



Youth in Transition: Changing Tracks to Successful Adult Lives

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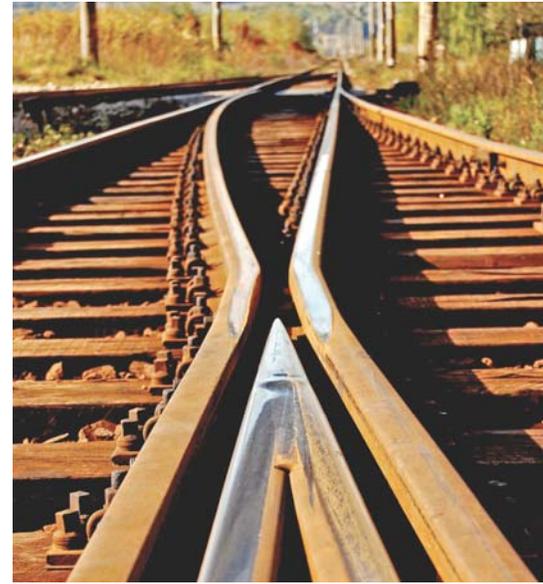
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This issue of the *Northwest Bulletin: Family and Child Health* illustrates the variety of transitions youth face in moving to adulthood. While the necessity for children with special health care needs to transition from pediatric to adult health care has long been recognized, Dr. TeKolste reports less than 50% of these children receive transition services. She provides guidelines for adolescents and their families, pediatricians, and adult health care providers, and also emphasizes that collaboration among the groups is critical for successful transitions. Dr. Coen describes first steps by pediatricians to help adult medicine practitioners in a predominantly rural state learn about treating the disabling diseases of children now living into adulthood.

The term "transition in health care" actually applies to a wide variety of situations as Dr. Neinstein, a national leader in the field, points out. All youth leaving home face a health care transition. While some families and institutions are supportive, many youth need professional help accessing health resources and many do not get that help: in 2006, 29% of the uninsured in the United States were young adults, aged 19 to 29 years.

In the editorial, Stephanie Lane describes barriers to services for youth in various types of transitions. Rick Butt describes the philosophy, services provided, and outcomes for adolescents leaving foster care. Georgina Ramirez, obviously a strong young person and talented writer, describes her experiences leaving foster care. Jim Theofelis describes how the Mockingbird Family Model prepares youth in foster care for adulthood.

Reports from the states of Alaska, Idaho, Oregon, and Washington describe supporting the transition of foster care and special health needs youth, as well as youth returning from out-of-state placements (Alaska). One aspect Northwest states have in common is the participation of youth in these programs, giving youth opportunities to take responsibility and gain competencies. ☒



Northwest Bulletin: Family and Child Health is intended for public health professionals working with families in Region X of the United States Health Resources and Services Administration.

It is published twice a year by a consortium of organizations, including the Maternal and Child Public Health Leadership Training Program at the University of Washington's School of Public Health; St. Luke's Regional Medical Center in Boise, Idaho; Public Health–Seattle & King County; and the state health departments of Alaska, Idaho, Oregon, and Washington.

It is sponsored by Project #T76 MC 00011 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, United States Department of Health and Human Services, and with additional grants and in-kind contributions.

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Editorial Board Updates

Welcome, Nurit Fischler, to the *Northwest Bulletin's* Editorial Board. Nurit is the MCH systems and policy specialist for the Oregon Public Health Division, Office of Family Health. She will serve as Oregon State's representative on the board.

We would like to thank Stephanie Lane for acting as guest editor and the authors who have contributed to this issue. And we would like to extend a special thanks to the editorial board for their continued support of the bulletin during these difficult economic times when public health department resources are stretched thin.

Editorial . . .

Barrier-laden Systems Create Rocky Road to Adulthood for Youth

Stephanie Lane

For youth in foster care or who have special health care needs, the transition to adulthood is difficult and made more so by barriers embedded in the very systems intended to help them. These service systems are fragmented at best; dysfunctional and abusive at worst.

Multiple system barriers at the federal, state, and community levels contribute to the problems youth, aged 16 to 24 years, face. Barriers to services occur nationwide and rarely vary according to state or service provider.

An Oregon State white paper listed the following barriers to services in the state: eligibility guidelines for financial and housing services; differences in “eligible” diagnoses between child and adult mental health providers; conflicting roles among service providers; culturally irrelevant services; lack of age-appropriate community resources, and a punitive approach to a youth culture that is often misunderstood and assumed to be difficult to engage. The paper also states that youth, aged 16 to 24 years, are 80% less likely than other populations with mental health needs in Oregon to receive services.

In addition to the lack of educational opportunities, high addiction and poverty rates, and skyrocketing pregnancy rates, transitioning youth are faced with few employment opportunities. In December 2007, Washington State’s seasonally adjusted unemployment rate was 4.8%. In counties bordering Oregon State (Pacific, Lewis, Wahkiakum, and Cowlitz), the unemployment rate now averages 13% to 14%, while the youth unemployment rate averages 18% to 23%.



The transition to adulthood is difficult for youth and made only that much more difficult by barriers erected by the very systems intended to help them

To help address these problems, Washington State’s Office of Consumer Partnerships, Health and Recovery Services Administration, applied for a \$3.6 million, five-year, Substance Abuse Mental Health Services Administration grant targeting counties in the state having the highest unemployment rates. The grant application focuses on the [Transition to Independence Process](#) (TIP), developed by Rusty Clark, PhD, University of South Florida, Tampa, and consid-

ered a best practice model. Connections made by work group members during the cross-system, cross-policy, and cross-consumer grant-writing process generated an unprecedented commitment to youth in transition, whether or not the grant funding is secured. In the state of Alaska, participants left a two-day summit committed to developing a plan for youth in transition focused on housing, access to services, communicating resources effectively, peer-to-peer mentoring, and adult mentorship; and to organizing a high-level policy group to approve and implement the plan.

All Health Resources and Services Administration Region X states of Alaska, Idaho, Oregon, and Washington are committed to securing and sustaining culturally relevant services to help youth successfully transition to adulthood. ✕

Stephanie Lane, MSW, is manager of the Office of Consumer Partnerships, Washington State Mental Health Department, Health and Recovery Services Administration. She has over ten years experience working with youth in transition. She is the co-founder Youth 'N Action, a youth organization considered a best practice model and duplicated at over 94 grant sites. She has received many awards, including a HERO award from the Washington State Provider Council.



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RESOURCES

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All Youth Face A Health Care Transition

Lawrence Neinstein

Transitioning in health care usually has referred to youth with special health care needs or youth aging out of foster care, but **all youth need to connect to the adult health care system**. Youth leaving home and entering or leaving college, incarceration, the military, or the work force—all transition. Unfortunately, many are not successful: in 2006, 29% of the uninsured were young adults, aged 19 to 29 years.

Meantime, young adults, aged 20 to 24 years, have the highest rates of unintentional injuries, motor vehicle accidents, homicides, suicides, and sexually transmitted infections. Overall, young adults need health screening, risk assessment, and preventive care. Fortunately, interest in improving the health among all transitioning youth is growing. ✕

*Lawrence Neinstein, MD, is professor of pediatrics and medicine, student affairs associate dean, college health chief, and health center director at the Keck School of Medicine, University of Southern California, Los Angeles. He and Helen Johnson are co-authors of *The Healthy Student Brochure: A Parent's Guide to Preparing Teens for the College Years*.*

The Society for Adolescent Medicine's [The Healthy Student](#) brochure contains information for parents on how to prepare teens for the college years. It can also be used to guide all transitioning teens. The brochure is available in PDF. Large quantities can also be ordered.

Crossing the Health Care Chasm: Transitioning Adolescents with Special Health Care Needs to Adult Health Care Settings

Katherine A. TeKolste

These resilient young adults require and deserve adult health care that manages their chronic childhood-onset conditions and prevents secondary disabilities

In Washington State, an estimated 14% to 17% of children, aged 17 years and under, have special health care needs—either a chronic childhood-onset disease, such as diabetes, congenital heart disease, cystic fibrosis, or sickle cell disease; or a developmental disability, such as autism, cerebral palsy, or spina bifida. Because of many advances in the past decades, including improved control of infectious diseases, better management of congenital defects and chronic childhood conditions, and new technologies, over 90% of these children survive past their 21st birthdays. Life expectancy for an individual with cystic fibrosis is now over 40 years; for an individual with sickle cell disease, over 50 years.

As a result of this remarkable success story, hundreds of thousands of adolescents with special health care needs transition into adulthood annually in the United States. They share the same hopes and dreams as all adolescents: living independently, pursuing a career or livelihood, and enjoying friendships and community and recreational activities.

These resilient young adults require and deserve adult health care that not only manages their chronic childhood-onset conditions and prevents secondary disabilities but also provides routine preventive care for diseases and monitors for depression and anxiety. In the Health Resources and Services Administration Region X states of Alaska, Idaho, Oregon, and Washington, families report fewer than 50% of adolescents with special health care needs receive the services they need to transition to adulthood.

Most providers of adult health care are unfamiliar with this new demographic of individuals with a broad spectrum of chronic childhood-onset conditions. Indeed, in a December 2007 American Academy of Pediatrics internal survey of transition efforts, members indicated the top priority should be to identify providers of adult health care for this population.

What is needed to improve this situation and ensure this population of young adults receives optimal health care into adulthood? Adolescents and their families,

pediatric providers, providers of adult health care, and health care systems all need to work together to bridge this health care chasm.

ADOLESCENTS AND THEIR FAMILIES: TAKE RESPONSIBILITY AND LET GO

When children with special health care needs reach their early teens, their families need to take steps to initiate the care transition. The adolescent needs to assume a new role as informed health care consumer while his parents “let go.”

It is important for parents to promote maximal independence by encouraging, to the extent possible, the



adolescent’s understanding of his medical condition and how to manage it. This includes such issues as how to explain one’s medical condition and its impact to peers and to health care providers; understanding the natural course of one’s disorder and what to do to prevent secondary complications; and knowing what symptoms require urgent attention and where to go for care, what medications are used for and their side effects, and how to order and refill medications.

CREATING A SUCCESSFUL TRANSITION: ADOLESCENTS AND THEIR FAMILIES

- ✦ Complete a health history summary together
- ✦ Use a skills checklists to monitor and advance abilities
- ✦ Use the transition timelines and transition resource notebook
- ✦ Address issues of guardianship, health decision-making authority, and health insurance coverage prior to the age of 18 years.

The Washington State [Adolescent Health Transition Project](#) provides a [Health History Summary](#) and [Adolescent Autonomy Checklists](#). The project’s [Adolescent Transition Resource Notebook](#) provides information on guardianship, decision-making authority, and insurance.

Seattle Children’s [Center for Children with Special Needs](#) has developed three simple, straightforward [care planning forms](#)—*Getting to Know Me*, *What’s the Plan?* and *In Case of Emergency*. These tools help teens share important health information and manage their own care, and were created with input from adolescents with chronic health conditions.

PEDIATRIC PROVIDERS: SMOOTH THE TRANSITION

Pediatricians responding to the Washington State Medical Home Provider Survey indicated particular difficulty transitioning adolescent patients with mental or behavioral health needs, including autism, and especially those on multiple medications. They were more successful transitioning patients with Down syndrome, asthma, and type 2 diabetes. Major barriers were availability of adult health care providers, especially adult specialty providers, and Medicaid acceptance.

Pediatricians in medical centers with multi-specialty clinics, such as family medicine, internal medicine, or combined internal medicine and pediatrics (Med-Peds), had better success identifying adult health care providers for patients. They also had better success making personal appeals to colleagues (personal communication).

Rhode Island Department of Health surveyed adult health care providers to determine current practices and gaps in transition care. Over three-quarters of providers never or rarely received written transfer summaries from pediatricians. And almost 70% never or rarely communicated with pediatricians who had previously cared for their patients with special health care needs.

The department’s Adolescent Healthcare Transition Program has available [provider resources](#) that include a checklist of steps to prepare for transition and critical medical information to be forwarded to the adult health care provider, along with medical records.

CREATING A SUCCESSFUL TRANSITION: PEDIATRICIANS

- ✦ Give a teaching physical exam. This exam informs the adolescent about her physical status, special problems, and care needs. This helps ensure that each adolescent knows her strengths, weaknesses, and needs.
- ✦ Compile a health history and transfer summary. This summary of pertinent medical information can eliminate the need to transfer lengthy medical records. For adolescents continuing with their family medicine providers, summaries may help in medical emergencies.
- ✦ Recommend support groups. These groups encourage adolescents to discuss issues and concerns about their health care, provide an opportunity to develop self-confidence and skills, and broaden support networks.

PROVIDERS OF ADULT HEALTH CARE: EXPAND KNOWLEDGE OF PEDIATRIC SPECIALTIES

A major barrier to the successful transitioning of young adult patients with special health care needs is the lack of adult health care providers willing to accept these patients. Providers are concerned about meeting the psychosocial needs of young adults living with chronic illnesses and may feel uncomfortable collaborating with a family member or caregiver on care management and adherence to therapy. They may also be concerned about

lack of access to medical sub-specialists, including psychiatrists, sufficient clinic staffing and infrastructure to manage complex care issues, and knowledge of community support services. Most providers express reasonable comfort treating obesity, hypertension, and diabetes but are not comfortable treating sickle cell disease, spina bifida, cystic fibrosis, or neuromuscular disorders.

CREATING A SUCCESSFUL TRANSITION:
ADULT HEALTH CARE PROVIDERS

- ✦ Communicate with the pediatric provider
- ✦ Learn about pediatric-onset chronic diseases and the psychological and social needs of patients with these diseases. The [Adolescent Health Transition Project](#) has some information on specific disorders.
- ✦ Learn about community resources to support youth and young adults

COLLABORATION AND COMMUNICATION ARE KEY

The 2007 American Academy of Pediatrics internal survey also identified as priorities the creation of transition tools and the development of guidelines and standards. Almost 95% of adult health care providers indicated health plans never or rarely assist with transfer of adolescents with special health care needs and almost 50% indicated these young adults experience gaps in care during the transfer from pediatric to adult health care.

In large part, difficulties for health care providers in assisting adolescents and their families with transition center on availability of and reimbursement for time spent in care coordination activities. Designation of and payment for a care coordinator or transition navigator may help solve these difficulties. Care coordinators can assist in pre-transition planning, develop care plans and portable health summaries, educate the adolescent about the expectation of self-management in the adult health care setting, and coordinate communications with the new providers.

Because most young adults are healthy and therefore are less connected to the health care system, and much of adult medicine is directed toward an older population, some have suggested establishing “young adult” clinics that would serve an intermediate age range, such as 18 to 30 years, and be staffed by both pediatricians and adult health care providers. Others suggest relying on

specialists in Med-Peds; however, the number of these specialists in the Northwest is fairly small.

Some of the most successful programs cross-staff both pediatricians and adult health care providers in clinics. This staffing model provides two essential elements for patients: 1) a pediatrician familiar to the family in the new clinical setting, and 2) access for the adult health care provider to the pediatrician’s expertise.

One example of such a program is the Adult Congenital Heart Disease Program at the University of Washington Medical Center in Seattle. Program clinics at the medical center and at Seattle Children’s Hospital are staffed with a pediatric cardiologist, an adult cardiologist, and a nurse practitioner. A number of adult clinics devoted to a specific disease, eg, cystic fibrosis, staff both pediatric and adult health care specialists. There is a need for similar collaboration among general pediatric and adult primary care providers. ✦

Katherine A. TeKolste, MD, a board certified developmental pediatrician, is a clinical associate professor of pediatrics at the University of Washington School of Medicine, Seattle. Since 1993, Dr. TeKolste has worked with the Washington State Medical Home Leadership Network to improve care for children with special health care needs. She is currently co-director of the Medical Home Project and director of the Adolescent Health Transition Project, which works to improve health transitions for adolescents with disabilities and chronic illnesses.

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Grand Rounds Expands Knowledge of Pediatric Specialities

Ronald W. Coen

Like many medical communities, we are aware that survival rates for children with lifelong illnesses have improved. In addition, many physicians in our area are not familiar with the management of these childhood illnesses and how they affect individuals, their families, and communities.

To help bridge this gap in knowledge, St. Luke's Children's Hospital and the Ada Canyon County Medical Education Committee introduced the first Children's Hospital Grand Rounds in Boise, Idaho, in 2007. Cystic fibrosis was the inaugural topic since it is encountered in both children and adults in this region and since our state has recently added it to the list of diseases that are screened in the newborn period.

To date, speakers have presented updates on cochlear implants, sports injuries, rheumatology, children's epilepsy, dental issues, late preterm infants, Down syndrome, and urology. Updates on the Idaho Newborn Screening Program, cardiology, hematology and gastroenterology are planned for the coming year.

Presentations will soon be available at www.acmec.org/ 

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Life After Foster Care: Successfully Transitioning into Adulthood

Rick Butt

Many youth exiting foster care lack the skills and abilities necessary for a successful transition into adulthood. Their life experiences place them at high risk for unemployment, poor education, poor health, early parenthood, homelessness, incarceration, and long-term dependence on assistance.

In 2005, Casey Family Programs released their findings from the Northwest Foster Care Alumni Study, which examined the outcomes of foster youth as they transitioned out of care and into adulthood. The results were alarming:

- + 33% have no health insurance compared to 18% of the general population
- + 54% have mental health problems compared to 22% of the general population
- + 22% are homeless for at least one night compared to 1% of the general population
- + 33% live below the poverty line, which is three times the national poverty rate for the same age group

Results from a Washington State's [Children's Administration 2006 Annual Performance Report](#) showed 60% of foster youth did not graduate from high school or obtain a General Educational Development (GED) credential compared to 24% of the general population.

Our goal should be that their 18th birthdays are not filled with worry and fear of the future but rather true rites of passage to adulthood

Outcomes for youth in foster care need to improve. It is critical that we not only support our youth while they are in care but also when they transition into adulthood. One way to provide transition support is to make sure each youth has a solid transition plan before he leaves foster care.

THE IMPORTANCE OF A TRANSITION PLAN

Transitioning from foster care should not just happen on a youth's 18th birthday. Planning should start much earlier—at least by age 17. The more involved youth are with planning their transitions the more likely those transitions will be successful. A strong plan should address, at a minimum, the key elements identified in the [Fostering Connections to Success and Increasing Adoptions Act \(H.R.6893\)](#): education, employment, housing, health insurance, local opportunities for mentors and support, employment services, and work place supports.

As they prepare to transition from foster care, youth often become overwhelmed with anxiety about what the future will be like. Their grades may slip and they may sabotage their foster home placement, have poor hygiene, become depressed, and withdraw socially. This is their way of dealing with the anxiety of separation and the fact that they will soon be living on their own. Therefore, it is vital that transition plans link youth to support systems in their communities.



RESOURCES AVAILABLE FOR YOUTH

It is important to know the resources available in your state when working with youth transitioning out of foster care. Contact your state's Independent Living Program Manager to find specific services. Contact information can be obtained by visiting the [National Child Welfare Resource Center for Youth Development](#). Valuable information is also available at [Washington State's Independence for Foster Youth](#).

[The Foster Care Independence Act](#), also known as the Chafee Act, provides federal funding to each state for the Independent Living Program and the Educational and Training Voucher Program. Casey Family Programs offers an array of tools and resources that are very helpful. One such tool is the [Ansell Casey Life Skills Assessment](#). This free Web-based assessment tool may be used to evaluate a youth's independent living skills. Once completed, it provides a baseline that can be used to plan life skill activities and exercises to support independent living.

HOW ADULTS CAN HELP

Youth in foster care and those aging out of care need supportive adults in their lives. These adults can make a difference by:

- ✦ Becoming informed of services available in their states
- ✦ Taking time to explain these services and benefits to youth
- ✦ Encouraging youth to become involved in these services and active in their communities
- ✦ Assisting foster youth in making connections, for example, by making introductions or providing transportation

Resiliency

Many youth in foster care are resilient and able to overcome overwhelming obstacles in transitioning to successful adults. Gilligan defines a resilient person as "one who bounces back from adversity and continues to function reasonably well, despite continued exposure to risk." Multiple studies on resilient youth have shown that they share similar characteristics, having:

- ✦ Self-esteem and self-confidence
- ✦ A sense of self-efficacy
- ✦ A range of social problem-solving approaches
- ✦ One significant adult
- ✦ An external support system

- ✦ Providing tips on healthy living
- ✦ Being available and listening to youth
- ✦ Believing in their abilities to succeed

If we raise our expectations and believe in them, they in turn will believe in themselves. Let's not have a youth exit foster care without a solid transition plan and the necessary supports. Our goal should be that their 18th birthdays are not filled with worry and fear of the future but rather true rites of passage to adulthood. ✦

Rick Butt, MSW, is the independent living program manager for Washington State's Department of Social and Health Services Children's Administration. He is responsible for the administration of the Independent Living Program and Responsible Living Skills Programs, which provide foster youth and alumni, aged 15 to 21 years, with the necessary skills to become self-sufficient adults. He also oversees the statewide youth advisory board for Children's Administration – Passion to Action. He has over 20 years of experience working in various child welfare systems in both Canada and the United States.



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Leaving Foster Care and Starting Life: One Person's Story

Georgina Ramirez

Going through foster care is a stressful experience characterized by multiple placements, transferring to multiple schools, attending dependency hearings, and wondering about siblings. Even though I was still categorized as a ward of the state, I had the opportunity to reunite with my biological family at the age of 16. Living with my family gave me a greater sense of connection; however, it also came with the responsibility of helping my great-grandmother raise my younger siblings. While many of my peers were focused on hobbies and social events outside of high school, I had to focus on working and providing for my family. I spent my entire childhood taking care of others.

When I transitioned out of foster care at the age of 18, I wanted to resurrect my dreams and ambitions that had been buried under a plethora of responsibilities. I decided to attend Xavier University of Louisiana in New Orleans. But when I arrived and registered for school, my sense of joy and glee quickly faded. Because of my care-taking responsibilities, I lacked many life skills necessary for independence, such as socializing with peers, voicing my needs, and truly engaging in life versus having everyone else make decisions for me.

In addition, all my family responsibilities followed me. Even with several states separating me from home, everyone was still looking to me as the family support, and I quickly lost focus on school. At the end of my sophomore year, while I was struggling without the proper social, financial, or mental guidance, my great-grandmother died. I was able to maintain employment and go to school part-time for a while; however, it was overwhelming. And then the unpredictable happened—Hurricane Katrina. Luckily my roommate, who was in Seattle at the time, was able to purchase me a one-way ticket hours before the airport shut down.

In Seattle, I reassembled my life. I started working part-time on the weekends as a prep cook and eventually had four part-time positions, working six days a week. With additional assistance from the Urban League (the league was offering assistance to Hurricane Katrina evacuees) and support from friends now considered family, I was eventually able to get back on my feet. Even though this was a strenuous and tiring experience, it provided me with employment skills and a strong work ethic.

At a meeting between the Urban League and Casey Family Programs, I met the director of family programs at The Mockingbird Society. She offered me the opportunity to use my experience and knowledge to work with youth in foster care to make sure their voices and needs are not only heard but also met. It feels great to inspire change for my community and even better to have a full-time position at such a great organization.

The Mockingbird Society has provided me with the support, guidance, and mentorship needed to once again give me a sense of hope for my future. Transitioning out of foster care can be a stressful and lonely process. Foster care doesn't really prepare youth for all of the demands life has waiting for them at the age of 18. These youth need so much more than classes on "independent living skills." Unfortunately, I feel as if my case is rare and many foster youth transition out of care into homelessness, unable to get the support they need to find a job and attend a community college or university. Foster youth need mentors and community support to guide and keep them motivated. ✦

Georgina Ramirez serves as the resource specialist for the Mockingbird Network at the Mockingbird Society (see article on page 12 on the Mockingbird Family Model). In her role, she works with youth in (King County) Region 4 to develop a local chapter lead by foster youth and alumni. Ms. Ramirez spent 12 years in the California foster care system. As an alumnus of foster care, Ms. Ramirez is excited to assist the Mockingbird Society.

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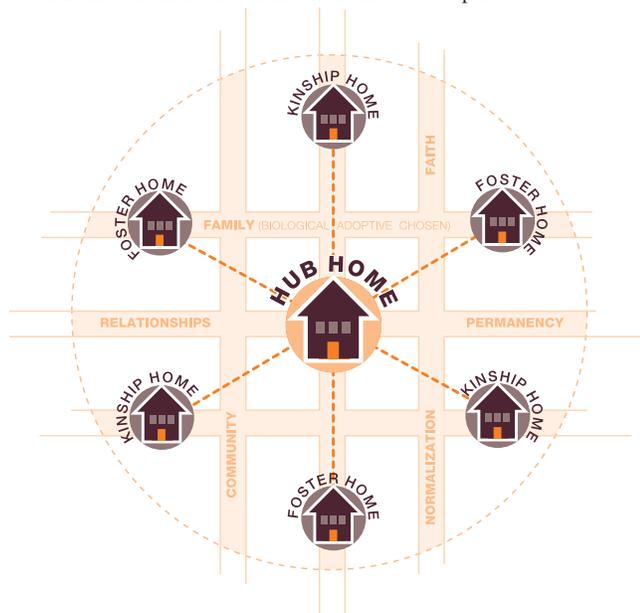
Creating a Constellation of Care: The Mockingbird Family Model

Jim Theofelis

Children, youth, and families who are involved in the foster care system may well be at the epicenter of this nation's greatest domestic failure. Today's critical issues are the same issues faced by the foster care system for decades: ensuring safety while in care, reducing multiple placements, providing culturally relevant care, connecting siblings with other family members, and recruiting and retaining quality caregivers. The Mockingbird Family Model is an innovative service delivery model based on the extended family concept that supports birth, kinship, and foster caregivers. The practical, replicable, and cost-effective care model helps stabilize children's behaviors, retain quality foster parents, and support permanency.

The model consists of a micro-community (constellation) of foster and kinship families (satellite families) and an additional licensed foster family (hub home) organized to support children living in the constellation (see figure). Caregivers in kinship homes are relatives—grandparents, aunts or uncles, older siblings—who may or may not be licensed foster parents. The hub home provides both planned and crisis respite, information and referral to community resources, emotional support, and a place for monthly constellation meetings. The hub

Figure. The Mockingbird Family Model. In a kinship home, relatives provide care and may or not be licensed foster parents. Caregivers in foster homes and in the hub home are licensed foster parents.



home parent is a seasoned foster parent who may or may not have other children living in the home but must have at least two beds available for planned and crisis respite for satellite families.

Both planned and crisis respite reduce the level of trauma experienced by children and caregivers. Planned respite offers safe and predictable “breaks” for satellite families. During times of genuine crisis, when placement may be at risk, children can live at the hub home so that they can continue to attend the same schools and participate in the same activities. As one adolescent describes his experiences living within a constellation, “Usually respite care means some adult needs a break from me so they won’t quit. In the Mockingbird model it means everyone gets a break so we don’t have more problems and we’re glad to see each other afterwards.”

Evaluation data for the Mockingbird Family Model is available at [The Mockingbird Society](http://TheMockingbirdSociety.org). One consistent finding is that planned respite significantly reduces the need for crisis respite. The model has 12 launched constellation sites nationally. ✪

Jim Theofelis, MC, LMHC, is the founder and executive director of The Mockingbird Society, Seattle, Wash. He has over 30 years of experience working with children, youth, and families.

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Many of the articles in this issue focus on supporting youth as they transition to adulthood. The goal of [The Mockingbird Society](http://TheMockingbirdSociety.org) is to create a new model of foster care that encourages resiliency and prepares youth for the demands of adulthood. Mockingbird programs include youth LEAD (leadership, employment/education, advocacy, and development), the Mockingbird Times, and the Mockingbird Family Model. The Mockingbird Times, a monthly newspaper distributed nationally, is written and produced by youth who have experienced foster care and homelessness. (See article by Georgina Ramirez on page 11.)

State Reports . . .



Alaska State Report: Results of Two-day Summit on Needs of Youth in Transition

Kristine Green

At a two-day summit held June 8th and 9th in Anchorage, Alaska, a large group of consumers, providers, and administrators met to discuss the needs of the state's youth in transition. The primary focus was on **youth aging out of the foster care system, children returning to Alaska following out-of-state placement for severe behavioral problems** (Bring the Kids Home Project), and **youth with special health care needs transitioning to adult living centers**.

Documentation provided for review prior to the summit included a 2006 revision of the [Alaska Youth with Disabilities in Transition Five Year Action Plan](#); Division of Public Assistance analysis of status of youth, aged 14 to 23 years, in the system; and data on youth and young adults.

YOUTH PANEL

A facilitator from the [National Network on Youth Transition for Behavioral Health](#) presented information on the [Transition to Independence Process](#). This system was developed to help professionals engage and guide youth and young adults with emotional and behavioral difficulties, provide them with appropriate services, and ensure family and community support.

In addition, a panel of young adults spoke of their needs, the challenges they faced in transitioning, and what would have made their transitions to independence easier. They reminded providers of the emotional toll caused by "trust" issues as a result of abusive relationships, family histories of alcohol and drug use, numerous foster homes moves, and what appeared to be illogical rules associated with adult decisions.

The youth spoke of feeling demoralized and having no voice in decisions affecting them. As a result, they felt the need to find a trusting mentor to help them navigate adult decisions and their consequences. No youth from the Bring the Kids Home Project or with special health care needs were able to participate.

PEER ASSISTANCE SCALE

Providers and program developers received training on a peer assistance scale¹. This scale helps community providers identify progressive levels of young people's participation for a systematic view of their inclusion at all levels of decision making. Hopefully, use of this scale will eventually improve feelings of trust for these youth. Providers also shared challenges in their work places, such as staffing to client ratios, staff turnover, funding, and gaps in the system.

As a result of this summit, participants left committed to using the Transition to Independence Process and the peer assistance scale. Two significant outcomes emerged: 1) a commitment to develop a plan for youth in transition focused on housing, access to services, communicating resources effectively, peer-to-peer mentoring, and adult mentorship; and 2) a commitment to organize a high-level policy group to approve and implement the plan. ✕

Kristine Green, MS, MAT, is program manager for the Neurodevelopmental and Autism Clinics, State of Alaska Health and Social Services, Division of Public Health, Section of Women's Children's and Family Health. She investigates, coordinates, and represents family needs in state policy, program, and service development.

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RESOURCES:

[Bring the Kids Home Project](#)

[Governor's Council on Disabilities and Special Education, 2006 to 2011 State Plan](#)

[What is Peer Mentoring?](#)

¹ adapted from Hart's Ladder, Youth Participation in Community Planning, the [Innovative Center for Community and Youth Development](#)



Idaho State Report: Easing Youth with Chronic Medical and Developmental Disabilities into Informed and Capable Health Care Management

Carol Christiansen

The [Idaho Children's Special Health Program](#) had three goals focused on transition for the past calendar year: 1) to develop a slide presentation on the topic of transition for youth with disabilities and their families, and focus groups and conferences interested in the topic, 2) to support existing groups in their mission to help youth with disabilities successfully transition to managing their own health care, and 3) to develop a system to provide transition education materials to children and families enrolled in our program.

DEVELOP A SLIDE PRESENTATION ON TOPIC OF TRANSITION

The slide presentation (Microsoft PowerPoint), *Be Prepared to Be Successful*, was introduced at the program's break-out session at the March *Tools for Life 2009: Secondary Transition and Technology Fair*, held in Coeur d'Alene, Idaho. The presentation allows room for discussion of the concept of transition and its application to health care management. For a copy of the presentation, contact [Carol Christiansen](#).

The fair was a collaborative effort sponsored by the Idaho State Department of Education, Idaho Assistive Technology Project, University of Idaho Center on Disabilities and Human Development, Idaho Interagency Council on Secondary Transition, and Idaho Council on Developmental Disabilities. Four hundred and seventy-two students, families, educators, and providers participated in the two-day conference designed to reach Idaho high school students with disabilities.

SUPPORT EXISTING GROUPS IN THEIR MISSION TO HELP YOUTH WITH DISABILITIES

One of the groups in attendance at the fair was Idaho Families of Adults with Disabilities. This support group provides information, networking opportunities, and advocacy for families of adult children with disabilities living in Idaho.

Earlier in the year, our program partnered with this support group to produce their new brochure, which provides information for youth with disabilities on how to successfully transition to managing their own health care and for families on what health care supports are needed for their 18-year-old children with disabilities.

DEVELOP A SYSTEM TO PROVIDE TRANSITION EDUCATION MATERIALS

We have assembled a transition education binder and accompanying children's workbook to be sent to families enrolled in the program. The binder includes resources; a timeline of age-appropriate activities; a knowledge, skills, and abilities checklist with related care plan templates to personalize; a tabbed organizational folder for educational records; a sample form and references to Web sites for designing and organizing medical records; and articles on finding a medical home and adult health care provider. In addition to workbooks, children also receive a knowledge, skills, and abilities checklist.

After the authorization process is complete, the binders and workbooks will be mailed to families when their children are aged 12, 15, and 18 years. It is hoped that this information will ease youth with disabilities and their families into informed and capable health care management. ☒

Carol Christiansen, RN, spearheads transition activities for the Idaho Children's Special Health Program and coordinates the Idaho Newborn Screening Program. For the last 12 years, she worked in Florida as a nurse case manager, where she helped children with chronic medical conditions and developmental disabilities transition from the Birth-to-Three Program to pre-kindergarten.

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RESOURCES:

[Center on Disabilities and Human Development](#)
[Idaho Council on Developmental Disabilities](#)
[Idaho Parents Unlimited, Inc](#)



Oregon State Report: Young Adults with Special Health Care Needs Advise Transition Planning

Marilyn Berardinelli

Young adults with special health care needs face an array of issues as they transition to adulthood. They must be equipped to meet both their complicated health care needs and obstacles to higher education, work, and independent living.

YOUTH ADVISORY GROUP

The [Oregon Center for Children and Youth with Special Health Needs](#)¹ supports a Youth Advisory Group that advises the center on obtaining and coordinating services for children with special health care needs, building capacities of community-based programs, and policy development. Members of the advisory group identify and prioritize transition issues and provide feedback on initiatives. Their perspectives are integrated into the center's program planning and activities. Through their participation, advisory group members develop leadership skills, become knowledgeable about issues surrounding transitioning to adulthood, and develop confidence in their abilities to live independently.

Leslie Gilbert developed skills while a member of the advisory group that she eventually used in taking on a paid position as the Youth Advisory Group Coordinator. She says of the leadership opportunities the group provides, "Any time you ask [young people about] what's going on with them and lead them in assessing needs, that's building leadership even if it's only within their own lives."

¹The Oregon Center for Children and Youth with Special Health Needs is Oregon's Title V MCHB Children with Special Health Needs Program. The center's community-based programs include Community Connections Network and CaCoon. Community Connections Network is a network of multi-disciplinary teams based in rural areas that provides evaluation, referral, and care coordination. CaCoon provides care coordination for children and youth with special health needs through a partnership with public health nurses in all 36 counties.

She also emphasizes that ongoing participation in the group is more valuable than the activities themselves.

BENEFITS OF ADVISORY GROUP

Members identified the following benefits the advisory group provides:

- ✦ A safe environment to practice self-advocacy skills
- ✦ Exposure to other members' unique perspectives and talents
- ✦ Opportunities to celebrate and learn from each other's successes
- ✦ Opportunities to learn and practice skills in unfamiliar environments
- ✦ A supportive environment to develop independence



Coordinator Leslie Gilbert (lower right) with member Sara Brewington, Youth Advisory Group

For programs wanting to establish a youth advisory group, we recommend meeting on a regular basis and providing time for socialization; and creating an environment where youth can build confidence in their roles as advisors, be comfortable taking on leadership opportunities, and feel supported as they work to transition to adulthood. By including youth as partners, programs empower youth on a personal level. ✦

Marilyn Berardinelli is a community consultant with the Oregon Center for Children and Youth with Special Health Needs located at the Child Development and Rehabilitation Center at Oregon Health and Science University, Portland. She works with multidisciplinary teams in communities around the state to provide care coordination for children and youth with multiple complex health needs and to support local collaborations in building systems of care.

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Washington State Report: Youth with Physical, Emotional, and Learning Disabilities More Likely to Engage in Risky Behaviors

Teresa Vollan

The Healthy Youth Survey provides important information to guide policy and programs that serve youth in transition. Every two years, students in grades 6, 8, 10, and 12 answer questions about disability status; physical activity and diet; safety and violence; alcohol, tobacco and other drug use; and related risk and protective factors.

YOUTH DISABILITY SCREENER

The Youth Disability Screener is a four-item measure based on self-reported disability status developed by the [Seattle Quality of Life Group](#) at the University of Washington, Seattle. The screener was used in the 2002, 2004, and 2008 Healthy Youth Survey with similar results all years.

Results from 2008 showed about 19% of 8th graders, 24% of 10th graders, and 25% of 12th graders reported a physical, emotional, or learning disability. While the analyses for the 2008 Healthy Youth Survey are ongoing, results from 2002 and 2004 show that youth who self-reported a disability were more likely to engage in risky health behaviors than their peers without disabilities.

A COLLABORATIVE EFFORT

The Healthy Youth Survey is a collaborative effort of Washington State's Office of the Superintendent of Public Instruction, Department of Health, Department of Social and Health Service's Division of Alcohol and Substance Abuse, Community Trade and Economic Development, Family Policy Council, and Liquor Control Board. State- and county-level Healthy Youth Survey data are available for 2002, 2004, 2006, and 2008 at <https://fortress.wa.gov/doh/hys/>.

State agencies and their community partners can use this information to guide policy and programs that serve youth. Information can also be used to identify trends in the patterns of behavior over time. The state-level data can be used to compare Washington to other states¹ that conduct similar surveys and to the nation. ☒

Teresa Vollan, MPH, is an epidemiologist for the Children with Special Health Care Needs Program, Washington State Department of Health. She is a 2004 graduate of the Maternal and Child Public Health Leadership Training Program at the University of Washington, Seattle.

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¹Data on youth from other Northwest states are available at the links below. Background information on these surveys is available on page 13 of the *Northwest Bulletin* summer 2008 issue, *Helping Communities Promote Youth Mental Health*.

[Alaska Youth Risk Behavior Surveillance System](#)

[Idaho Youth Risk Behavior Surveillance System](#)

[Oregon Healthy Teens Survey](#)

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Maternal and Child Public Health Leadership Training Program

The [Maternal and Child Public Health Leadership Training Program](#) offers a two-year, in-residence interdisciplinary program that leads to a Master of Public Health degree with a focus on maternal and child health. The program is one of only twelve schools of public health training programs sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Students graduate from the program with the skills and competencies to become leaders in improving the systems, programs, and policies that support the health of children and families in the United States. The following students were admitted for the 2009 academic year:

Sarah Charlesworth earned a BS in psychology from the University of Toronto, Ontario, Canada. She is interested in how environmental exposures disrupt normal fetal and child development, and the relationship between psychological and reproductive health. Most recently, Sarah worked as a clinical research coordinator at Stanford University, Calif.

Wendy Ellis earned a BS in general science at Seattle University and is interested in the mental health of mothers and children. While a student, she wants to learn skills in advocating for early interventions and developing effective treatment models to break the cycle of family abuse. She was a juvenile rehabilitation officer at Echo Glen Children's Center, Snoqualmie, Wash.

Taylor Ellsworth earned a BA in law and society from American University, Washington, D.C. She is interested in women's sexual and reproductive health and plans to use her new skills to strategize, develop, and implement effective sexual and reproductive health education programs. Taylor has worked with Planned Parenthood.

Marlana Evans earned a BA in economics at the University of Washington, Seattle, and is interested in early childhood nutrition and oral hygiene. Her goal is to assist in the development and implementation of a public health nutrition program in the Northwest. She has worked as a health insurance consultant for a private payer insurance company and for California State Medicaid services.

Yolanda Evans earned a medical degree from Oregon Health Sciences University, Portland, and completed her pediatric residency at Seattle Children's Hospital. She is currently an adolescent medicine fellow at Seattle Children's Hospital and the University of Washington. She plans to study the impact of parent involvement in preventing high-risk behaviors and sexually transmitted infections in minority teen males.

Amanda Harris recently graduated from Tufts University, Medford, Mass., with a BS in biology and community health. She is interested in reducing health disparities by empowering women's health choices. She was an intern with the Cambridge Doula Program, Cambridge, Mass., and a volunteer with the Teen-to-Teen Clinic, Nashua, NH.

Julia Lehnert earned a BA in sociology and a BS in nursing from the University of New Mexico, Albuquerque. Her interests are in adolescent health, advocacy, at-risk groups, mental health, program evaluation, public policy, and statistical analysis. Her nursing experience has been with neonates.

Carrie Pettler earned a BS in social work from New York University, New York. Her interests are in program design and evaluation. She has worked for the past several years as director of social services for a skilled nursing facility. She also has leadership experience with NARAL of North Carolina.

Ameera Thomas earned a BA in anthropology from Princeton University, New Jersey, and a Doctor of Medical Dentistry and Master in Bioethics from the University of Pennsylvania, Philadelphia. She is currently in the Department of Pediatric Dentistry at the University of Washington, Seattle. Her interests are in access to pediatric dental care for underserved and special needs populations.

Julia Yoshino earned a BA in public health and molecular and cellular biology from the University of California at Berkeley. She currently works as a research coordinator for clinical studies at the Children's Hospital and Research Center in Oakland, Calif. Her goal is to implement programs and pursue research that improves the lives of children. ❖

Resources . . .

Adolescent Health Transition Project
<http://depts.washington.edu/healthtr/>

The Center for Children with Special Needs
 Seattle Children's Hospital
<http://cshcn.org/>

Centers for Disease Control and Prevention. *School Connectedness: Strategies for Increasing Protective Factors Among Youth*. Atlanta, GA: United States Department of Health and Human Services; 2009.

Children and Adolescents with Special Health Care Needs Knowledge Path: Adolescent Transition (March 2006)
 Maternal and Child Health Library
www.mchlibrary.info/KnowledgePaths/kp_CSHCN.html#transition

The Healthy Student: A Parent's Guide to Preparing Teens for the College Years. 2008-2009 ed. Society for Adolescent Medicine
 Contact Alice at 816-224-8010 to order. \$30 for 100 or \$100 for box of 400 (spring/summer sale prices)

The Jim Casey Youth Opportunities Initiative
www.jimcaseyyouth.org/

Lotstein DS, Ghandour R, Cash A, et al. Planning for health care transitions: Results from the 2005-2006 National Survey of Children with Special Health Care Needs. *Pediatrics*. 2009;123(1):e145-e152. Abstract available at <http://pediatrics.aappublications.org/cgi/content/abstract/123/1/e145>.

McMillen J, Raghavan R. Pediatric to adult mental health service use of young people leaving the foster care system. *J Ado Health*. 2009;44:7-13.

National Child Welfare Resource Center for Youth Development
www.nrcys.ou.edu/yd/default.html

Peter N, Forke C, Ginsburg K, Schwarz D. Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*. 2009;123:417-23

Raghavan R, Shi P, Aarons G, Roesch S, McMillen J. Health insurance discontinuities among adolescents leaving foster care. *J Ado Health*. 2009;44:41-47.

Transition Tools
 American Academy of Pediatrics
www.medicalhomeinfo.org/tools/trans.html

Williams R. Fumbling the handoff: Managing the transition to adult care for adolescents with chronic conditions. *J Ado Health*. 2009;44:307-8.

Youth in Transition
 National Conference of State Legislatures
www.ncsl.org/IssuesResearch/HumanServices/Youthin-Transition/tabid/16449/Default.aspx

Youth and Family Perspectives on Transition
 National Center for Cultural Competence, Georgetown University Center for Child and Human Development
www11.georgetown.edu/research/gucchd/NCCC/perspectives/transitions.html

Youth 'N Action!
www.youthnaction.org/index.shtml

Youth Transition Funders Group
www.youthtransitions.org/

Teens from the Idaho Coalition Against Sexual & Domestic Violence* Appear on Oprah Winfrey Show

James Walker

This past spring, I and other members of the Teen Dating Violence Advisory Council of the Idaho Coalition Against Sexual & Domestic Violence appeared on the Oprah Winfrey Show via Skype. Her show was our stage to talk about teen dating violence to millions of American families.

It was one of the most exhilarating experiences of my life and on an issue I hold close to my heart. That day we were part of something real, something powerful—we were teens standing up against something we will not accept. ☒

James Walker is past member of the Idaho Teen Dating Violence Advisory Council. He will be a sophomore this fall at the University of Idaho, Moscow.

*An article on the coalition's Idaho Teen Dating Violence Awareness & Prevention Project was published in the winter 2009 issue of the Northwest Bulletin.