies**

Key resources for the facilitator are the people in the hospital and community. The facilitator can benefit from asking for help and learning as much as possible from other people in the hospital. When questions or issues arise, the facilitator should seek out advice from more than one source. Families, religious leaders, teachers and other community resources can also be excellent sources for ideas, support, help and feedback. The facilitator may choose to visit to a local community technology center such as Intel's Clubhouse or Plugged In to learn about what other people are doing in this field.

When possible, the facilitator should encourage peer mentoring. Patients with skills in particular area can be a wonderful help and resource for others learning new skills. Pairing children with different skills or encouraging them to work together on projects can aid with management of larger or multi-age groups. Children can serve as an important resource as they will discover things that can add to the facilitator's knowledge and experience. See the list of possible allies in the Resources section.

## **K. The Gallery**

### Description

The gallery is a virtual space on the web where the facilitator can post the child's work. It offers an opportunity for an authentic audience and for broader feedback. The gallery contains opportunities for viewers to provide feedback to the artists.

### Purpose

- Provide an opportunity for an audience
- Enhance communication
- Validate the child's work through sharing his/her creations with an audience
- Contribute to assertiveness by developing communication skills

### Management

The facilitator will need to adapt the content and structure of the gallery to the needs of the particular situation. In accordance with present child safety laws, the facilitator should seek the child's permission to post his/her work and should only display the child's first name. Children may want to create flyers or send email messages to announce their additions to the gallery.

## **L. Useful Equipment**

### Hardware

- scanners
- digital cameras or regular cameras
- digital video camera (optional)
- CD burner (optional)
- wiring for video download (optional)
- small computer top cameras (optional)
- audio recorders, microphones

### Software

- Word processing software
- Graphic manipulation software (ex: Adobe PhotoShop, Adobe Photodeluxe, Macromedia Fireworks, Adobe Illustrator, Art Dabblers)
- Web design software (ex: Macromedia Dreamweaver, Microsoft Frontpage, Adobe GoLive)
- Video manipulation software (ex: iMovie, Adobe Premiere, Finalcut Pro)
- QuickTime player and QuickTime VR (both free Internet downloads)
- Sound digitizing software (ex: SoundEdit 16, windows media player, or built in sound program)
- Animation software (ex: Macromedia Director, GIF animator (free))

## **M. Resources**

### **Websites**

Band-aids and Blackboards: <http://funrsc.fairfield.edu/~jfleitas/contents.html>

A great resource for children with medical conditions, their families and friends to find information, share experiences and information, and play games.

Bravekids: <http://www.bravekids.org>

A website with health care resources, medical information and emotion support for children with chronic or life-threatening illnesses, their families and the health care professionals that serve them.

Experience Journals: <http://www.merl.com/projects/hospital/xpjournal/index.html>

A description of an application that helps people record, organize, and tell stories about themselves or loved ones with illnesses

STARBRIGHT Foundation: <http://www.starbright.org/>

This Foundation is dedicated to the development of projects that empower seriously ill children to combat the medical and emotional challenges they face on a daily basis. STARBRIGHT projects do more than educate or entertain: they address the core issues that accompany illness – the pain, fear, loneliness, and depression that can be as damaging as the sickness itself.

### **Community Centers Using the Internet**

Fifth Dimension: <http://www.ucerc.edu/ffthd/fifthd.html>

An afterschool program to build community and peer mentoring

Intel Computer Clubhouse: <http://www.computerclubhouse.org>

An afterschool program that teaches technology skills and community building

Plugged In: <http://www.pluggedin.org>

A community organization with a teen online magazine edited and created by teens

### **Other Children's Hospitals**

These hospitals provide examples of work other people are doing in this field and how they have structured their Child Life programs.

Children's Hospital Boston: <http://www.childrenshospital.org/>

Children's Hospital Oakland: <http://www.kidsfirst.org/>

Children's Hospital of Philadelphia: <http://www.chop.edu/index.html>

Valley Children's Hospital of Fresno: <http://www.valleychildrens.org/>

### **Child Life**

Child Life Council: <http://www.childlife.org/>

The Johns Hopkins Child Life Department:

<http://www.med.jhu.edu/peds/childlife/childlife.html>

## VI. Activities

The activities in *Digital Voices* are deliberately self-contained and can be adapted to the variable environment of the children's hospital. Each activity provides a lesson plan for the facilitator with suggestions for extensions, challenges, and adaptations for different age groups. These activities also contain reminders for filling out evaluation forms and updating the Gallery. Electronic wizards will accompany each activity as well and can be used when a facilitator is unavailable or to reinforce particular skills.

As the students become proficient in the curriculum, they can advance their skills by working with the facilitator to brainstorm challenging applications of the technology, and by serving as a technology aide. The technology aide serves as a peer mentor to help the facilitator with multi-age and group populations.

### Other Possible Activities

- Use a digital camera and PhotoShop to create a self-portrait.
- Interview an interesting person you have met.
- Write an advice column.
- Express yourself. Speak out on an issue close to your heart and tell the world what you think.
- Compose a new song or sing an old favorite.
- Share your passion for turtles, movies, or chocolate. What should people know?
- Tell a joke or two.
- Draw a cartoon.
- Design a computer game.
- Poetry is the music of the soul. Share it.



## Digital Art: Create a Collage!

**Age Range:** 4-17 can be tailored as necessary. Children can work alone or in groups.

**Time:** At least 30 to 45 minutes.

### Objectives

- Learn to put physical art into digital form
- Manipulate images on the computer
- Communicate through groupings of visual images

### Before you begin

#### Materials

- Digital Camera, photographs and/or previously created artwork
- Some photo manipulation software
- Scanner

To work with this activity, it is best if the facilitator has some knowledge of scanning and using the photo manipulation software. Perhaps before attempting the computer portion of the activity, talk about paper collages, how they are created and what they can communicate. It might even help to create a paper collage and use the terminology in the software, so that the children are familiar with the words. Help children explore what they might want to communicate with a collage. How could this art form help express complex experiences or emotions or even work as a multi-layered self-portrait?

### Resources

These websites may help with ideas for collages.

Global Collage: <http://www.globalcollage.com/> - collages in museums.

Everyday Magic: <http://www.everydaymagic.com/ColagTOC.htm> - examples of an artist's work and tips on designing digital collages.

### Lesson

#### *Challenge Level I:*

1. Brainstorm about collages and what they can communicate.  
Write down topics and ideas of items to include in each collage. If children are having trouble understanding what a collage is, have them construct a paper collage first.
2. Gather materials  
Have children either bring together items they plan to include in their collage (ex: pictures or drawings they have made, or have them take digital pictures to download onto the computer). Show them how to scan these pieces of artwork into the computer.

### 3. Introduce the software

Discuss the features of the software they will use to put together the various images of their collage. Show them how to "copy" and "paste" multiple images onto one canvas to create the art.

#### *Challenge Level II:*

You can build on Challenge Level I by showing children how to use the manipulation features of the photo software or have them create art using only the tools of the photo software. Some suggestions are to add text to the artwork and create effects to the text like drop shadows; layer images and then add layers of computer generated paint or computer generated objects that will be sent through various "filters" in the software to create effects.

#### **Wrap Up**

- Please fill out the *Activity Assessment* form in the appendix.
- Don't forget to ask if the artists would like their work published in the *Digital Voices* Gallery.
- If appropriate, have the participants complete the *Your Opinion* handout.



## Intrepid Explorers Wanted

---

**Age range:** 10+, can be tailored as necessary. Children can work alone or in groups.

**Time:** 45 minutes to an hour, can be completed in short segments

### Objectives

- Express feelings by preparing a gift for someone special
- Learn about a particular topic or location
- Build Internet research skills
- Share knowledge by organizing and annotating a list of links

### Before you begin

#### Materials

- Computer with Internet access
- Microsoft Word or another word processing program
- Printer (optional)
- Gallery space on the website (optional)
- Email account (optional)

This activity will be most successful if the participants are at least somewhat familiar with Internet research. Help beginners by providing a few general sites to serve as a starting place for useful and appropriate links. For younger children, Yahoo!igans! offers sites that are prescreened for content and reading level. You may wish to bring up issues of safety and etiquette on the web discussed in the Concerns and Questions section of this facilitator guide.

### Resources

These websites may help generate ideas and provide good places to begin research.

Brittanica.com: <http://www.brittanica.com>

National Geographic: <http://nationalgeographic.com>

Yahoo!igans: <http://www.yahooligans.com>

YourExpedition.com: <http://YourExpedition.com/>

### Lesson

While there are fabulous sites on the Internet, finding them can be a real challenge. Help children express how they feel by preparing a gift for someone special with a personalized web tour. If a patient's aunt loves the snow, help design a tour of the South Pole complete with pictures and information about snow, animals, ice, the ocean and Antarctica. The child may want to take a friend or relative on a virtual visit to the White House, a chocolate factory, Mt. Fuji, or the Mayan city of Tikal. A webcam may provide a different kind of journey into an ant colony or to an African watering hole. Plan an internal journey and visit the human heart or travel through the circulatory system.

1. Help brainstorm a topic.  
Before you even get to a computer, talk about what to look for and where to look. List good search terms to generate a number of options.
2. Get started on the web.  
Begin by modeling with a few ways to find information and some good sources. The child may want to bookmark sites or copy and paste addresses in a word processing document. If appropriate, share Internet research skills. For example, searching for *South Pole* may achieve different results than “*south pole*”.
3. Create the tour.  
The child should select the best web pages and place them in order or simply make a list of interesting sites. Annotate the sites to provide guidance and direction.
4. Share the results.  
Decide how to present the links. Would printing a list be better or easier? Is sending email the best way to communicate? Although this may be a gift for an individual, it could be posted to the *Digital Voices* Gallery for the general public as well.

### **Wrap Up**

Please fill out *Activity Assessment* form in the appendix. If appropriate, have the participants complete the *Your Opinion* handout as well.



## Documentary 101: Sharing Your Life

---

**Age range:** 8-11 is suggested, but can be used for younger children with more assistance. Activity questions can be adapted for older patients, and more technical skills/equipment can be incorporated. With a large group, children can work in teams. In this case, consider placing older, more experienced children with younger ones.

**Time:** At least one hour. Allow 20 minutes for pre-activity discussion and time at the end for editing. Depending on time constraints, age-level, ability, and interest, this activity could even last for several sessions. If more technology is used, allow more time.

### Objectives

- Promote self-expression
- Encourage creative ways of thinking about one's life and ways to construct narratives about it.
- Develop skills using recording equipment and/or photography, as well as how to put sound and/or scan photos on the computer.
- Develop interview skills/collecting oral histories (may or may not be applicable)
- Develop word-processing skills
- Develop writing skills

### Before you begin

#### Materials

- Camera and scanner, or digital camera
- Audio recorder and microphone (or can use external microphone on computer)
- Word-processing program
- Video editing software such as iMovie

Facilitator should be comfortable using mini-disc recorders and cameras. Depending on the age and skill level of the group, facilitator may need to provide different levels of assistance with equipment, or may want to focus particularly on one type of equipment to work with. This project can also be done effectively even if only word-processing software is available. It may be advisable to limit the group to the word processing program, and then add other equipment as participants develop skills and become more familiar with the activity.

This activity can be tailored to a variety of age groups, interests and skills. The key is to help children think about their lives and how they can document them. It might be helpful to discuss what makes a memoir. This might include a brief discussion of what defines an autobiography (as opposed to a biography). Autobiographical books and movies could also be shared and discussed as an introduction before launching into the activity. It could also be helpful to discuss the elements of a story: characters, plot, and narrative.

## Resources

Here are some interesting resources involving documentary studies and children:

Center for Documentary Studies (at Duke University): [www.cds.aas.duke.edu/](http://www.cds.aas.duke.edu/)

Sound Portraits Production: [www.soundportraits.org](http://www.soundportraits.org)

Consulting with teachers, therapists, parents, and other figures in children's lives may shed new light on how this activity could take shape. Also, involving parents or friends to work with their children could also be very effective.

## Lesson

### 1. Choose the right tools

After pre-activity discussion, have children decide what tool they want to use to record their memoir: audio, visual, written word etc. This will depend on the age-level, time, ability and interest of children, and availability of equipment.

### 2. Brainstorm questions.

Depending on the medium, begin by brainstorming some questions like the ones included in the activity handout (i.e.- if using audio, ask questions about sounds).

### 3. Teach the technology.

Provide children with mini-lessons on using equipment. This could be a lesson in using Microsoft Word by highlighting basic features of how to create, save and edit a document. With older children, or just one or two children, this could include a mini-lesson in using cameras or audio recording.

### 4. Start writing, recording or shooting photos.

### 5. Edit and share the projects.

Make sure to leave time at the end of the session to edit pieces, to scan photos or put sound clips onto gallery space and to share work with other children.

### 6. Save the projects.

If children do not complete projects in the given time and would like to continue later, show them how to safely save and store their materials for future sessions.

### 7. Share the results in the *Digital Voices* Gallery.

When appropriate, post the projects for friends, family and the general public to see.

## Wrap up

Please fill out *Activity Assessment* form in the appendix. If appropriate, have the participants complete the *Your Opinion* handout as well.

## Activity Handout

The following page is a sample activity sheet. Depending on the age-level of the children, this sheet may need to be adapted. If children are younger, the questions may need to be presented by the facilitator, and for older children, the facilitator may wish to give them copies of the sheet to use on their own.



## Documentary 101: Sharing Your Life

---

**D**escribe the world from your perspective. Nobody else can tell this story better than you can! Write a journal entry about your day. Describe your life, using whatever mediums you choose. Write about what you do. Describe the people in your life. Tell us what happens. Add detail. Make your readers feel like they are there with you. Remember, good writing can let readers travel to other places!

If you would like, take photographs of your day.

Here are a few ideas:

- What's under your bed?
- Who do you talk to during your day?
- Do you know a secret spot in the hospital?

Why stop there? You can also share some of the sounds that you hear during your day.

- What's the first thing you hear when you wake up?
- What's the loudest noise you hear?
- What's the funniest?

You can even test your listeners' hearing and imagination by recording a sample of the sounds you hear in your day. How about your own voice? You can recite a poem (even one you wrote) or sing your favorite song, or even bring your favorite CD and include it in your finished product. You can interview your doctors, family and friends! What do they have to say?

Anything goes here. Just figure out what you want to share about your life and start writing, recording or photographing. Good luck!

## VII. Assessment

By relying on multiple forms of assessment and including many voices, the hospital staff will be able to successfully evaluate the *Digital Voices* curriculum.

### Forms of Assessment

	<b>Child's Growth</b>	<b>Activities</b>	<b>Digital Voices</b>
<b>Child</b>	<i>Your Opinions Form</i> Guestbook	<i>Your Opinions Form</i>	Guestbook
<b>Facilitator</b>	Child Rubric Guestbook	<i>Activity Assessment</i> Activity Rubric	<i>Digital Voices Assessment</i> Guestbook
<b>Supervising Staff</b>	Child Rubric Guestbook	<i>Activity Assessment</i> Activity Rubric	<i>Digital Voices Assessment</i> Guestbook
<b>Viewer</b>	Guestbook		Guestbook

**Viewer Feedback.** A guestbook in the virtual gallery will provide an opportunity for the community to give feedback on the items displayed in the gallery and on *Digital Voices* as a whole.

**Child Feedback.** After completing each activity, children can fill out *Your Opinions*, feedback forms about the effectiveness of the activity and their comfort with the technology skills. These forms serve to track effectiveness of activities and the children's progress. Children can also provide feedback to their peers through the guestbook.

**Facilitator Feedback.** There are three levels of assessment that the facilitator can use as resources. Guided by child and activity rubrics, the facilitator can complete activity assessment forms thus building an archive to improve and enhance activities and *Digital Voices* as a whole. These forms provide a space to share thoughts about the effectiveness of the activity, suggest improvements, and make recommendations to future facilitators using this curriculum. The facilitator is also encouraged to assess the entire curriculum through the *Digital Voices Assessment*. A final level of assessment is the guestbook, where facilitators can provide informal feedback on the creations in the gallery.

**Supervising Staff Feedback.** The hospital staff also needs to evaluate *Digital Voices'* success since they allocate resources, such as the technology volunteers. The staff will have the facilitator and patient feedback as well as gallery viewer feedback for use in their evaluation. Staff supervising the facilitator (child life specialists and recreational therapists) can also complete an assessment of the effectiveness of the activities as well as using the guestbook.

Each of these forms of feedback will comprise the assessment for the curriculum, thereby providing a direction for improvement.

## Child Rubric

Here are some guidelines to assess the child's growth in regards to *Digital Voices*. Remember that the skill level and age of participants must be taken into consideration when using this rubric.

	<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Technology Skills</b>	Child shows little understanding of technology skills. Needs constant assistance.	Child demonstrates a basic grasp of skills. Generally works independently.	Shows solid understanding of skills and can apply them beyond the particular activity. Works independently and may serve as peer mentor.
<b>Encourage Self Expression</b>	Child demonstrates limited communication skills.	Communicates experiences and feelings in more than one medium.	Demonstrates increasing confidence and willingness to communicate using a variety of mediums.

## Activity Rubric

Here are some guidelines to help assess the activities in *Digital Voices*.

	<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Technology Skills</b>	Technology does not necessarily enhance the activity.	It is apparent that technology adds value to activity.	Technology definitely adds value to activity, as well as greatly enhancing other components of curriculum.
<b>Encourage Self Expression</b>	Activity encourages limited opportunities for child to develop and demonstrate self-expression.	Activity provokes good opportunity for self-expression.	Activity allows child to successfully share his/her feelings and thoughts in a variety of mediums and in a way that promotes confident self-expression.



# Activity Assessment

Please take a moment to fill this out after completing an activity.

Facilitator's name:  
Date:  
Number of participants:  
Age of participants:  
Activity:

Did you find the activity:	<u>agree</u>		<u>disagree</u>
1. easy to read and understand?	1	2	3
2. possible to complete in a manageable time frame?	1	2	3
3. engaged participants' interests and imaginations?	1	2	3
4. provided a space for them to express themselves and develop their self-expression?	1	2	3
5. helped develop the stated technical skill objectives?	1	2	3

Please record any responses from children:

---

---

Other suggestions to improve this activity for future facilitators:

---

---

Any additional comments:

---

---

Thank you.

# Digital Voices Assessment

Please take a few minutes to provide feedback on *Digital Voices*.

Supervisor name:

Date:

Do the activities provide an effective opportunity for children to express themselves?

---

---

Do the activities provide an effective opportunity for children to learn and use technology skills?

---

---

Do the activities seem to be both appropriate and engaging for the various-aged participants?

---

---

Can you offer any suggestions for improving the curriculum?

---

---

Please feel free to include any additional comments.

---

---

Thank you.

## VIII. Appendix

### A. Resources

#### Hospital Programs<sup>10</sup>

**StoryTime** is an expressive arts program offered two times a week to provide emotional support, nurturing and inspiration to patients and their families. The program highlights the Resource Center's recreational collection through storytelling, music, theater, dance and art. In addition, our StoryLine at 49-STORY (497-8679) offers an opportunity for children to call in and hear a read-aloud story. Stories change weekly.

**Volunteer Bedside & Clinic Programs** in which volunteers bring the "Resource Center" directly to inpatients at bedside each evening and to outpatients each morning and afternoon in the Clinic waiting rooms. These programs combine eager young readers and listeners with talented volunteers who read, tell stories and provide play activities.

**Closed Circuit TV** broadcasts television-programming chosen especially for the educational and entertainment needs of pediatric patients and families. A weekly TV Guide is distributed each Friday and lists the specific programs that broadcast each week.

Channel 22 - Patient/Family Education Channel

Channel 23 - Children's Movie Channel

Channel 24 - Relaxation Channel

**Reach Out and Read**, a pediatric clinic-based early literacy program, provides children between the ages of two months and five years with age-appropriate books at every well-child visit while also providing instruction to their parents in the importance of literacy development.

#### Hospital Allies: Who's Who For Patients & Visitors<sup>11</sup>

##### The Health Care Team

All members of the Lucile Packard Children's Hospital staff are specially trained to meet the needs of children and families. A team of health care professionals with highly specialized skills works together to care for each child. Every team member is dedicated to a philosophy of caring for the whole child, including his or her physical, emotional, developmental, and social needs.

##### Admissions

---

<sup>10</sup> Lucile Packard Children's Hospital website.

[http://www.packardchildrenshospital.org/services/other\\_services/index.html](http://www.packardchildrenshospital.org/services/other_services/index.html), February 10, 2001.

<sup>11</sup> Lucile Packard Children's Hospital website.

<http://www.packardchildrenshospital.org/patients/whoswho/index.html>, February 10, 2001.

Admissions personnel expedite the admission process by screening both medical and insurance information.

### **Doctors**

Attending physicians are members of the medical staff. They determine and supervise the course of treatment. Each patient is assigned to an attending physician, who has primary responsibility for that child's care at the hospital.

Fellows are physicians who have completed their residency training and are pursuing additional specialized training in pediatrics. Fellows work with attending physicians in providing patient care.

Interns and residents are physicians in specialized training from Stanford University School of Medicine. They work with attending physicians in patient care.

### **Hospital Support Services**

Chaplaincy staff participate in an inter-faith, hospital-based program designed to help meet the spiritual and religious needs of patients and families. They offer support, spiritual resources, and comfort during the difficult experiences of illness and hospitalization. Chaplains also help families who wish to contact clergy from their own faith tradition.

Family Resource librarians help patients and families use library resources, such as books, pamphlets, computer databases, audio and videotapes, as well as opportunities for experiential learning.

Financial counselors assist patients and families with financial matters related to medical care.

Housekeepers ensure that the hospital is clean and neat.

Interpreters help patients, parents and staff to communicate in their native language about medical and other information.

Laboratory phlebotomists draw the blood samples used in diagnosing a child's condition.

Nutritionists and diet technicians help prepare special diets according to medical, ethnic, religious and personal preferences. They also educate parents about their children's nutritional needs relative to their medical conditions.

Occupational therapists help children with physical limitations become more independent and adapt activities of daily living to their special needs.

Patient Relations staff serve as advocates for both patients and their families. They can intervene to help resolve problems encountered during a hospital stay, including providing helpful information in crisis situations.

Pharmacists prepare and distribute medications and are available to provide information on how to use a medication properly, how drugs may interact with each other, and how a drug may affect the progress of a disease.

Physical therapists treat infants and children with acute or prolonged physical dysfunction or pain, with emphasis on movement disorders.

Psychologists assist children in dealing with the normal effects of illness (such as pain and anxiety) and help them find ways to live with the demands of illness and treatment in their everyday lives.

Radiology technologists perform X-rays, ultrasound, CAT scans, MRI scans, and other tests to help physicians with diagnosis and treatment.

Recreation therapists use play, recreation, education, self-expression and theories of child development to help normalize the hospital experience and reduce the stress children and families associate with health care experiences.

Respiratory therapists focus on restoring and maintaining proper and healthful breathing.

School teachers help patients in grades K-12 keep up their studies. They contact students' home districts and facilitate school re-entry upon hospital discharge.

Social workers offer crisis intervention, information and referral to community agencies and other services.

Speech therapists evaluate and treat children with communication problems.

Volunteers are community members who generously give their time and talents to the hospital. They work in a variety of areas providing both direct and indirect patient care.

### **Nursing**

Case managers are registered nurses who coordinate and manage care throughout hospitalization and plan for discharge.

Charge nurses are responsible for overseeing the nursing care on a unit during a particular shift.

Clinical nurse specialists and nurse practitioners are registered nurses who possess additional preparation and skills in physical diagnosis, psychosocial assessment, and management of health-illness needs in primary care.

Nurse managers (clinical operation managers) are responsible for managing the nursing care on all shifts of a particular unit.

Nursing staff are the caregivers who work with physicians and other health professionals. Nursing care is provided to children around the clock by registered nurses, licensed vocational nurses, milieu counselors and nursing assistants.

Unit service assistants provide clerical support to the nursing units and direction to visitors.

### **Job Description for the Technology Intern<sup>12</sup>**

#### **Technology Intern, The Young Zone**

The Recreation Therapy/Child Life Department offers hospitalized children and their families several ways to use technology as a form of recreation. Technology can help families find answers to medical questions and educational games that enable players to learn about their illnesses. The Department also provides children with opportunities to learn or reinforce their computer skills while hospitalized.

The intern will work with the Technology Coordinator of Recreation Therapy/Child Life to support the program. She will work closely with pediatric patients and their families. She will teach patients and families how to use the equipment, give support to patients as needed, set up equipment, escort patients to the room or bring the computer system to their room, help maintain the equipment, and report on patients' progress to her supervisor. She may update and develop manuals, and perform other tasks as needed.

Timing: Feb 1 to May 1. Four hours a week, any days except Friday.

Qualifications: Must be comfortable working with patients and computer systems. Prior experience working with children required. Knowledge of computers, especially IBM/Windows 95. Ability to motivate and work with patients and families; ability to teach computer skills to children; ability to work independently and under supervision of director. Must be at least 16 years old.

---

<sup>12</sup> Castilleja School Internship Program, Internal document.

## Technology Standards for Children<sup>13</sup>

1. Basic operations and concepts
  - Students demonstrate a sound understanding of the nature and operation of technology systems.
  - Students are proficient in the use of technology.
2. Social, ethical, and human issues
  - Students understand the ethical, cultural, and societal issues related to technology.
  - Students practice responsible use of technology systems, information, and software.
  - Students develop positive attitudes toward technology uses that support lifelong learning, collaboration, personal pursuits, and productivity.
3. Technology productivity tools
  - Students use technology tools to enhance learning, increase productivity, and promote creativity.
  - Students use productivity tools to collaborate in constructing technology-enhanced models, prepare publications, and produce other creative works.
4. Technology communications tools
  - Students use telecommunications to collaborate, publish, and interact with peers, experts, and other audiences.
  - Students use a variety of media and formats to communicate information and ideas effectively to multiple audiences.
5. Technology research tools
  - Students use technology to locate, evaluate, and collect information from a variety of sources.
  - Students use technology tools to process data and report results.
  - Students evaluate and select new information resources and technological innovations based on the appropriateness for specific tasks.
6. Technology problem-solving and decision-making tools
  - Students use technology resources for solving problems and making informed decisions.
  - Students employ technology in the development of strategies for solving problems in the real world.

---

<sup>13</sup> International Society for Technology and Education. <http://cnets.iste.org/sfors.htm> March 1, 2001.

## Websites

Band-aids and Blackboards: <http://funrsc.fairfield.edu/~jfleitas/contents.html>

A great resource for children with medical conditions, their families and friends to find information, share experiences and information, and play games.

Bravekids: [www.bravekids.org](http://www.bravekids.org)

A website with health care resources, medical information and emotion support for children with chronic or life-threatening illnesses, their families and the health care professionals that serve them.

Experience Journals: [www.merl.com/projects/hospital/xpjournal/index.html](http://www.merl.com/projects/hospital/xpjournal/index.html)

A description of an application that helps people record, organize, and tell stories about themselves or loved ones with illnesses

STARBRIGHT Foundation: <http://www.starbright.org/>

This Foundation is dedicated to the development of projects that empower seriously ill children to combat the medical and emotional challenges they face on a daily basis. STARBRIGHT projects do more than educate or entertain: they address the core issues that accompany illness – the pain, fear, loneliness, and depression that can be as damaging as the sickness itself.

## Community Centers Using the Internet

Fifth Dimension: [www.ucerc.edu/ffthd/fifthd.html](http://www.ucerc.edu/ffthd/fifthd.html)

An afterschool program to build community and peer mentoring

Intel Computer Clubhouse: [www.computerclubhouse.org](http://www.computerclubhouse.org)

An afterschool program that teaches technology skills and community building

Plugged In: [www.pluggedin.org](http://www.pluggedin.org):

A community organization with a teen online magazine edited and created by teens

## Other Children's Hospitals

These hospitals provide examples of work other people are doing in this field and how they have structured their Child Life programs.

Children's Hospital Boston: <http://www.childrenshospital.org/>

Children's Hospital Oakland: <http://www.kidsfirst.org/>

Children's Hospital of Philadelphia: <http://www.chop.edu/index.html>

Valley Children's Hospital of Fresno: <http://www.valleychildrens.org/>

## Child Life

For more information about Child Life, visit these websites:

Child Life Council: <http://www.childlife.org/>

The Johns Hopkins Child Life Department:

<http://www.med.jhu.edu/peds/childlife/childlife.html>

## **B. Contributors**

Lucile Packard Children's Hospital

Lisa Karpanty, RTC, CCLS, Child & Family Life Services

Nanci Kauffman, volunteer

Cammy Sunde, lead teacher, k-4 classroom

Thayer Gershon, high school teacher

STARBRIGHT World

Jordana Huchital, Director of Healthcare Initiatives

Stanford University School of Education

Denise Pope, professor

Marjorie Bullitt, teaching assistant

Heidi Chang, student

John Wong, student

Adrienne Slaughter, student

Stanford University, School of Medicine

Dr. Michael Rotherberg, Medical Intern

University of California, San Francisco

Dr. Brie Williams, Medical Resident

## C. Process

### **Phase 1: Group Formation** January 19 –31

Heather Laird, Anuja Dharkar and Tacy Trowbridge began to work as a team with the general goal of creating a meaningful curriculum using technology for children in a hospital. On January 19th, Tacy made the initial contact with Nanci Kauffman, a volunteer at the hospital. Nanci was quite enthusiastic and thought our ideas would fit into the mission of the hospital. She forwarded our email to the appropriate people on the hospital staff. We began to research children's hospitals.

### **Phase 2: Goals Come Together** February 1 – 7

We met in class on February 1 and had our first real breakthrough. Using Wiggins' backwards planning model, we began to develop a solid idea. It was difficult to proceed without knowing enough about the context and so we spent a fair amount of time trying to imagine what the constraints and issues would be. This was an exciting period for us as we loved our idea, felt we could produce a really meaningful curriculum and could see broad applications for our work.

Tacy summarized this work in an email to Nanci that evening:

Our main goal is to address isolation children may feel while in the hospital. We would like to expand the possible means of communication to their communities outside of the hospital (friends, school, families, sports teams, religious organizations etc.) and to other children in hospitals. We would like to design a series of activities to help children create a multimedia "newspaper" on the web. Kids could write poems, articles, personal reflections, draw cartoons, record interviews etc to publish on the web. They could send out email announcements or postcards to people they know to "advertise" and announce their publication. These would be voluntary activities designed for kids of all ages, attention spans and abilities. This is just a quick overview of the ideas we discussed in class today.

This is our initial idea and we would welcome feedback. Of course, we would love to visit and get a sense of the kids, their needs and circumstances. It would also be helpful to talk to staff members such as art therapists etc. to learn from their expertise.

Due to Nanci's family emergency and unexpected complications from surgery for our contact at the hospital, we did not hear from the hospital until a week later on February 8th.

Tacy and Heather both interviewed doctors working in children's hospitals about this project and received positive feedback from their peers: both interns and residents. Tacy exchanged messages with a psychiatric intern as well.

In the mean time, we focused our research on three different areas: community building, youth publications on the web, and Child Life programs in hospitals. We did this to inform our design of a community curriculum and to explore possibilities for the zine structure and content. Unable to visit our site, we tried to research and understand what we could about our context. We each took on one area and reported to the group. Tacy discovered STARBRIGHT, a web-based chat program for kids in hospitals and emailed for more information. We met on February 5th and 7th, to plan, write and edit our curriculum rationale and outline.

This was a particularly exciting time as we could see possible career directions and were ready to commit to this project beyond the scope of the class.

### **Phase 3: First Contact** February 8-14

Nanci Kauffman gave us an email address for Lisa Karpanty, a Child Life specialist at the hospital. Here is the way in which we conceived of the project at this point.

As Nanci Kauffman may have told you, two classmates and I are working on a curriculum project in Stanford's School of Education. We have begun to develop a project focused on informal learning for children in a hospital setting. After speaking with a doctor and a psychology intern, we know we have a great deal to learn about the constraints and realities of life for a child in a hospital. Anuja, Heather and I would love to visit your hospital and perhaps speak to a staff member or two.

Our main goal is to expand the available means of communication to communities outside of the hospital (friends, school, families, sports teams, religious organizations etc.). We plan to design a series of activities to create a multimedia "zine" or newspaper on the web. Children could write poetry, articles or personal reflections, draw cartoons, create short movies, or record interviews to publish on the web. They could send email announcements or postcards to friends and family to announce their publication. These would be voluntary activities designed for kids of different ages, energy levels, interest and abilities. We would welcome any feedback or thoughts you may have as we are in the early stages of exploring our idea.

Our curriculum portfolio is due on March 19th and would consist of several non-linear lessons, a written guide for a facilitator and a reference guide of resources. We would be happy to give you a copy when we are finished. Anuja, Heather and I are very excited about this work and would all be interested in developing aspects of this project later in the spring.

If possible, we would love to arrange a visit to the hospital sometime in the next two weeks. In the mean time, I would be happy to answer any questions you may have.

We met to formulate questions and write up our curriculum goals. In our first round of feedback, John Wong and Heidi Chang reminded us that we needed to clearly articulate how theory informed our project.

**Phase 4: First Site Visit** February 15 - 20

Our first visit to the hospital gave us new insight into this project. We met with Lisa and learned a great deal about Child Life, the hospital programs and technology use. We quickly began to realize that our project would have to change. Since we had been unable to visit the site until we were fairly far along in the planning, it was hard to realize that some of our ideas would not work well in this particular setting.

Key points:

- Children do not stay in the hospital for long periods of time because of the current structure of health insurance so the inpatient population changes often
- Children are now readmitted more often.
- Children are not allowed to participate in the STARBRIGHT network unsupervised because of access to health information
- STARBRIGHT is being tested in homes
- The Child Life Program helps children reenter their lives outside of the hospital so do not want to become too attached or keep in touch
- Child Life “is a right, not a service” at Lucile Packard.
- Teachers do not plan much curriculum; they work closely with the home schools
- Patients come from all over the world
- Educating home teachers, counselors, principals helps the child and the family
- Kids need to learn to be assertive
- There are many classes and activities planned for patients in the recreation room but most of them are arts and crafts projects
- Activities for older patients seemed directed towards watching movies

We had anticipated a core group of patients who would be in the hospital for a long period of time and so needed to change our conception of this project. Lisa gently encouraged us to consider working to support the teachers rather than focusing on the Recreation Room.

At this point, we thought our curriculum project might fit better with the teachers and that they might be able to provide us with more direction for our project.

**Phase 5: Second Site Visit** February 21

Two teachers, Cammy Sunde and Thayer Gershon, met with us and shared a tremendous amount of information. There were numerous needs and possible projects. Technology seems to offer important advantages in that their students are most often working independently, the Internet may offer resources in other languages, high school science classes cannot effectively do labs so computer simulations would be useful.

We met again in the afternoon to plan our new strategy to discuss our new understanding of the site and its constraints.

We could no longer plan to encourage much community building in the hospital as patient stay in the hospital is sporadic and both the Child Life and the school focus on encouraging children to re-enter their home schools and communities.

While this hospital has chosen to devote staff time, energy and resources to the Child Life and school program, there does not seem to be a possibility for a full-time facilitator or for training for the existing staff.

After overcoming our initial disappointment, we bounced around several ideas and ultimately toned down our project a great deal. We eliminated the communication and community-building aspects of our original idea and shifted towards small individual projects focused on self-expression. We changed the role of the facilitator and made the final product much more flexible. We also design a less structured end product as the zine would have required too much management and too many resources. Creating a curriculum made up of small components seemed more appropriate for this setting.

#### **Phase 6: First Draft and Peer Review** February 22- March 1

We compiled all of our drafts into one draft document. We began to seek feedback from three main sources:

- Our classmates, John Wong and Heidi Chang offered more advice and helpful comments both directly and by sharing their work with us.
- Marjorie Bullitt read our draft and offered provided written feedback.
- Professor Denise Pope also read this draft and provided helpful written feedback.

#### **Phase 7: Revision and Preparation for the Presentation** March 2-15

After initial revisions and writing other missing components, we each printed out the next full draft and read through for consistency, logical flow and coherence. We met all day on March 10 to make changes, add improvements and to bring forward all of our ideas in discussion.

After passing the final draft around through email for a final edit, we met to plan our presentation in class on March 15.

#### **Conclusion**

*Despite difficulties accessing our visit and having to make major changes to our project, we worked beautifully as a team, sharing the work, encouraging each other and contributing evenly to our ultimate project.*

## **D. Interviews and Observations**

### **Dr. Brie Williams, Medical Resident, University of California in San Francisco**

Tacy Trowbridge

2/1/01

#### Key Points

- Keep it non-academic in focus.
- Target ages 4-14.
- Think about peer mentoring (different ages, experiences with newspaper or illness)
- Design a non-linear curriculum
- Think about the difference between children with chronic illnesses and children in intensive care
- Talk to art and music therapists and incorporate their expertise
- Consider children in the psychiatric ward have to write for 30 minutes a day as part of their therapy; they are physically healthy and often bored
- Take advantage of a good opportunity to teach low-income children about technology.
- Some stay longer in the hospital because they have nowhere to go
- Include children who are immune compromised cannot have contact with other people (cancer, AIDS)
- Think about children on ventilators
- Use focus groups of children and staff
- Help children contact people when their work is published (postcards, email...)

She would be happy to continue to consult with us and has offered to find other contacts. She reminded me of a mutual friend, Nancy Hoopes, who has worked on the psychiatric ward at the Oakland Children's Hospital.

### **Lisa Karpanty, child life specialist, Lucile Packard Children's Hospital**

2/15/01

Lisa provided a brief tour of the hospital, including waiting rooms, interfaith "chapel" area where memorial services are often held, as well as the school and Forever Young facility.

She described LPCH as an "acute care hospital", remarking that the patient population fluctuates dramatically. Lisa explained that the hospital is following the trend of adult-care hospitals of gearing more towards outpatient care, rather than long-term, inpatient care. Thus, patients at LPCH are usually in for "short spurts", and re-enter more often, rather than staying for one large block of time. The patients' length of stay is determined by their health insurance and family situation. As expected, many problems arise from these changes, especially for families who commute from the Salinas area (of which there are many, Lisa said) and are limited to public transportation (which is quite poor coming

from Salinas to Palo Alto area.) Additionally, lodging is very expensive in this area. Often, families can stay at the Ronald McDonald house across the street from LPCH. Lisa's main point in our discussion of all this was that children's services at the hospital are largely influenced by these health insurance and health policy issues that control patient population.

After an overview of the basic services provided for patients in regards to child life/recreational therapy (we discussed the difference between these two often-conflated fields), Lisa also gave us an overview of the school at LPCH. There are three special education teachers (part of Palo Alto Unified School District). Much of the teachers' jobs actually ends up being to educate counselors, teachers and principals in schools about children's' situations and how their health status affects their lives at school.

We discussed different resources available on the web for patients and their families. Brought up Starbright (which Tacy had previously discovered and shared with us earlier), as well as one called Bravekids.org, a resource for kids in hospitals and their families, and another that Lisa highly recommended, Band-Aids and Blackboards.

We presented our idea to Lisa and discussed more some of the things to be aware of in terms of the population when thinking about creating a curriculum. Specifically, issues like not being able to mix immuno-suppressed patients with cystic fibrosis patients. We talked a bit about where this curriculum might best 'fit'. (i.e. school area versus recreational area.) We all agreed it would be best to talk to teachers in the school and get their comments.

She then took us to the school and introduced us to the head teacher, Cammy Sunde. We made an appointment to meet with her at a later date.



**Cammy Sunde and Thayer Gershon, Teachers, Lucile Packard Children's Hospital**  
2/21/01

We met with head teacher Cammy (elementary) and Thayer (high school) teacher for an hour in school at LPCH. They provided us with informational pamphlets about the school, which was started in 1924.

Both teachers discussed what they did, some of the difficulties they encountered in their work, and things that they would like to see happen at the school.

In the last ten years, there has been a push to get schools in hospitals. Much of this has to do with children surviving longer than they did in the past. So, this factor has contributed to schools becoming more the norm in children's' hospitals.

Cammy, the elementary school teacher, talked about how the elementary curriculum is more similar across different school districts, so there was more of a unified sense of things that needed to be covered. All of the curricula is individualized for each student, so teachers at LPCH school have quite a task- they must create (often, older children bring in their own work from school to do) and specifically tailor work for each student.

Up through eighth grade, the content of what children are learning is not as critical, teachers assert, the important thing is that they need to be doing something. It helps keep them on track and seems to assist in the healing process.

Conversely, high school students come in with a full course load usually, so work with teachers on their own work. They register in Palo Alto Unified district and children usually start attending classes within the first three days of entering the hospital. The high school teens are usually at the LPCH longer than younger ones. Usually, teachers here see about 10-15 children a day (including at 'bedside').

What the age level, curriculum needs to be flexible (especially when children are not feeling well). Curriculum also needs to have real meaning in only a few sessions (since sometimes that is all students have.) Most of the patients who stay the longest are the ones in the psychiatric unit.

Patients in the psychiatric unit are the only ones required to attend school. All other patients are 'encouraged'. Teachers said children in psychiatric unit are about 2/3 high school teens, and 1/3 middle school. Most are in for eating disorders or pain management. This is one of the few populations in the hospital where the trend is that they are staying longer (as opposed to shorter stays for most other patients). Teachers also commented that often teens here have really high expectations (the older ones in the psychiatric unit) for what they thought they should be doing, how they thought they should be performing, so teachers often had to try to work with them to create realistic goals.

Teachers also commented that there was a lot of camaraderie among the patients. This was wonderful to see. The downside was that patients also learned behaviors from each other (could be unhealthy, self-destructive behaviors).

Some things the teachers said they would like to see would be science units- maybe incorporating technology. Many labs like dissections cannot be done here, so teachers suggested things like computer simulations. Also, there are many patients who come in with different language skills and abilities (many non-native English speakers), so teachers said they would like to see curricula (even CD-ROMs?) with beginning English skill developing material, particularly for older students.

Bedside, children all have VCRs, computers, and some rooms are linked to the Internet (cannot have wireless because it interferes with machines). High school teens use email.

Teachers reiterated what Lisa told us in the previous meeting: namely, that teachers act as educators to students' home community, and provide long-term support. They also said they help parents to become advocates (many are already, but teachers say they try to help with this process.)

## LPCH HOSPITAL SCHOOL PROGRAM<sup>14</sup>

The School at Lucile Packard Children's Hospital @Stanford provides an instructional program for hospitalized students in Kindergarten through 12th Grade. Three teachers, three instructional aides and a secretary from the Palo Alto Unified School District form the School staff.

The primary goal of the LPCH School is to provide a basic educational program for hospitalized students with serious and/or chronic health problems. Honors and Advanced Placement classes are not part of the basic Hospital School program. LPCH School provides instruction in the four core subjects:

1. English (Reading and Language Arts in Elementary Grades)
2. Social Science
3. Mathematics
4. Science

It is the experience of both the medical and educational staff that hospitalized students should not be expected to maintain the same level of commitment and achievement in their studies as they did prior to their hospitalization. If you have any questions regarding your hospitalized student's school program, please contact your student's teacher.

Students who are hospitalized for periods of time longer than two weeks, or whose chronic condition requires repeated hospital stays, may need to have their school programs modified to accommodate their health needs. Critical and chronic health conditions may qualify a public school student for an OHI (Other Health Impaired) Individual Education Plan, if requested by a parent. It is easier to request modification of assignments, both during and after hospitalization, if such a plan is in place in the home school district. Private schools, while not offering Individual Education Plans, may be willing to modify the program of a critically or chronically ill student.

Students are encouraged to bring books and assignments from home to help facilitate the transition back to their regular schools after hospitalization. Hospital School teachers contact students' home schools/teachers on a regular basis to update assignments and send finished work back to the schools.

Some students' schools are willing to continue to send assignments for longer than two weeks but when they are not, Hospital School teachers will design appropriate curriculum in core subject areas.

High School students may earn I unit of credit per subject for 18 days of enrollment in the Hospital School, provided assignments are completed. Elementary and middle school students receive attendance credit for each day they are in class or are seen bedside.

In some cases, students enrolled in Advanced Placement classes, Lab sciences or in 3rd, 4th or 5" year language classes may be able to continue these subjects by requesting enrollment 'in their home schools' Independent Study programs. This is advisable only if the student is capable of working independently 'in the subject area(s) chosen.

---

<sup>14</sup> Flier from the Hospital School at the Lucile Packard Children's Hospital

**Jordana Huchital, Director of Healthcare Initiatives, STARBRIGHT World**

From: tacy trowbridge <[tacyt@stanford.edu](mailto:tacyt@stanford.edu)>  
To: <[jordana@starbright.org](mailto:jordana@starbright.org)>  
Sent: Monday, February 12, 2001 2:38 PM  
Subject: From [www.starbright.org](http://www.starbright.org): Research Information

I am a graduate student in a program within the School of Education called Learning, Design and Technology and am particularly interested in designing for children around health issues. I would like to receive more information about your projects.

Thank you,  
Tacy Trowbridge

**From:** "Jordana Huchital" <[jordana@starbright.org](mailto:jordana@starbright.org)>  
**To:** "tacy trowbridge" <[tacyt@Stanford.EDU](mailto:tacyt@Stanford.EDU)>  
**CC:** "Tal Gilad" <[gilad@starbright.org](mailto:gilad@starbright.org)>  
**Subject:** Re: From [www.starbright.org](http://www.starbright.org): Research Information  
**Date:** Tue, 13 Feb 2001 10:35:09 -0800

Tacy,

Thank you for your note and interest in STARBRIGHT. I will be glad to send you a packet of materials describing our program and research initiatives. Let me know where I should send them. As a note, the STARBRIGHT World computer network is installed at Lucile Packard Children's Hospital (one of our first sites!) and also, one of the research studies to examine STARBRIGHT World was conducted by investigators at Stanford University.

Please feel free to contact me if you have any additional questions at 1800-315-2580 x0, or via email at [jordana@starbright.org](mailto:jordana@starbright.org)

Regards,  
Jordana

**Date:** Tue, 13 Feb 2001 11:11:16 -0800 (PST)  
**From:** Tacy Trowbridge <[tacytrow@yahoo.com](mailto:tacytrow@yahoo.com)>  
**Subject:** Re: From [www.starbright.org](http://www.starbright.org): Research Information  
**To:** Jordana Huchital <[jordana@starbright.org](mailto:jordana@starbright.org)>  
Jordana,

Thank you for your quick reply, offer to send a packet and willingness to answer further questions. I am working on a curriculum project using technology for children in hospitals with two of my classmates. We were thrilled to find STARBRIGHT on the web and to notice your connection with Stanford. We will actually be visiting that hospital on Thursday to learn more about child life, their work in education and their use of technology to enhance opportunities for communication. I'm sure we will have further questions about STARBRIGHT and hope will we learn more at Lucile Packard Children's Hospital.

I look forward to learning more about this area!  
Thanks again,  
Tacy Trowbridge

**From:** "Jordana Huchital" <jordana@starbright.org>  
**To:** <tacyt@Stanford.EDU>  
**Subject:** Re: From www.starbright.org: Research Information  
**Date:** Tue, 13 Feb 2001 13:48:19 -0800

Tacy,

I've put a package of materials in the mail. Let me know if you have any questions after you receive this. Also, we would love to hear more about your project. Please give me a call or email at your convenience.

Regards,  
Jordana

Jordana R. Huchital  
Director of Healthcare Initiatives  
STARBRIGHT  
11835 W. Olympic Blvd., Suite 500  
LA, CA 90064  
310-479-1212 (ph)  
310-479-1235 (fx)  
[jordana@starbright.org](mailto:jordana@starbright.org)  
[www.starbright.org](http://www.starbright.org)