

breaking ground

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Reimagining Supports for Families of Tennesseans with Disabilities



also inside:

- *Borderless Arts in Egypt*
- *Helping People Have Good Lives*
- *Inclusion is a Right*
- *Project SEARCH*
- *Programs to Promote Safety*



Council on
Developmental Disabilities

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Reimagining Supports for Families of Tennesseans with Disabilities

by Emma Shouse Garton, Director of Communications, Council on Developmental Disabilities

In 2013, the Administration on Intellectual & Developmental Disabilities funded a grant to identify and implement policies and practices that will help support families with members with intellectual and developmental disabilities across the lifespan. A national “Community of Practice” was established, a learning “community” that began with five states, including Tennessee, and then expanded in 2016 to include 11 other states across the country. In Tennessee, the Council on Developmental Disabilities and the Department of Intellectual and Developmental Disabilities (DIDD) have partnered together to coordinate this initiative.

The grounding principles of this learning community are known as the “LifeCourse Framework”. The core belief guiding this work is that all people and their families have the right to live, love, work, play and pursue their life aspirations. The efforts of this community of practice are leading a national conversation about how states and families can reimagine what it looks like to truly offer meaningful supports across the lifespan for all members of a family experiencing disability. The goal of this work is to maximize the capacity, strengths and abilities of families so they are able to nurture and support all individual members, including the person with a disability, to lead meaningful lives.

Reframing our thinking and messaging


The LifeCourse framework brought a new perspective to Tennessee’s disability system. While Tennessee had been a national leader for many years in promoting “person-centered” thinking, organizations and systems, we realized that by only focusing on the individual with a disability, we were often overlooking the key influences, contributions and needs of the person’s family unit. We all exist within the context of our families, whether that “family” is our family of origin, our partners and children, and/or other loved ones who we have chosen to care for and be close to.

When Tennessee started on this journey in the Supporting Families Community of Practice, one primary LifeCourse concept that resonated with us was the concept of “the all”. This refers to the fact that nationally only about 25% of individuals with intellectual and developmental

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What is the LifeCourse Framework?

Practical, family-friendly framework based on life course theory and focused on quality of life for the individual and family. Designed to assist people with intellectual and developmental disabilities in achieving a vision to live, work and play just like any citizen.




ALL/THE 100%

ALL people are considered in our vision, values, policies and practices for supporting families of people with disabilities (including the over 75% of families who don't receive paid services through the developmental disability service system)




FAMILY SYSTEM

People exist and have reciprocal roles within a family system, which adjust as the individual members change and age




LIFE STAGES & TRAJECTORY

Past, current and future experiences impact an individual's life trajectory




LIFE OUTCOMES

Focus on life experiences that support someone's life trajectory towards a good quality of life and build self-determination, social capital, economic sufficiency and community inclusion




LIFE DOMAINS

People lead whole lives made up of specific and integrated life domains (such as daily life and employment, community living and housing, healthy living, social and spiritual life, and so on)




THREE BUCKETS

Providing support to individuals with disabilities and their families includes not only 'goods and services' for their day to day needs, but also the information and emotional support they need. Supports should adjust as family members age and roles change



INTEGRATED SUPPORTS

Individuals and families access an array of integrated supports to achieve a good life, including those that are publicly or privately funded and based on eligibility; community supports available to anyone; relationship-based supports; technology; and supports that take into account the assets and strengths of the individual and family



POLICY AND SYSTEMS

People with disabilities and families direct supports and influence all levels of policy and practices

Charting the LifeCourse™ and LifeCourseTools.com is a project of the University of Missouri–Kansas City Institute for Human Development, Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD).

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disabilities receive long-term disability services and supports. That means that when state systems or policymakers only focus on how we can improve the disability service system, we are overlooking at least 75% of individuals with disabilities and their families. We must find other ways to reach “all families”, and go beyond just improving disability-related services when we want to improve the lives of Tennesseans with disabilities and their families. What policies, practices and programs can help really transform our states and communities to assist families beyond that 25% of folks who are connected to the long-term service system?

Supporting families in TN

For the first couple of years of this initiative, Tennessee’s team focused specifically on a few areas, including building our own familiarity and expertise in using the LifeCourse principles and tools to change our own thinking.

Letting the experiences and priorities of families guide our thinking and work is a key part of the LifeCourse framework, so we also solicited feedback and stories from Tennessee families. We hosted focus groups at the TN Disability MegaConference to ask families how they were helping their loved one with a disability connect to their community, often without the support of disability services and just using their own creativity and generic community resources. For a few years, we offered a dedicated email newsletter about this initiative where we asked families about their needs and their experiences. We partnered with Vanderbilt Kennedy Center and TN Disability Pathfinder to develop a special edition of “Kindred Stories”

that shared anecdotes of the successes and challenges that Tennessee families experienced around disability services, community and social engagement, employment, transportation, informal supports, future planning and other critical issues.

Another priority was sharing the message of the LifeCourse framework with our existing partners. With a focus on peer-to-peer supports for family members, we worked to inform people about the Family Voices of Tennessee “Parent to Parent” mentoring initiative that pairs parents of children with disabilities to help one another and about TABS (TN Adult Brothers and Sisters), the statewide sibling support network for siblings of people with disabilities. We also worked with the Governor’s Children’s Cabinet and KidcentralTN to expand disability resources available on KidcentralTN.com, which is a platform that can impact “ALL” families in the state, whether or not they’re connected to disability-related services.

One of the best connections the Council made through this Supporting Families



Amanda Northrup and daughter Coco



The McGee Family



Jason Oliver and his daughter



Bousquet dad Brant with sons Robert and Paul

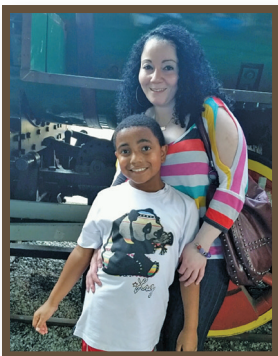


Kendyl Schwindt with her cousin and sister

initiative was with the University Extension network in the state. The University of Tennessee and Tennessee State University Extension networks have offices in every county of the state, and one of their roles is to provide families in local communities with trainings and information and resources that they need. We have built a strong partnership with the UT and TSU Extension offices by disseminating disability resources to their county agents, providing training on disability sensitivity and family experiences, and offering our office as a go-to resource when those Extension agents encounter families with members with disabilities who need help connecting to appropriate services.

Training individuals and families on LifeCourse Framework and tools

One of the main focus areas of Tennessee’s work through this initiative has been sharing the message and resources of the LifeCourse framework and toolkit with individuals with disabilities and their families. Over the past five years, we have delivered more than 40 trainings and presentations about these concepts and tools. We trained and talked to families and self-advocates on our Council, in our Partners in Policymaking and Vanderbilt’s Volunteer Advocacy Project-Transition programs, at



DeShun and DeAnna Parker

transition conferences hosted by school districts, at family employment coalition meetings, and through a number of different family workshops and conferences coordinated by various advocacy organizations and providers.

We presented more than a dozen sessions in recent years about different areas of the LifeCourse framework at the Tennessee Disability MegaConference, the largest statewide cross-disability conference for Tennesseans with disabilities, families and professionals. In addition to spotlighting LifeCourse tools and key resources, we also used these sessions as opportunities for families to share their stories with one another and to brainstorm ways that they can build better relationships in their communities, without needing to depend on supports through the disability service system. For the 2017 annual “Think Employment” Summit hosted by TennesseeWorks - a statewide collaborative of people invested in increasing employment opportunities for Tennesseans with disabilities - the Council and DIDD developed tracks for self-advocates and family members to help them understand the employment service system, use LifeCourse tools to develop a vision for employment, learn about best practices in employment for people with disabilities, and hear employment success stories from other Tennessee self-advocates, family members and employers.

Helping professionals use LifeCourse Framework and tools

In addition to training self-advocates and families, we’ve also done outreach and training to professionals who

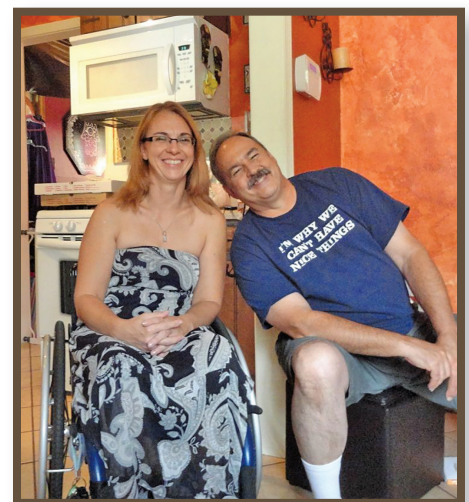
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Steve Sheegog and family



The Jones Family



Partners grad Christy Earheart and dad Joe Bledsoe

A Tool for Helping People Have Good Lives

by **Ned Andrew Solomon, Editor-in-Chief, Breaking Ground, Council on Developmental Disabilities**

“All people have the right to live, love, work, play and pursue their dreams in the community,” said Michelle (“Sheli”) Reynolds of the University of Missouri, Kansas City Institute for Human Development, one of the leaders of the national Supporting Families Community of Practice.

And it’s absolutely true. But, as those of us who live with disabilities or are family members of people with disabilities know, having that right and enjoying the benefits of that right can be two very different things.

Instead, individuals with disabilities and their families often feel isolated from the community, and too few get to live a well-balanced life where they might come into contact with others, which might lead to friendships, romantic relationships, cultural enrichment or employment opportunities.

For those fortunate enough to have long-term disability services – about 25% of the national number of individuals with developmental disabilities – sometimes those services can actually cut people off from the community if providers aren’t intentional in providing opportunities

Families ... *Continued from page 5*

interact with individuals with disabilities and families across the lifespan. We provided presentations and trainings on the LifeCourse framework and tools at the statewide special education conference, Statewide Employment Consortium, to DIDD support brokers and at a special retreat for DIDD case managers to focus on learning to use LifeCourse tools. The first two classes of the Leadership Academy for Excellence in Disability Services, a new intensive leadership development program created by the Council and delivered by the TN Department of Human Resources that includes representatives from all disability-related agencies in State government, have received training on how to use the LifeCourse framework and concepts to guide their work serving Tennesseans with disabilities and their families.

We also made an effort to embed some of these concepts at the systems level by hosting cross-agency “lunch and learns” about different aspects of the



Cynthia Salem and family

LifeCourse framework, including: peer-to-peer support networks for family members (self-advocates, parents and siblings); connecting families to information and systems navigation help that they need; involving families in policy and planning; and how technology can be used to support individuals with disabilities and their families. Representatives from a variety of State agencies got together at these events over the span of a couple of years to brainstorm how our system as a whole could improve in offering these types of supports to families, and to hear what other agencies do to address the needs of their customers using these kinds of strategies.

Using LifeCourse Framework to shape policy

Early on in this work in Tennessee, the Department of Intellectual and Developmental Disabilities used the LifeCourse framework and tools to evaluate their “front door” to services, what families were experiencing when they called with questions. They examined how they could revise DIDD policies and practices and support their staff to better understand family concerns to improve those experiences. They continue to provide staff working directly with families, like case managers and independent support coordinators, with resources like LifeCourse and person-centered thinking tools to have productive conversations with families and individuals about their goals for the future and what supports they need.

for true community participation. How many people with disabilities do we know whose closest relationships are with a paid caregiver, instead of with someone who truly chooses to be in their lives, with no strings attached?

On most days I get up and share a coffee with my wife. Then I drive downtown to an office of seven other people – who I have known for years – in an office building that holds hundreds of people from different agencies. I say hello and have quick conversations with maybe 25 of them each day – and through those brief chats learn about books read, movies seen, unique foods eaten, community events and activities that I may not have heard about.

On the way to work I may stop for a second cup of coffee and have a lovely interaction with the barista behind the

counter, or the person standing next to me in line. These encounters happen all day long – on lunch breaks, cashing a check at the bank, stopping for gas or by a grocery or convenience store on the way home. As a presenter for our Partners in Policymaking Leadership Institute once said, “I don’t announce, ‘honey, I am going into the community now!’” I am already part of the community. So how can we help people with disabilities have good lives, with satisfying and meaningful engagement with the world around them?

The Integrated Supports Star is a good tool to help us think about moving closer to the life that most of us want. The Supports Star encourages all of us to think about

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In 2016, before the launch of the new Employment and Community First (ECF) CHOICES program that provides long-term services and supports to Tennesseans with intellectual and developmental disabilities and their families, the Council and Vanderbilt Kennedy Center hosted two stakeholder forums for providing family and self-advocate feedback to Tennessee’s managed care organizations (MCOs) that would be running the new program. We wanted to make sure that MCO policymakers and leaders heard from self-advocates and families about their expectations and needs before the program even started, just as TennCare had developed the program based on input from families.

In creating the ECF program, TennCare used the LifeCourse framework and input not only from families currently receiving services through Medicaid waivers overseen by DIDD, but also those families outside of the service system because of waiting lists or ineligibility for services under previous criteria. New and innovative services were developed in ECF that help families and self-advocates find support, build their knowledge and skills, and connect meaningfully to their communities (i.e., Family Caregiver/Individual Education and Training; Family to Family/ Peer Supports; Counseling & assistance with health insurance, conservatorship/supported decision making, etc.; and Community Support Development, Organization and Navigation). MCOs were encouraged to familiarize their staff with the LifeCourse framework and tools, as well as person-centered planning resources. A key principle of the LifeCourse framework is that family and self-advocate voices should

drive policy change and practices at every level and stage of a process, like rolling out a new disability program – and to provide families the opportunities, information and assistance they need in order to be involved in these ways.

Lessons learned, moving forward

Over the past five years of participating in this learning community, we have seen firsthand that the LifeCourse framework and tools resonate with both families and professionals and shift thinking in important ways. We have heard from folks in our trainings that these concepts and tools help people think about the future differently, problem solve and strategize about issues when they feel “stuck”, and creatively reimagine what supports for people with disabilities might look like. A major challenge of this initiative has been measuring the true long-term impact of these efforts that last beyond a training or presentation. We hope that lots of families and professionals are using these concepts and tools in their everyday lives – if you are, please let us know! The Council would love to find new opportunities to share the message and resources of the LifeCourse framework and tools. We want to continue to discover ways we can incorporate LifeCourse principles and values into all the things our state and communities are doing to improve the lives of Tennesseans with disabilities and their families. To learn more about the LifeCourse framework and tools, visit www.lifecoursetools.com.

If you are interested in trainings about the LifeCourse framework and tools, please contact Emma Shouse Garton at emma.shouse@tn.gov.

Helping ... *Continued from page 7*

the various strategies and places where we can find the supports that we need to achieve the goals we have for ourselves and our families. Far too often, families can feel stuck when they aren't able to access "formal" services and supports for a family member with a disability – the Supports Star is a tool for problem solving, strategizing and brainstorming for where we can find or intentionally develop supports to help us lead the lives we want, in addition to government services someone may be eligible for because of their disability, age or income.

Let's begin this "Supports Star" exercise with the notion of "independence". I do trainings for youth with disabilities where I talk about the need to "be more independent", to have greater control of your life. But as much as I talk about "living independently" it really is a misnomer. Very few of us actually live "independently". We all rely on others to help us accomplish important asks in our lives. I rely on my wife to fix things around the house; she relies on me to cook most of our family meals. I rely on my teenage kids to teach me how to use my cell phone. When my car breaks down, I call Kwame at the car dealership.

We all use resources and supports to get through our daily routines. We also use our personal skills and talents to help others get through their daily lives. Which brings us to the first section of the Integrated Supports Star:

Personal Assets and Strengths. Personal assets and strengths are those things that a person or a family can contribute to society and that can help them pursue goals that are important to them. What do you do well or have a great passion for that might be beneficial to someone else, or even an employer? What are those aspects of your personality that make people want to engage with you? Are there strengths you have, skills you could learn or resources your family brings to the table that could help you move towards your goals? This is an opportunity for you to brag on yourself, so don't hold back! Starting with mapping out the strengths, assets and resources we have or that we could develop is an encouraging and empowering place to start when thinking about how to move closer to the life we want.

Moving along the points of the Star, **Relationship-Based Supports** are those things that the people closest to you – like family, friends or neighbors, co-workers or people who are members of your faith community – might be able to help with. Who's a part of your life, and what

resources and supports can they bring to your life? Is your neighbor across the street good at building things? Could your co-worker drive you home a couple of days a week? Didn't your friend at church say he was looking for seasonal help at his bookstore – and wait – didn't you say you love to read? All of us rely on others for support – the "relationship-based supports" part of the Supports Star reminds us that there may be people in our lives or our family's life that could help us in moving closer towards achieving our employment, independent living or education goals. In exchange, how can we offer supports to others, using our strengths and assets? If a person doesn't have family or friends or neighbors that can provide some support in living their version of a good life – how can we begin to develop more opportunities for someone to build those types of reciprocal relationships?

Let's move on to **Technology**, which has become omnipresent in our lives. Think about your specific needs, and then brainstorm about a piece of technology that might help satisfy that need. Too often, when we think about technology to support people with disabilities, we may think about highly specialized assistive technology or apps designed specifically for users with disabilities – but all of us use technology in all sorts of ways to connect with others, learn new information, meet our needs and get through our day more effectively. Maybe you have trouble being and staying organized. Can you set reminders or tasks on your cell phone that will alert you when things need to be done? Does your inability to read or see medicine labels make you dependent on someone to give you your meds? What if you had a pill dispenser that alerted you when it was time to take a pill, and then automatically only dispenses the prescribed amount? What home access technology could you have that turns on and off lights, changes or sets temperatures or opens and closes the door to your home?

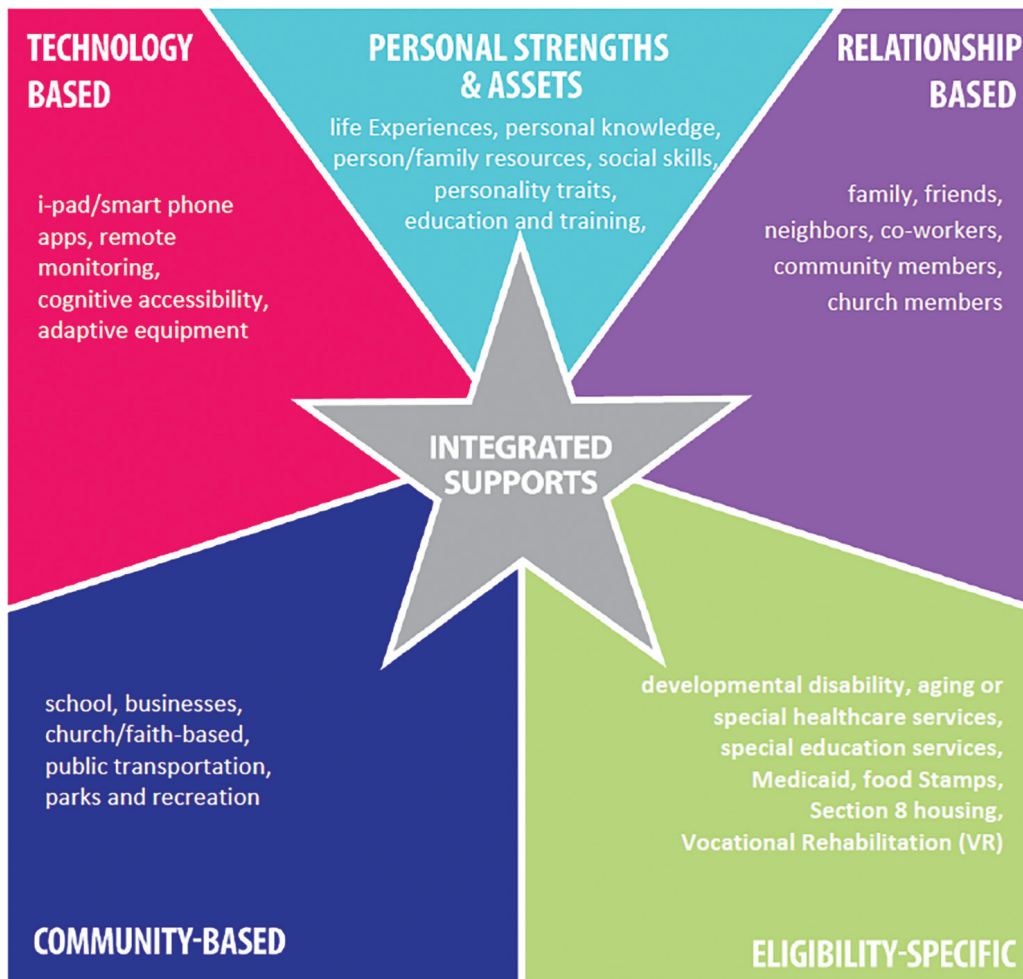
Community-Based Supports is another point on our Supports Star. These are the supports that anybody can take advantage of, like public parks, public transportation, recreation centers, libraries, hospitals or free clinics. It might be helpful to make a list of these entities that your community offers, and then check out their websites or get on their mailing lists so you don't miss beneficial offerings or special events. The library is offering a cooking class; the park is having a free classical concert; the local rec center is teaching a self-defense class; your local American Job Center is teaching classes on interview

skills. Get with the program and connect up with your community! We sometimes can overlook or forget all the resources available through our community that can help support us in leading good lives and working towards achieving our goals.

The last point of the Star is **Eligibility-Specific Supports**. These are the services or resources that a person is eligible to access based on their disability, age, income, geographical location or other criteria. An example of these types of supports could be home- and community-based services through a Medicaid waiver for people with disabilities, food stamps, special education services, Vocational Rehabilitation or Section 8 housing vouchers. If you live in one of Tennessee’s big metropolitan areas, there may be quite a few of these resources nearby. If you live in a more rural area, you might have difficulty accessing a particular service, even if you are eligible. Too often, this is the point of the Star that most people think of first when trying to find supports for an individual or family that experiences a disability.

In fact, Eligibility-Specific Supports may be the ONLY point of the Star that people consider. *Which is the point of this exercise.* All of us need to build an “infrastructure” of integrated supports that work together – we are short-changing people with disabilities if we only consider formal government services as the way to help someone achieve their goals. Beyond the fact that these types of government services are limited in their capacity to serve all eligible individuals, truly supporting individuals with disabilities to live good lives in their communities means helping people access all types of different supports, the same way that all of us rely on various strategies, resources and relationships. We don’t want to “put all of our eggs in the one basket” of eligibility-based supports – to lead full, rich lives, people need to find and develop supports in all “parts of the Star” when they can.

We have to widen the lens to make sure we think about ALL the options at our disposal that will lead us toward the life we want to live. What combination of Personal Assets and Strengths, Technology, Relationship-Based Supports,



Community-Based Supports and Eligibility-Based Supports will help us have the lives we want, with meaningful activities and relationships to fill our days?

So, take a few minutes and fill out your own Integrated Supports Star, or help someone you know and love fill it out about their life. You can download a clean copy of it at the website lifecoursetools.com. Reminder – this isn’t meant to be a tool filled out just once; the Supports Star helps us problem solve, brainstorm and strategize any time someone needs support with any area of life. I think it’s a great tool to at least start the conversation.

If you have any questions about how to use the Integrated Supports Star, please feel free to contact me, Ned Andrew Solomon at ned.solomon@tn.gov or 615.532.6556, or Emma Shouse Garton at emma.shouse@tn.gov or 615.253.5368.

Two Chattanooga Programs Promote the Safety of Individuals with Disabilities

by **Ned Andrew Solomon, Director of Partners in Policymaking Leadership Institute, Council on Developmental Disabilities**

When Captain Skyler Phillips of the Chattanooga Fire Department became a father of a son on the autism spectrum, he had no idea how his avocation, and his role as a dad, would intersect.

But today he uses his own experiences and learning curve with his child, and his concerns about his son being in the midst of an emergency situation, to train other firefighters about what they need to know if they encounter an individual with autism or other developmental disabilities. SNAP, or the Special Needs Awareness Program, is a First Responder Training Course developed with Lisa Mattheiss of LifeLine, a family support entity in Chattanooga, based on scenarios encountered by families who experience disability.

“This class is not about teaching people how to answer calls,” said Captain Phillips. “This class is about helping first responders make these calls go easy. The whole purpose – and this is what I tell them in my class – is to make the world safer for people like my son and to be better prepared to respond.”



SNAP Firefighter training program led by Captain Phillips

Although Captain Phillips’ primary focus has been his firefighting peers, the ultimate purpose of SNAP is to equip police officers and emergency medical services to respond with the greatest level of support and dignity when they interact with someone living with a disability. The training includes insights about intellectual, sensory, behavioral, physical, medical and communication challenges that might occur in crisis situations involving individuals with disabilities.

The SNAP training teaches attendees how to better understand:

- Challenges faced by families and how those issues might affect their interactions with first responders
- Potential responses of someone overwhelmed by sensory stimulation
- Potential triggers for someone in an emergency situation and ways to avoid those triggers
- Multiple de-escalation techniques and strategies
- Ways to identify someone with an invisible disability

SNAP’s goal is to train as many fire departments as possible. Captain Phillips has taught numerous departments himself, representing more than 2,000 individuals, including first responders in neighboring Georgia. His expertise has been requested far and wide. “I can’t possibly teach the 450 departments in the state,” Captain Phillips said. “So we’re going to come up with a train-the-trainer program. That way we can give them access to the PowerPoint and let them teach their own departments.”

There’s another very practical component to the SNAP

initiative. Captain Phillips linked up with the Hamilton County 911 system, collaborating with a staff member who also has a son with autism, and who teaches 911 Communicators how to interact with people with autism during a 911 emergency call.

“We developed a process where you can enter your name, address, telephone number, the disability and who in the household has the disability – all that sort of thing gets programmed into the 911 system,” explained Captain Phillips. “Police, firefighters, County Sheriff – we all have the same computer system, so if people have registered, that information pops up on our computers when that address comes up.”

In addition, a first run of 2,000 stickers with the SNAP logo, funded by the Chattanooga Fire Fighters Association, were distributed to people in the community to put on their cars and houses. “So that when firefighters, or Emergency Medical Services or the police respond to their house, or if they see that sticker on the back of their car during an accident or whatever, they know that someone with a disability might be inside,” said Captain Phillips.

All of these efforts are meant to make emergency calls easier for emergency personnel, the individuals and families that experience disability, and to better prepare everyone for what could be an intense life or death situation. “We don’t want to get that call,” said Captain Phillips. “We’re afraid that it’s just going to turn into violence, so we just restrain people. We’re so worried about ourselves that we don’t take the time to think about what the real cause might be. So we try to open their eyes by telling them, ‘look, if you just step back and given them some space, you may find that you get a better outcome.’”

Take Me Home

Captain Phillips has also helped another important safety program get up and running in Chattanooga. The free Take Me Home program allows family members and legal



Roddey Coe, member,
Council on Developmental Disabilities

guardians to register emergency contact information for individuals with intellectual and developmental disabilities which first responders can then access in emergency situations. When a vulnerable individual is found wandering alone or has been reported missing, police and other emergency services personnel can search for contact information, a detailed physical description and the individual’s photograph. The program is voluntary and all information is kept confidential.

Take Me Home was initiated with the support of advocates in the Chattanooga autism community, including Roddey Coe of Ooltewah. Roddey is a Governor-appointed member of our Council on

Developmental Disabilities, a 2017-18 graduate of the Council’s Partners in Policymaking™ Leadership Institute, and is the father of a son with autism. Take Me Home also represents a collaboration between Chattanooga’s police and fire departments and the Chattanooga Autism Center.

In an interview with the Chattanooga Times Free Press, Roddey said, “I have friends whose kids have disappeared, and this tool for law enforcement will allow them to see who they’re looking for. If officers approach someone on the street who may be unable to communicate because of autism, dementia, Alzheimer’s — anything that can take away somebody’s ability to speak or tell them where they may be — this will allow them to pull up a picture and take that person home instead of to a jail cell.”

The Council is planning to work with Roddey and other stakeholders to explore making this program available in communities across the state.

Chattanooga-area caregivers can enroll family members, friends or clients with disabilities in the Take Me Home database online at <https://tmh.chattanooga.gov>. For more information, email takemehome@chattanooga.gov.

For more information about SNAP, contact Captain Phillips at skyleer.phillips@lifelinefamilies.org. There is no cost for the training.

Borderless Arts Breaks Ground in Egypt

by Lori Kissinger, Executive Director, Borderless Arts TN

Borderless Arts Tennessee, a statewide arts program for individuals with disabilities, was recently invited by the Alwadna International Arts Forum for the Gifted to represent the United States in Egypt. Members of the Borderless “Movement Connection” dance program performed in costumes made by members of the Borderless “Teapot Diplomats” visual arts program, in a piece developed by Borderless Arts last summer. That piece was integrated into the Frist Center for the Visual Arts’ Nick Cave exhibit. A member of the Alwadna International Arts Forum committee saw a

video of this dance program, and invited the young Tennesseans with disabilities who participated in this Borderless Arts program to visit Egypt and represent the U.S.

Due to funding constraints and restrictions by the Forum, the traveling artists were limited to a small participating party. It was decided that one of the dancers would be one of the Teapot Diplomats that helped make the



Caitlin Bernstein on stage during the Alwadna opening ceremonies



Borderless Arts TN dancers performing for the Alwadna opening ceremonies



Borderless Arts dancers meet with Nadia Elarabie, an Alwadna Forum organizer

performance costumes. The dancers from “Movement Connection” included Grace Dodd, Caitlin Bernstein, Danielle Clement and Teapot Diplomat Hope McKee.

The participants arrived in Egypt in the late afternoon of April 26. They were immediately whisked away to a rehearsal that lasted into the night. Early the next morning, the group toured some of the area’s sites before heading to an evening opening ceremonies performance that took place in the theater at the University of Cairo. The entire visit was a whirlwind that included a second day of performances at the Civic Education Center in Cairo, as well as sightseeing and then a quick return to the United States.

A trip highlight was meeting other performers from all over the world, who were excited that the United States was able to be present at this event. In all, 31 nations participated, primarily of African and Arabic backgrounds.

This opportunity was a major step for our organization. Borderless Arts Tennessee is a small organization, but we have big dreams. However, the biggest accomplishment for me was watching our participants grow. They grew by watching and learning about cultures that are very different from what they have experienced in the States.

They also grew by expanding their own abilities. I saw them be flexible with schedules, endure hugs and kisses when some have sensory issues, out of respect for other cultures, and push past exhaustion to perform at their very



In Egypt at the Great pyramids and the Sphynx. L-R: Kathleen Dodd and Grace Dodd in front of her, Lori Kissinger, Sylvia Goodman, Danielle Clement, Caitlin Bernstein, Monique Bernstein, Crystal McKee and Hope McKee



Caitlin Bernstein is greeted by an Egyptian dancer between performances

best because they knew that they were representing more than just themselves. I sat holding my breath as these travel-worn dancers were about to take the stage, knowing that they waited in the wings for over eight hours. They were venturing out onto a stage with an unexpected light show behind them and a sea of over 4,000 foreign faces in front of them. I had no idea if they would step onto the stage or possibly freeze in place! The announcer said, "And now representing the United States of America..." and my heart skipped a beat. And here they came with smiles on their faces to perform the best performance I have ever seen them give - the show of their lives.

"The best of humanity was shown at this forum through the harmony created by imagination and artistry by all of the countries represented," said Hope McKee, the Teapot

Diplomat representative. "The kinship and goodwill made this trip truly awe-inspiring."

For a few days, countries came together to celebrate abilities and the ties that bring humans together - the need to connect, the need to communicate and the need to create. And it was performers with disabilities that brought us to that place to remind us that what binds us together is far greater than what keeps us apart.

About Borderless Arts Tennessee

Established in 2001, Borderless Arts Tennessee, formerly VSA Tennessee, is a 501c3 organization that works in partnership with and in support of artists, parents/guardians and educators to ensure there are resources, tools and opportunities for arts programming in schools and communities statewide. Borderless Arts Tennessee offers quality dance, music and visual arts programs for people with disabilities. For more information, visit borderlessartstn.org.

Free Trainings Offered by the Council

Informing and educating Tennesseans about disability issues, policies and practices is one of the Council's primary goals and roles in the state. We accomplish this through a number of communications activities, including this magazine, but another strategy is community outreach through trainings and presentations. The Council can provide trainings not only for individuals with disabilities and families, but also to professionals in the disability field, advocacy and community groups, policymakers and any group who would benefit from greater awareness of the disability-related topics listed below. Most presentations can be

adapted for any audience size, type of audience, or length of time and can be delivered anywhere in TN, as schedules allow.

If your agency, organization or community group is interested in these topics, invite the Council to present at your existing events, conferences or meetings, or contact us to schedule other types of training opportunities. In addition to the list of presentations below, we can also always share basic information about the Council, our programs and our role in Tennessee.

Continued on page 14

Training ... *Continued from page 13*

Partners in Policymaking™: An Overview

The Partners in Policymaking™ Leadership Institute is the Council's free leadership and advocacy training program for adults with disabilities and family members of persons with disabilities. Originated in Minnesota in 1987 and established in Tennessee in 1993, more than 500 Tennesseans have graduated from the Partners program.

Supported Decision-Making

Decision-making is a fundamental component of a person's dignity and sense of humanity, but for people with certain labels – like age, disability, or behavioral health diagnoses – the freedom to make their own decisions can be taken away. This presentation covers three general themes: What is Supported Decision Making; Why incorporate Supported Decision Making into supporting a person; and Strategies to begin using Supported Decision Making, including concrete tools and resources.

LifeCourse Tools / Supporting Families Community of Practice

The Supporting Families Community of Practice is a national initiative focused on best policies and practices to support families impacted by disability across the lifespan. The guiding principles are known as the LifeCourse Framework. LifeCourse tools help individuals with disabilities, families, and professionals in their lives have productive conversations about goals, needs, life transitions and supports for the future. Council staff can provide presentations about this national initiative and the LifeCourse framework, as well as interactive trainings using LifeCourse tools.

Youth Readiness Days

An interactive training program for high school students with disabilities to help them think about educational, employment and independent living plans after leaving high school. Staff can offer free one-day trainings at the request of school systems or excerpts of the curriculum for shorter presentations, including an "Independent Living Reality Checklist" activity.

Public Policy 101 & Legislative Updates

The "Public Policy 101" presentation provides an overview of how the state and federal legislative processes work and

strategies for how individuals with disabilities and families can effectively participate in those processes. The Council can also provide an overview of current state and federal legislation and public policy issues impacting Tennesseans with disabilities and their families.

Disability Awareness & Sensitivity

This interactive session strives to break down barriers to community inclusion by presenting most appropriate ways to communicate and interact with persons with disabilities.

Learning to Speak Up for Yourself: The importance of self-advocacy

This interactive training provides strategies for how individuals with disabilities can become empowered to speak up and advocate on their own behalf, and addresses some of the challenges to doing so.

Turning Lemons into Lemonade

This presentation provides strategies for how to turn negative situations into positive advocacy and other constructive outcomes, specifically focusing on additional challenges faced by families and individuals that experience disability.

Providing Support That Truly Supports

This interactive training provides strategies for how individuals with intellectual and developmental disabilities can be supported without taking away their independence, sense of self, and ability to make choices and have control over their lives.

Trainings being developed for 2019

- Training for Advisors to Self-Advocacy groups
- History of the Disability Experience
- Building Inclusive Communities
- Journey to Employment
- Navigating the Disability System

For more information about scheduling a presentation from the Council, fill out our "training request form" on our website at tn.gov/cdd ("Trainings and Presentations" under "Training and News" on our homepage) or contact Communications Director Emma Shouse at emma.shouse@tn.gov or 615.253.5368.

Inclusion is a Right

by Sheila Carson, Partners Graduate, 2017-18 Class

The disability issue that I am most passionate about is inclusion in the schools, in the workplace, and in our communities. Every person has the right to live life to the fullest and to strive to reach his or her potential. Every citizen has the right to life, liberty, and the pursuit of happiness. And every person has the right to feel, and be, included.

Everyone benefits from inclusion because we learn from one another. Some don't see it that way. Some are resistant to change or to do anything that, in their mind, means they lose somehow if everyone is included. This is where education comes into play.

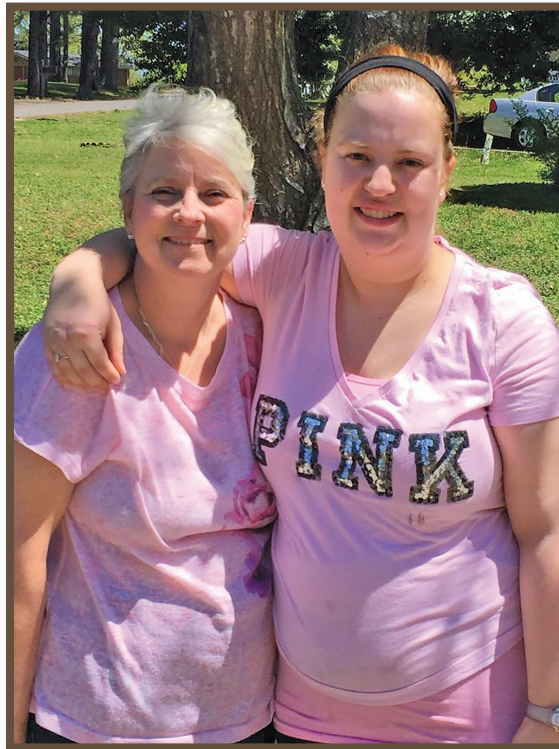
I must confess as a mom, there have been times when I have wanted to keep my daughter protected "in a bubble", because the world is not always a kind place. I have steered her toward places and people where I felt she would be more accepted. But is this truly allowing her to spread her wings and reach her potential? Life is a risk. From risks come rewards.

Inclusion has to start early in the schools. Special education policies have evolved over time, in some areas faster than others. In my experience, guidance counselors and teachers are beginning to have more open and honest conversations about what is best for our children.

But some of this is on US. We have to take the responsibility to teach everyone that will listen that ALL students have value. We all learn differently, and that's okay. Kindness and compassion should be encouraged, and praised.

Parents have known for years that if they are visible and

helpful in the schools, their children are more likely to be supported and included. We must, as advocates, let school officials know that hiding our loved ones away is no longer acceptable. Instead of threats, we must educate ourselves about our rights, and we must use that knowledge to support our children.



Sheila and Sarah Carson

Voting for school board members that share our vision, or becoming a school official ourselves will help us move forward in making inclusion a reality. Being as visible as possible, participating in every meeting, volunteering in the classroom and at all the special school events lets everyone at the school know that you are invested in your child and his or her future – as well as the entire school community. Early on, my daughter was very active in scouting. To give her more opportunities, I first became a leader, and eventually, a major player in Girl Scouts in our area.

That's what it takes to make change happen in the schools. We have to be a part of the process to

change the process. To sum this all up:

- Education is the key. We have to know our rights and be willing to stand up for our rights and the rights of our children.
- Visibility is imperative. We spend time on the things that are most important to us.
- Numbers count. We must band together and support each other to make change happen.
- We must vote for representatives that further our cause.

And finally, as someone very wise once said ...

- Be the change you wish to see in the world.

East Tennessee Project SEARCH[®] Collaboration:

A guidepost for successful transitions

by Tammy Hearon, Project SEARCH Instructor, Blount County Schools and Devin Stone, Public Information Officer, Tennessee Department of Human Services

Blount County Schools and Maryville College have teamed up with The Access Program and Tennessee Department of Human Services to implement a truly successful Project SEARCH[®] partnership. Project SEARCH is a one-year internship program for students with disabilities in their last year of high school or for young adults working with a disability service provider. For this partnership, Maryville College serves as the community job site for the interns.

Designed for young adults whose goal is competitive, integrated employment within their communities, the interns get hands-on training, learn work skills, and have real-world opportunities to strengthen their independent living skills. The Tennessee Department of Human Services has helped implement the program, in partnership with organizations across the state, by providing Workplace Readiness Specialists, training, and technical assistance from the national Project SEARCH organization. Tennessee currently has 10 active Project SEARCH programs.

Parents and students have been very engaged and enthusiastic about the program since it started and are a key part of the team. In addition to the parent and

student, the Maryville Project SEARCH team consists of the instructor, Workplace Readiness Specialists, a Maryville College representative, a vocational coordinator, a community resource provider and a Blount County Schools representative. Parents are included at employment meetings, and a core group meets every month to discuss intern progress, direction, expansion of the program and upcoming deadlines.

Maryville College's Project SEARCH program has resulted in successful employment outcomes for all of its interns since the program began. Blount County Schools launched the program in the 2015-16 school year at William Blount High School with five interns enrolled. Students interned with Metz Culinary Management, which provides dining services at Maryville College. The interns had four rotation options that included the Metz Café dining hall, the dish room, clerical work and housekeeping.

All interns proved to be very good at their jobs, and before the spring semester, Metz had inquired about hiring an intern. By the end of the semester all five of the interns were hired within their communities and remain employed. Besides the Metz Café, employers that hired interns have included Blount County Schools, McDonald's, Mamma Gillana's and Lowe's.



Lester Phinney



Jacob McLemore



Brittany Norrod

The following school year, the program expanded to include seven more interns from Heritage High School and an additional Metz service rotation. All members of the Blount County Schools' intern class of 2016 - 17 were employed by April of 2017 and continue to maintain employment.

In the 2017-18 school year, The Access Program joined the partnership as a community service provider. The Access Program supplies a job coach and follow-along services paid through Vocational Rehabilitation. Currently five interns are enrolled and all have started their employment journey at five different employment sites.

The Blount County Schools/Maryville College Project Search experience is beneficial for all involved for a number of reasons. Student interns are able to experience campus life and work environments firsthand, while learning skills that help to keep them engaged and employed. Students have expanded their independent living skills by using public transportation provided by the local community action agency to get to and from their work sites. During the past three years, the host business and community have become more aware of the capability of the interns. When speaking of the job skills at the



Lester Phinney

internship site, the Maryville College Manager of Custodial Services, Mary King, said, "The Project SEARCH interns have proven that they can do the job."

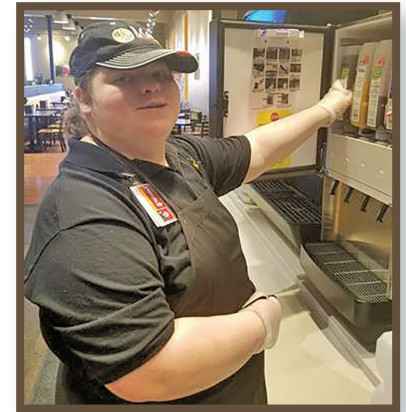
Metz Culinary Management not only trains interns with a high quality of instruction and work ethic, but also hires interns to be part of their staff. James Dulin, an avid supporter of hiring individuals with disabilities, stated that the Project SEARCH interns at the Metz Café are "contributors".

Blount County Schools

has also been a huge partner for hiring interns in their system as well, under the leadership of Karen Helton, Food Nutrition Supervisor.

Regarding the intern he hired, Lowe's Store Manager, Patrick McConnell, said, "Lester has been a pleasure to

work with! He has integrated himself very well into our store and our associates have welcomed him into our Lowe's family with open arms. We are excited about what Lester's focus will bring to our team and look forward to his career with us. Lester fits so well into our purpose of helping people love where they live. I am personally excited to see him here every day and look forward to many days together with him!"



Emily Medlin

To learn more about Project SEARCH visit: <https://www.projectsearch.us/>. Project SEARCH is currently available through the following partnerships:

- Downtown Sheraton Hotel, Shelby County School System – Memphis, TN
- West Tennessee Healthcare, Jackson-Madison County School System – Jackson TN
- Vanderbilt Children's Hospital, Progress, Inc. – Nashville TN
- Embassy Suites, Nashville Public Schools – Nashville, TN
- Amerigroup, Progress, Inc. – Nashville, TN
- Montgomery County Government, Clarksville/Montgomery County Schools –Clarksville, TN
- Embassy Suites, Rutherford County Public Schools – Murfreesboro, TN
- East TN Children's Hospital, CP Center – Knoxville, TN
- University of TN Medical Center, Breakthrough Corp. – Knoxville, TN
- BlueCross/Blue Shield, Hamilton County Schools – Chattanooga, TN (opening August, 2018)

In 2013, the Council on Developmental Disabilities funded and coordinated the expansion of Project SEARCH internship sites across Tennessee. Now, this initiative is overseen by the Department of Human Services, with partnership from the Tennessee Departments of Education and Intellectual and Developmental Disabilities.

Siblings in the Spotlight

by **Tricia Hedinger, MS, CCC-SLP**
and **Allison Wegman, MS, CCC-SLP**

Finally, after years of struggling for equality in education and society, children with disabilities are gaining recognition by landing roles on the screen. With popular shows like “Speechless”, kids with physical and intellectual disabilities are being written as fully-developed characters with a variety of interests, skills and personalities.

As the media progresses in changing public perception of those impacted by disabilities, a new role in pop culture has emerged: the sibling of a child with a disability. Until recently, this character was a rarity.

Sibling relationships are among an individual’s longest-lasting relationships*. That relationship often serves as an important source of companionship and emotional support. Siblings, as most parents know, can have significant, meaningful and lasting effects on each other’s development and life choices.

Lydia Lowe, age 24, is a newly-graduated speech-language pathologist in Knoxville. Early in the morning before heading off to work with several toddlers recently diagnosed with autism, Lydia sat at the table in her comfy clothes and practical shoes to explain what life was like growing up with her 18-year-old brother, Kevin, who has autism.

“He’s not what most people think autism looks like,” she said with a smile. “He LOVES people. He’s affectionate. He runs up to say hello to me after I’ve been away for a while. He’ll take off my jacket and hold onto me for hours.”

Kevin is non-verbal and uses assistive technology to communicate. Besides people, he loves McDonald’s cheeseburgers, Disney characters and sticking his head out the window to feel the wind on his face. When he was diagnosed with autism, Lydia was five years old. The family created a therapy room in the basement, and an autism specialist came to the house every six months to develop and monitor a home program.



Lydia (age 24), hangs out at home with her brother, Kevin (18) who has autism



Therapists often included Lydia in circle time and songs and other activities. “I was like a little therapist,” recalled Lydia. “I liked it. It made me feel important.”

Lydia has always felt a responsibility for her brother. “When something happens to your parents, you know you’re up next,” she said.

When Lydia’s mom passed away, her dad remained the primary caregiver. Still, in her young teens, Lydia took on many of the adult responsibilities in caring for her brother.

It wasn’t always easy. Lydia remembered that it was hard to have friends over as a kid. She also recalled embarrassing moments, like when he ran into her high school gymnasium with a blanket over his head and sat in the middle of the floor while she was running for homecoming queen.

Kevin influenced some of Lydia’s life decisions, like where she attended college, her career choice, and even how she found a boyfriend. “I always knew I wanted to work with individuals with autism,” said Lydia. “And I could only really look at colleges nearby. When I was dating, I looked at how people interacted with Kevin.”

Sometimes being the “typical” sibling of a child with a disability can result in emotional disturbances.**

However, the very same experiences can stimulate growth and personal philosophies about fairness and justice. Research indicates that it is the way that the sibling deals with or processes difficult situations that determine whether an outcome will be positive or not. ***

Lani Slack, age 12, has a twin sister Chloe, who is deaf and has learning and intellectual disabilities. Since kindergarten the twins have not been in the same class. "I am too overprotective of her," said Lani.

When their parents aren't around, Lani gives Chloe her medications and helps take care of her cochlear implants, though Chloe is learning to take on more responsibilities.

Chloe takes gymnastics and loves video games. Lani plays basketball, soccer and softball, swims, dances, and enjoys hanging out with her friends. "We have different sets of friends," said Lani. "But we are just like normal sisters. We are silly together. We argue. We do family things."

With the amount of extra attention required, it seems likely that there would be a history of excessive attention paid to Chloe. But their family seems to have achieved a good balance. "I know Chloe is different," Lani said. "I protect her, but I don't get mad at my parents. They take time with me, too. It feels pretty equal."

Like Lydia, Lani consistently speaks lovingly about her sibling. "Chloe is my whole life. And no, she has never held me back."

Crystal Slack, mother of the twins, spoke about the sibling relationship between Chloe and Lani. "They fuss and pick on each other like any other sisters. I would say that even though they are twins, Lani does take on the big sister role. If Chloe has any questions, she always asks Lani."

Since birth, Chloe has been in and out of hospitals with various health problems, which can be challenging for siblings – especially twins - to handle. "One time that stands out is the day Lani had to get tubes put in her ears," recalled Crystal. "She had been to every doctor visit and hospital stay with Chloe since they were born. It was supposed to be her day. This was also the day Chloe had her first seizure and had to be airlifted to Children's



Lani & Chloe
(12-year-old twins)
spend time together
after school



Hospital. That was one of the times we felt Lani wasn't getting her share of attention."

The entertainment industry is closer to accurately portraying the reality of growing up with siblings who have disabilities. In "Wonder," movie watchers feel the older sister Via's protective nature, along with her efforts to minimize the extra stress on her parents' lives. In shows like "Speechless," viewers see how JJ's brother and sister act like part of his team: they support him, tease him and confide in him, as well as have lives and storylines of their own.

Which is promising, since the roles most siblings play last far longer than a 90-minute film or a 30- or 60-minute television show.

Tricia Hedinger, MS, CCC-SLP and Allison Wegman, MS, CCC-SLP are both Assistant Professors/Clinical Supervisors at the Hearing and Speech Center, University of Tennessee, Knoxville

*Derkman, M., Scholte, R.H.J., Van der Veld, W., and Engels, R. (2010). Factorial and Construct Validity of the Sibling Relationship Questionnaire, European Journal of Psychological Assessment, 26(4): 277-283

** Furman, W. and Buhrmaster, D. (1985). Children's perceptions of the qualities of sibling relationships. Child Development, 56, 448-461

*** Bedford, V. (1989). Sibling Research in Historical Perspective: The Discovery of a Forgotten Relationship. American Behavioral Scientist, 33 (1)

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