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Technologies for Self-Determination for Youth with

Developmental Disabilities

Technologies for Voice: A Critical Issues Brief

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Abstract

This paper focuses on "technologies for voice" that are related to the self-determination of youth with developmental disabilities. The authors describe a self-determination model that values family-focused, community-referenced pedagogies employing "new media" to give voice to youth and their families. In line with the adage that a picture is worth a thousand words, many youth and families find they are better able to convey their life situations and express their hopes and fears using multimedia (e.g., camcorders, voice recorders, digital cameras, PowerPoint) to find their voices in transition and IEP planning meetings. Systematic strategies are described to support teachers and other youth advocates to employ multimedia technologies as tools of self-determination.

Technologies for Voice: A Critical Issues Brief

Whether they are ready or not, young adults with disabilities are expected to become self-determining, that is, to assume increasing responsibility for their own goal setting, transition planning and life "visioning." In support of this effort, young persons are expected to participate in "circles of support" and to find and share their own voices in the planning process (e.g., individualized education program (IEP), transition, case conference, wraparound) (Kelly, Skouge, & Thomas, 2005; Martin, Marshall, & Dupry, 2004; Thoma, Rogan, & Baker, 2001). Regardless of disability, it is the young adult, him or herself, who is at the heart of this evolving social value called self-determination (Martin, et al., 2004; Mason, McGahee-Kovac, & Johnson, 2004; Torgerson, Miner, & Shen, 2004).

We take the position that special educators are best able to support the realization of self-determination for youth with developmental disabilities when they use family-focused, community-referenced pedagogies explicitly designed to give voice to youth themselves and their families. This paper promotes the use of *new media* to achieve this goal. In line with the adage that a picture is worth a thousand words, many youth and families find they are better able to convey their life situations and express their values, hopes and fears through "technologies for voice" (e.g., camcorders, voice recorders, digital cameras, PowerPoint) than using words that may not resonate with others who lack experience living with developmental disabilities. Technologies for voice can be particularly useful for enhancing understanding among people of different cultural backgrounds, as the authors have found through considerable experience working with Asians and Pacific Islanders with developmental disabilities and their families, including native Hawaiians, Samoans, Micronesians and youth of "mixed" Asian and Pacific backgrounds.

Historical Evolution and Significance of Self-Determination

Self-determination is considered to be both a *civil right* and a *civic responsibility,* emanating from the "normalization", independent living and self-advocacy movements originating in the 1960's. Both the Americans with Disabilities Act (P.L. 101-336) and the Individuals with Disabilities Education Act include specific provisions pertaining to self-determination (Field, Martin, Miller, Ward, & Wehmeyer, 1998). There is a growing body of evidence that people with disabilities who are supported to gain greater self-determination achieve better outcomes, including making better career choices, improving the quality of their lives, and giving more back to their communities (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Wehmeyer & Schwartz, 1998).

Since the 1960's, a variety of curricula and programs have been developed and implemented to support people with developmental disabilities to gain the self-determination that most people take for granted. These initiatives generally recognize that self-determination requires two things: (1) a social environment that provides opportunities and supports to make choices and set goals without undue influence, and (2) a range of relevant attitudes, skills, and knowledge on the part of the individual, such as an orientation to the future, awareness of one's own strengths and limitations, and ability to foresee and compare the consequences of different choices (Abery & Stancliffe, 2003). Educational approaches have fallen into two strands: (1) the choice strand, and (2) the goal setting and attainment strand (Martin, et al., 2004). The choice strand integrates "choice making" and "learning to make choices" into the educational curriculum, including a progression of simple to more complex choice making. The goal setting and attainment strand is "outcomes based" in which youth set their own goals and outcome

measures. This process involves identifying needs, interests and expected outcomes across functional domains.

In a comprehensive synthesis of the literature, Wood, Test, Browder, Algozzine and Karvonen (1999, revised in 2004) compared 60 self-determination curricula across such variables as choice/decision making, goal setting/attainment, problem solving, self-evaluation, self-advocacy, IEP planning, relationships with others, and self-awareness. The authors noted that many of the curricula link self-determination with transition planning, citing evidence of a positive relationship between self-determination skills training in high school with positive post-school transition outcomes. Some of the more comprehensive curricula they identified are listed in Table 1.

<insert Table 1 about here>

Digital Storytelling and New Media

Special education has a longstanding, proud history of valuing student-centered, family- and community-referenced pedagogy, especially in the design of educational interventions for children with developmental disabilities. We also have considerable experience applying *assistive technologies* to support augmentative and alternative communication, including extensive use of auditory and visual communications, such as picture symbols, drawings, photographs, video and other multimedia expressions. The values expressed and the technologies that are described below are extensions of these well-established practices in special education.

Speaking Up and "Finding Voice" in IEP Transition Meetings

The IEP transition process can be designed to provide a structure for self-determination, through which a young person prepares his or her story (past, present and future) referenced to

several or more of the generative themes described above. One promising approach is to conduct

two IEP meetings when it is time to create a transition plan, in order to give youth the

opportunity and motivation to deeply participate in their own planning process at this critical life

juncture. The first of these meetings is a community gathering, perhaps 60 – 90 minutes in

duration, designed to showcase the youth's voice. Ideally, the youth "hosts" the gathering

(perhaps with support from significant others chosen by the youth) in which his or her story is

shared; a transition plan is proposed; and insights, suggestions and support from the participants

are solicited. The prospect of putting on a public performance, and the process of creating

performance materials using *new media*, can help motivate and guide the youth to critically

examine his or her current situation and possible post-high school futures. This community

gathering is followed by the formal IEP meeting (on the same or a later day) to finalize and

approve the transition plan. In order to successfully realize this process, the guidelines

summarized in Table 2 should be considered.

<insert Table 2 about here>

In this model, IEP transition meetings become part of a *rite of passage*, in which a

youth's voice is expressed through a multimedia presentation honoring the beauty of place,

family and community; documenting personal strengths, skills and interests; depicting career

goals and choices; expressing gratitude to family, community role models and teachers; and

committing to self, family and community. Choices for multimedia expression are summarized

in Table 3.

<insert Table 3 about here>

The following true case example of Sean (a pseudonym) serves to illustrate the potential impact of this model (Kelly, 2006).

Sean's Story

Sean was a creative 12-year-old who had spent many years moving in and out of juvenile justice and mental health facilities. Because of multi-agency involvement, there were many participants scheduled at an upcoming transitional IEP meeting with attendees from both his current school and a new school where Sean's family wanted him to attend the following year. His case manager was concerned that while Sean had made a lot of progress and had an important perspective to share, it would be overlooked in favor of his large case file and his extensive history. She encouraged Sean to develop a multimedia presentation for his upcoming IEP meeting.

Sean was very interested in the project and took an active role in developing a PowerPoint presentation. He took photographs, created video clips, and clipped pictures from magazines with science fiction graphics and quotations. One graphic used as the first slide of his presentation was filled with monsters and the phrase "In a world of villains, a goddess reborn, struggles to fulfill a prophecy" which he used to describe bullies at school and his desire to change and achieve his goals.

Sean also photographed family members, pets, and his trailer home. He asked others to take pictures of him doing activities like karate, mowing the lawn, and spending time with his relatives. Fishing was something he and his father used to like to do, so they made time to go fishing and he helped make a short video about the experience. He thought carefully about each picture he added to his presentation and narrated a short story about each. He also selected

specific clips from songs like "I Am" by Eminem and "I Believe I Can Fly" by R. J. Kelly that

he felt expressed his sentiments. Lastly, he outlined his goals and hopes for his future.

Sean was eager to share his presentation at his IEP meeting. He was currently in a

segregated, self-contained classroom, but felt ready to be in a more inclusive environment at his

new school. The change was supported by his parents, case manager, and probation officer, but

school personnel did not understand his hopes for a "fresh start" and were hesitant of any change

in placement.

At the meeting, Sean was not invited to attend until the end. Before he entered, a number

of concerns were raised about Sean as his large school file was gingerly pushed from the current

behavior specialist to the new school's specialist. It was then Sean's turn to participate. He

entered the room and sat in front of a laptop computer that was set up to show his presentation.

He hesitantly but firmly pressed the computer keys and began his presentation.

After Sean shared his presentation, the team members were visibly moved, with many

wiping tears from their faces. The vice principal from the new school, the person responsible for

making the final decision on classroom placements, looked Sean directly in the eye, shook his

hand, and said he would make sure Sean was fully included in school the following year. Sean

smiled and his mother nodded enthusiastically.

The following year, Sean was fully included in his new school. He became active in

wrestling, an audio-visual program, and went to all of his school dances. His favorite class was

science. He had no disciplinary actions and he remained at home without any outside

placements in mental health or juvenile justice facilities. Sean, his parents, and his case manager

credit the process of developing and showing the presentation and being listened to by others at

the meeting as having helped him have a successful transition to the new school.

Themes of Affirmation: Self-Determination Curriculum

Although not exhaustive, Table 4 includes 12 "generative" themes that support young

people with developmental disabilities to explore pathways to self-determination by building

self-awareness, self-esteem and self-efficacy. The themes are "generative" in the sense that they

encourage creative, reflective, affirming expressions among many youth with developmental

disabilities and their families.

<insert Table 4 about here>

The themes are not new to special education. In fact, there are numerous career

education, independent living, values clarification and self-determination curricula that value

similar constructs and suggest varying ways for youth to explore them, often within the context

of semester or year-long career education or transition classes in high school. What is

innovative, however, is the expression of these themes using *new media* (photography, audio and

video recording, multimedia presentation), which promise to give voice to youth with

developmental disabilities who might otherwise be excluded (Kelly, 2007; Kelly, Skouge, &

Thomas, 2005; Skouge, 2007).

Encouraging Professionals to Re-Tool Their Technology Skills

In order to creatively and effectively integrate the "new media" into classroom practice,

teachers are encouraged to engage in a continuous process of technology re-tooling. *New media*

skills can be acquired through many venues including workshops, courses and Internet tutorials.

As a note of encouragement, the technology skills described above are taught within the

framework of a one-semester university course at the University of Hawaii, including digital

photography; video and audio recording and editing; and *PowerPoint* presentation.

At present, Microsoft *PowerPoint* is the most universally available "portfolio" software for digital storytelling (although *Keynote* and *iWeb* provide exciting opportunities for Macintosh users). These software programs permit the construction of multimedia presentations that include all of the elements described above.

The *new media* are now fully embraced in the consumer marketplace, including digital cameras, audio recorders, and software for editing and sharing; and it is now commonplace for youth to be at the forefront of technology adoption (Tapscott, 1997). Educators are advised to collaborate with students in this "re-tooling" adventure. Recommended components of their "toolkit for voice" are provided in Table 5.

<center><insert Table 5 about here></center>

For readers who are new to this process, we suggest that teachers and youth advocates begin by working with just one student or client. As shown in Table 6, the process includes, first, deciding on content and gathering together relevant materials, including photographs, text and music; then, utilizing video or multimedia technology to organize the presentation, perhaps using PowerPoint or some other familiar presentation software; and, then, empowering the youth to share his or her "story", by having the "first voice" in a planning meeting or celebratory gathering.

<center><insert Table 6 about here></center>

Honoring Privacy and Confidentiality

The new media present *ethical challenges*, however, including protecting the confidentiality of youth, their families and communities. The implications of digital communications in terms of public exposure and risk cannot yet be fully comprehended. As we

value youth, family and community voices, and capture and share those voices with digital tools, we must be vigilant that what is shared is appropriate, respectful and confidential.

Technology means "change", "globalization" and "access." For those of us who work for agencies and schools, it is likely that procedures and legal protections are in place, requiring "informed consent" from consumers and/or legal guardians to permit information sharing. These legal protections are important, but *they may not be sufficient*.

Digital information can now be disseminated almost instantaneously wherever the high speed Internet is in place, including text, picture, sound, movie and "real time" imaging. With this opportunity, however, comes our responsibility to counsel and protect the privacy and confidentiality of the consumers with whom we partner. People may say and do things differently in the privacy of their homes, little realizing that an audience of "strangers" may see the situation completely out of context. As professionals, it is essential that we develop and practice techniques to fully inform consumers of the possibilities, the risks and realities of such digital communications, including safeguards to insure that consumers have the right to review, delete and edit digital information before dissemination.

A Challenge to Educators

This paper challenges educators to construct a vision of IEP transition planning that values student-centered, family and community-referenced engagement. In special education, we have a rich history of making this leap, recognizing that school, family, and community partnerships are *essential* to support children and youth with special needs. The *new media* enrich these possibilities and widen the net to include a broader representation of marginalized youth. Today, as never before, we have the opportunity to invite digital storytelling into our classrooms through the voices of families, community role models and youth themselves and, in

so doing, support young people from diverse cultural backgrounds to become confident, goal

directed, responsible citizens. Are we up for the challenge?

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Table 1. Self-Determination Curricula (Woods, et al., 1999, Revised 2004)
ChoiceMaker Self-determination Curriculum (Martin, Marshall, Maxon, & Jerman, 1996).
Lessons For Living: The 20 Self-Determination Skills and Self-Advocacy for People with Developmental Disabilities (Kurland, Hampton, Rush Simms, & Beckwith, 1995).
Self-determination for Youths with Disabilities: A Family Education Curriculum (Abery, et al., 1994).
Speak up for Yourself and Your Future! A Curriculum for Building Self-Advocacy and Self-Determination Skills (Furney, Carlson, Lisi, & Yuan, 1993).
Take Charge for the Future (Powers, Turner, Westwood, Loesch, Brown, & Rowland, 1998).
The Transition Handbook: Strategies High School Teachers Use that Work! (Hughes & Carter, 2000).

Table 2. Preparing and Implementing IEP Transition Meetings

Prior to the first meeting:

• Script and rehearse the multimedia presentation *in the youth's voice* (under the guidance and support of a teacher or other youth advocate).

• Invite a diverse mix of participants, perhaps totaling 7-9, including professionals, family members and "critical friends."

• Identify a location that lends itself to distraction-free, multimedia projection and round-table discussion.

During the first meeting:

• Include a protocol (spiritual or secular) for opening and closing.

• Give *first voice* to the youth to make his or her presentation (perhaps 20-30 minutes' duration), followed by round-robin affirmation by participants.

• Facilitate questions, discussion and suggestions.

Prior to the second meeting:

• Solicit "after thoughts" and suggestions from participants through follow-up interviews.

During the second meeting:

• Delineate the written elements of the transition plan, including

 - Prioritizing goals,

 - Formalizing a support team ("circle of support"),

 - Identifying needed resources,

 - Mapping short-term goals and steps of progression, and

 - Identifying strategies for assessment.

Table 3. Choices for Multimedia Self-Expression

• Portrait, landscape and seascape photography and imagery celebrating people, places, and
activities.

• Video recording of role models, family and friends, including interviews, stories, and
demonstrations and expressions of encouragement.

• Audio recording of songs, music, prayers, stories, poems, voices and environmental sounds.

• Self-recording of role plays and skill performances ("video feed forward") depicting life
 choices and skills that youth have visualized but not yet attained.

• "Gifting" multimedia expressions to family and community, in the form of digital slide shows
and recordings.

Table 4. Generative Themes for Self-Determination
• Introducing my family
• Journaling my day
• Accepting responsibilities
• Sharing joys and sorrows
• Celebrating beauty and wonder
• Giving voice to family and friends
• Acknowledging my accomplishments
• Learning from role models
• Visualizing my future: Goal setting and planning
• Expressing appreciation
• Giving back to community
• Committing to personal growth and change

Table 5. Technologies for Voice Toolkit Recommendations

Computer

• PC or Mac with current operating system (no more than 5 years old)

• PowerPoint or Keynote (or other multimedia "presentation" software)

• USB port for digital camera / Firewire port (IIEE 1394) for video camera

• Music importing / recording software (e.g., iTunes, Audacity, Windows Media Player)

• Microphone to record narration

• Speakers or headset to hear sound

Camera

• Digital camera (3.1 megapixels or larger)

    - Alternative: Use film or disposable camera. A photo processing facility can put pictures on a disk,

   or use a scanner or take digital or video pictures of paper-based photographs.

Video Camcorder

• Digital video camcorder (e.g., mini-dv format)

• Handheld microphone and headphones

• Tripod

• Editing software – iMovie (Mac) or Microsoft Movie Maker (PC) are included with current computer

   operating systems

Table 6. Typical Digital Storytelling Procedures		
Step 1. Planning	**Step 2. Producing**	**Step 3. Presenting**
Gather Information and Materials	**Utilize Technology Resources**	**Share Digital Stories**
• Question prompts (e.g., interview, survey, self determination curricular worksheets) • Pictures (e.g., people, places, things, events) • Videos (e.g., activities, family, friends, self) • Audio (e.g., music, narration interviews, readings) • Artwork (e.g., drawings, graphics, magazine art, websites) • Writing (e.g., poems, blogs, stories, songs, raps, homework, scripts)	• Record materials using a computer or video camera • Add text and images to introduce and reinforce content • Record youth voice describing the content or message of product • Incorporate selected music • Edit and make finishing touches to enhance flow and organization of presentation	• Identify appropriate context for youth to share presentation (e.g., planning meeting, special gathering, special attendees) • Youth actively participates in and/or facilitates gathering • Team members view presentation and are prepared to ask questions, make comments, and utilize the information shared • Follow-up is essential