



CALIFORNIA PROMISE . . . Promoting the Readiness of Minors in Supplemental Security Income

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LESSONS LEARNED FROM CaPROMISE¹ YOUTH AND THEIR FAMILIES

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Executive Summary

CaPROMISE is one of six projects funded nationally under *Promoting the Readiness of Minors in Supplemental Security Income (PROMISE)*, by the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, US Department of Education. The goal of CaPROMISE is to increase the self-sufficiency of transition-age youth receiving Supplemental Security Income (SSI) and their families. For the past five years commencing on October 1, 2013, CaPROMISE staff have used a variety of educational, personal, community and work strategies to fulfill this goal and ultimately reverse the cycle of poverty and the adverse impact of disabling conditions for participating youth and their families. Throughout the implementation of CaPROMISE, a question that keeps emerging is *“why is this attainment of self-sufficiency and independence so difficult?”* Furthermore, *have our expectations and systems become so categorical and complex and at times contradictory, that we have lost sight of the expectations and complex needs of the youth with disabilities and their families?*

This report seeks to answer these questions from the lens of system and culture change. Lessons learned from CaPROMISE are described and provide the framework for continued system and culture changes for the benefit of youth with disabilities and their families – in essence for each of us and our communities. The six Lessons are:

1. Rethinking the culture of expectations is essential to increase self-sufficiency.
2. The primary focus must be the impact for the youth and their families.

¹ Disclaimer: CaPROMISE is funded through a cooperative agreement with the U.S. Department of Education, Office of Special Education Programs (OSEP) Grant #H418P130003. The contents of this paper do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government.

² This report was prepared by Drs. McFarlane and Guillermo with collaboration from staff affiliated with CaPROMISE, SDSU’s Interwork Institute and selected national experts in rehabilitation and education.

3. Family engagement is essential in the youth's attainment of self-sufficiency.
4. Community perceptions and stigma about disability limit potential for integration.
5. Collaborative interagency and cross-organizational engagement are essential for increasing the youth's self-sufficiency.
6. Organizational structures and resulting expectations present opportunities and challenges.

Delving deeper, beyond legislative mandates and departmental silos, these lessons focus the discussion on the culture of our organizations, the expectations of both parents and professionals, and the limitations imposed by system-centered vs. person/family-centered paradigms. Drawing on these lessons, six recommended actions are presented that serve as foundational efforts to *change* the cultural norms surrounding transition efforts for youth and their families; *increase* the chances of sustainability and scalability that enable youth with disabilities to increase their opportunities for increased self-sufficiency; and *influence* current and future transition public policies. These actions are:

1. Ensure the articulation of transition services and outcomes is clearly understood by all through written, visual, technological and spoken media.
2. Identify community partners that are participating in the majority of these programs and merge local collaborative "program sites" that target career and employment outcomes.
3. Develop and implement, with equal representation of the authorizing organizations, the expected vision, mission, values, outcomes and framework for transition efforts with youth and their family members as the primary focus.
4. Ensure direct service staff have the latitude to provide youth and family specific services and outcomes while senior administrators ensure legal and fiscal mandates are met.
5. As the six PROMISE research and demonstration efforts are completed, it is critical for the Federal partners to examine the results and determine which policies and regulatory requirements should be refined to increase impact and scalability in service delivery models.
6. As legislative reauthorization is considered with these various Federal agencies, we urge that the classification systems used for identifying the disabling conditions of the youth be aligned with common titles and definitions.

Public policy and cultural change is complex, takes a focused and long-term commitment and will require regular reviews and refinements. All partners must have the political will to take the necessary risks and actions if true, meaningful, and substantial change is to occur.



Lessons learned from CaPROMISE youth and their families¹

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There are very few people, even with the most severe disabilities, who can't take control of their own life. The problem is, the people around us don't expect us to.

Ed Roberts

For the past five years commencing on October 1, 2013, we have used a variety of educational, personal, community and work strategies to reverse the cycle of poverty and the adverse impact of disabling conditions for youth who are Supplemental Security Income (SSI) recipients and their families.

CaPROMISE is one of six projects funded nationally under *Promoting the Readiness of Minors in Supplemental Security Income* (PROMISE), by the Office of Special Education Programs, Office of Special Education and Rehabilitative Services (OSERS), US Department of Education. The focus of this research and demonstration effort is to increase the self-sufficiency and independence of youth receiving SSI, with support and engagement of the family, as they transition from K-12 education to adulthood. These youth are recipients of SSI because they were deemed “disabled” by the Social Security Administration. In most instances these youth³ are entitled to Special Education during their K-12 education and are eligible for vocational rehabilitation services through their State rehabilitation agency as they enter adulthood and strive to secure employment with a living wage. While there are a myriad of Federal, State and local programs and resources that can assist these

¹ These observations emerged during the five years of CaPROMISE. They reflect our journey and the transitions during this learning experience. Over 100 staff, representing Local Education Agencies (LEA), Department of Rehabilitation staff, undergraduate and graduate interns, selected Family Resource Center staff and Independent Living staff have participated in CaPROMISE.

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³ For purposes of this document, youth are defined as individuals from entry into K-12 education through their 22nd birthday and may include enrollment in postsecondary education and/or training. These parameters are consistent with prevailing Federal legislation such as IDEA and WIOA.

youth and their family during their transitions, the programs and resources are often unknown to potential users, underutilized and/or designated for a specific categorical need (i.e., disability classification and level of severity, education level, or services such as tutoring, paid and unpaid work experiences, internships, transportation, etc.).

A question that keeps emerging is “*why is this attainment of self-sufficiency and independence so difficult?*” Why do less than 2% of these youth on SSI who enter adulthood become employed and economically self-sufficient? Are the families unaware of or disconnected from government resources and community supports? Are the policy makers, the administrators and the service providers, unable or unwilling to address the complex circumstances the families face? Do they lack knowledge, legislative authority, and/or are constrained by legislative requirements and funding to provide the necessary supports and resources? Have our expectations and systems become so categorical and complex and at times contradictory, that we have lost sight of the expectations and complex needs of the youth with disabilities and their families?

In many instances these youth and families are us. They are members of our families, our neighbors, friends of our children, classmates, colleagues and associates, and members of our communities. After five years, the realization is that we are not studying and learning about another society or a *unique group of youth and families* – we are examining us – as members of our communities, as leaders, business partners, service providers, colleagues, friends, educators, researchers, parents and grandparents. This is a study about our society and our communities, and ultimately about our beliefs and values. It is about what we need to do to improve the lives of all of us. This is no simple task! Substantive system and service delivery changes have a beginning; however, there is no ending to the need for refinements and changes. We will never get our systems 100% right, but we must continue to create and sustain more efficient and effective programming to increase individual opportunities for self-sufficiency through education, employment and quality of life. If we can make significant and small incremental positive changes, we will leave “us” better than we were when we started this research and demonstration effort.

Background and Literature Review

In September 2013, the U.S. Department of Education, in collaboration with the Departments of Health and Human Services and Labor and the Social Security Administration, awarded \$211 million in grants to six programs across the country under the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE). The purpose of funding six model demonstration projects (i.e., five individual states and one consortium of six states, <http://www.promisetacenter.org/promisemdps>) was to support the delivery and coordination of services leading to improved education and employment outcomes for youth who are recipients of Supplemental Security Income (SSI) and their families and to research the efficacy of the various

models. The US Department of Education's vested interest in this area can be traced back to the 1980s with funding authorized under the Education for All Handicapped Children Act Amendments of 1983 for the first model demonstration projects to provide transition services for youth with disabilities (DeStefano & Wermuth, 1992). The priority on transition was elevated with the reauthorization of the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476), which for the first time, mandated all States to provide transition services. This was strengthened with the reauthorization of IDEA in 2004 (PL 108-446).

Transition services have evolved with a new phase most recently initiated by the reauthorization of the Rehabilitation Act in Title IV of the Workforce Innovation and Opportunity Act (WIOA) of 2014 (PL 113-128). The significance of the WIOA mandate is that State Vocational Rehabilitation agencies must provide pre-employment transition services. In this new phase we see the direct mandate for vocational rehabilitation, who traditionally serve adult consumers, to expand their services to youth with disabilities. The WIOA legislation supports the 2015 report by the Federal Partners in Transition (FPT) workgroup which stated:

Our vision is that all youth programs are based on universal design principles so that youth, regardless of their individual challenges, including disability, are equipped to pursue a self-directed pathway to address their interests, aspirations, and goals across all transition domains including community engagement, education, employment, health and independent living that will ultimately result in positive, everyday social inclusion. (p. 11)

The vision of the FPT supports each of the PROMISE projects, including CaPROMISE, implemented statewide in California. This vision is also embodied in the Office of Special Education and Rehabilitative Services principles (2018) that requires we:

- address deeply embedded and complex issues;
- question systems that do not facilitate the kind of improvement we know is necessary;
- confront structures that limit opportunities for individuals with disabilities;
- change policies and practices that put the needs of a system over the needs of an individual; and
- challenge mindsets that appear intent on preserving the status quo.

On the national level, the Council of State Administrators of Vocational Rehabilitation (CSAVR) launched Vision 2020 in 2017. They outlined five operating principles. The first operating principle states: *Innovating Solutions to achieve greater access to and use of vocational rehabilitation services. Our goal is to achieve the most effective outcomes for our customers.* Embedded in this Principle are six objectives linked to collaboration, partnerships and transition efforts as required in WIOA and supported by the FTP and OSERS statements cited above. This is further strengthened by the national collaboration between the National Association of State Directors of Special Education (NASDSE) and CSAVR. On a Federal level and with the two national organizations representing special education and vocational rehabilitation, there is concurrence on the alignment of the desired systems to create and sustain transition efforts that strengthen both education and employment outcomes.

IDEA and WIOA mandates collaboration between education and rehabilitation in the provision and coordination of services to youth with disabilities. The outcomes for both Federally legislated mandates (IDEA of 1990 and 2004, WIOA of 2014) includes employment, education, independent living, and community participation for individuals with disabilities through high school and young adulthood at the same level as their peers without disabilities. In other words, the hope, vision, and expectation for all individuals with disabilities is the improved educational attainment and employment that is unique to each one, yet not less than the attainment of individuals without disabilities.

Results from scores of research and demonstration efforts over the past three decades provide evidence of strategies, processes, models, and programs that lead to successful outcomes for youth with disabilities after they leave high school. For example, students with disabilities who experience work while in high school, especially paid employment, are more likely to obtain successful employment as adults (Carter, Austin, & Trainor, 2012; Cmar, McDonnall, & Markoski, 2018; Mazzotti, Rowe, Sinclair, Poppen, Woods, & Shearer, 2016). Post-high school outcomes for youth with disabilities in employment, education, and independent living is greater when youth, parents, and professionals have expectations that the youth will succeed in adulthood (Carter, Brock, & Trainor, 2014; Chen & Gregory, 2010; DeBacker & Routon, 2017; West, Sima, Wehman, Chan, & Luecking, 2018; Zhang, Haddad, Torres, & Chen, 2011). The involvement of youth and parents in the development of the Individualized Education Plan (IEP) is critical and necessary to ensure goals and objectives are based on the needs, interests, and preferences of the youth (Wilt & Morningstar, 2018; Childre & Chambers, 2005; Connor & Cavendish, 2018; Griffin, Taylor, Urbano, & Hodapp, 2014; MacLeod, Causton, Radel, & Radel, 2017). Many myths abound regarding the ability of individuals with significant disabilities to work and are often linked to fears of losing social security benefits, healthcare and other government supports. Low expectations on the part of families, educators and service providers is a clear barrier to improved life outcomes. Providing information and education about work and benefits planning is an important and must be addressed to facilitate effective transition planning and successful employment outcomes (Carter & Bumble, 2018; Fabian, Dong, Simonsen, Luecking, & Deschamps, 2016; Kregel, 2012; Kregel & O'Mara, 2011; McLain & Walus, 2015; Sulewski, Kugler, & Kramer, 2010). Furthermore, collaboration among the systems providing transition services is critical and demonstrated to be effective in improving outcomes (Albright, Hasazi, Phelps, & Hull, 1981; Kohler, 1993; Luecking, Fabian, Contreary, Honeycutt, & Luecking, 2017; Oertle & Trach, 2007; Noonan, Erickson, & Morningstar, 2013; Noyes & Sax, 2004).

The research demonstrates that we have the solutions to improve transition services and outcomes for youth with disabilities (Honeycutt & Livermore, 2018). Yet, despite the evidence-based practices, we continue to grapple with what to do to facilitate more seamless transitions for youth with disabilities into adulthood. The emphasis going forward should not be solely on implementing these proven transition strategies and practices; rather it should be changing the expectations and culture within our systems that will support programs, professionals, youth and their families to fully

implement transition services. **In other words, the barriers and challenges are not the services themselves; rather the systems responsible for delivering these services often present the greatest barriers.**

Removing these barriers requires a culture change and a reshaping of our expectations, problem-solving, and decision making. Elements of this culture change are reflected in the six Lessons learned from CaPROMISE during the last five years. Data have been collected from all the stakeholders involved in the project documenting interventions, participation, and outcomes and the stories from youth, families, and professionals have added depth and meaning to the statistics (Matulewicz, et al, 2018). Several manuscripts featuring various analyses of the data are currently in progress and/or in review. This paper strives to consider the “big picture” perspective, drawing from multiple perspectives from those who have been on this journey and those who are leading changes in our systems and organizational cultures.

Lessons learned and reflections for culture and system changes

The following are six Lessons learned during the past five plus years. These Lessons provide the framework for continued system and culture changes for the benefit of youth with disabilities and their families – in essence for each of us and our communities. The six Lessons are:

1. Rethinking the culture of expectations is essential to increase self-sufficiency.
2. The primary focus must be the impact for the youth and their families.
3. Family engagement is essential in the youth’s attainment of self-sufficiency.
4. Community perceptions and stigma about disability limit potential for integration.
5. Collaborative interagency and cross-organizational engagement are essential for increasing the youth’s self-sufficiency.
6. Organizational structures and resulting expectations present opportunities and challenges.

While these Lessons pose as many questions as they provide answers, they are at the core of “why” our expectations, public policies and engagement must focus on the youth and their families and not solely “how” to meet legislative intent and compliance.

Lesson One: Rethinking the culture of expectations is essential to increase self-sufficiency

Lesson One focuses on reconceptualizing the “why” of transition services and the evidence-based outcomes for the youth and their families. This goes beyond the legislative mandates at the Federal, State and local governance bodies. This Lesson focuses on the beliefs and values of our educational institutions and organizations and those communicated by the family, the youth and the various administrators, educators, and service providers. The following points of discussion are offered when “reconceptualizing” the “why” of transition services and outcomes.

- The expectation and desired outcomes (i.e., continued education, training, competitive employment and increased self-sufficiency) must be included in all communications and services. Setting high expectations will help shift the culture of our services from discreet interventions and programs to a coordinated approach for the youth and their families.
- Positive expectations for individuals with disabilities specific to employment and career success on the part of many educational and organizational stakeholders are often limited or missing and lead to unemployment and/or underemployment. There is a stigma associated with disability that often results in the marginalization of people with disabilities and lower expectations for their ability to be self-sufficient. When this stigma is coupled with low educational achievement, low income, poverty and/or identification with traditionally underrepresented groups the expectations and opportunities for employment and career success are diminished.
- Changing organizational and individual beliefs and culture is challenging and difficult. These changes require continuous attention, focus and time, and the willingness to do so. When possible, evidence and data must inform and support the cultural and organizational changes.
- When an individual is identified as having a disability, regardless of their age, the initial discussions focus on the person's limitations and what compensations and accommodations are needed for their self-sufficiency, as these elements drive the funding for resources. There is less discussion, at least initially, about their assets, capabilities, and potential for positive educational and employment outcomes.
- Our education system is based on specific learning outcomes and metrics that target graduation criteria. When a youth does not meet the expected K-12 graduation criteria and the predetermined timelines we add metrics with fewer expectations (i.e., a certificate of completion or an adult transition program). Do these additional metrics add recognized credentials by the greater community and strengthen the youth's opportunities for self-sufficiency or do they diminish the youth's opportunities for moving toward self-sufficiency?
- Our training and employment systems are measured by the number of individuals who are employed – there are few expectations for creating a *“career of lifelong learning, development and employment.”* Most recently, there has been the development of Career Pathway Programs for youth in many of the Local Education Agencies (LEAs) throughout California. However, these Programs only attract and/or recruit a small percentage of youth with an identified disability.
- Our organizational systems and outcome metrics are built on time, costs and traditional societal expectations such as full-time employment and no or little reliance on government programs. The individuals who learn differently, take non-traditional paths and/or lack the familial and financial resources, are considered “exceptional” or “special” and often are considered non-conformists to our traditional organizational systems. They are often considered non-participatory, too difficult to serve and/or are not considered employable.

Lesson Two: The primary focus must be the impact for the youth and their families

Lesson Two focuses on the youth and their families as the primary stakeholder for education and transition efforts. This Lesson looks at changing the paradigm from a system-driven focus to a person- and family-driven focus. While both are important, addressing decisions from the perspective of the youth and their family members changes the discussion and the expectations. The following points of discussion are offered for shifting the primary focus to the youth and their family members.

- Youth-Driven and Family-Centered actions are the key factors in identifying, implementing and achieving significant and sustainable changes.
- Often the youth's disabling condition(s) are unexpected by the family and there is a sense of loss and frustration with the common laments *why us?* and *what do we do?* Families are discouraged from dreaming too big or having "unrealistic expectations." Addressing these frustrations and questions is critical to moving the discussion to the hopes, dreams and positive actions for the youth and their family.
- There are typically additional or increased disability-related costs for healthcare, supports, time demands and resources such as respite care, assistive technology, tutoring and transportation. These are often unanticipated expectations and costs which adding excessive an additional financial burdens for with the family.
- Issues related to health insurance, pre-existing conditions and planning for future supports of the youth emerge as they approach adulthood and switch from the educational system to adult services. These issues are heightened when there is a possibility of the loss of SSI and other health related resources. How to address these multiple demands and emerging challenges often cause significant stress in the family unit.
- Families want assistance, but are often at a loss as to what is needed, where to go for services, how to ask for supports and what is possible and needed with the youth. The maze of programs and the various governmental acronyms often become overwhelming, resulting in the families often not being able to follow-through. Benefits planning and management are essential, but rarely available to families. As a result, they may be labeled as non-compliant or disinterested.
- Often there are extenuating circumstances that result in the family being in poverty and uncertain how to balance their competing demands especially related to basic living requirements (i.e., housing, utilities, food, healthcare, communications, transportation and other related supports).
- The significance of the disability is often a barrier to accessing work-based learning opportunities due to a lack of knowledge on the strategies and accommodations that can be used to support students in community-based settings. Additional challenges to work-based learning includes a lack of administrative support in the LEA, lack of parent buy-in, insufficient transportation supports and individual job supports, minimal engagement of the employer, and limited

business site availability. Educators are often not provided training and support for creating work-based learning opportunities of their student.

- Work-based learning experiences are integral to supporting self-sufficiency for the youth and the family members. There must be a tangible benefit with these experiences that will increase the knowledge and confidence of the youth and demonstrate the actual and potential capabilities of the youth to the family, the educators, and other professionals supporting them.

Lesson Three: Family engagement is essential in the youth's attainment of self-sufficiency

Lesson Three is at the crux of developing long-term sufficiency. The inclusion and engagement of the family members is essential. Family members serve as role models for the youth, shape and reinforce behaviors and expectations, and influence the youth in all of the hours beyond school and during their development until adulthood. These influences can be supportive or stifling for the youth. The following points of discussion are offered for engaging the family members in the youth's development.

- Discussions about education and work should begin at an early age – there is a need to set the expectations for a “life of self-sufficiency” and not a “life of dependency.” This attitude needs to be fostered and maintained with both the youth and the family members. Parent to parent support can help them become familiar with the skills and strategies, directly linked to self-determination, that can be taught and promoted and that lead to successful independent living, employment, and life long career development.
- When working with the youth there must be the involvement of the key family members in the discussions, decision making and implementation of all interventions. The family's engagement is critical to strengthen the understanding, the short- and long-term expectations, follow-through for all interventions and the attainment of career relevant employment.
- When needed, there should be the provision of supports and/or services for all family members – not solely the youth. These supports and services can include housing, food, mental health supports, medical supports, job assistance, transportation, postsecondary education and/or vocational training.
- Engagement of family resource services – at an early age if the youth has a congenital or early onset of a disabling condition(s) – is especially critical to promote short and long-term expectations for education, career relevant employment and self-sufficiency.
- There must be support and “translation” of various government services including their purpose, benefits, expectations and resources. Often the family becomes overwhelmed with the various services and expectations and are unable to act. A referral to an agency or service is not enough. As we learned from our families, a “warm handoff” (i.e., person to person contact vs. a list of names and numbers) is critical in introducing resources that can provide assistance. Through warm handoffs, families learn how to contact, access, utilize and request, when needed, on-

going services and support. The youth and family members must acquire the knowledge and skills to be self-advocates.

- Financial and benefits planning skills are critical for the buy-in of families to support employment related programming. There is a real fear to losing their guaranteed benefits. As an example, financial and benefits planning includes having knowledge of the ABLE Act Saving accounts which are intended to improve the long-term quality of life for individuals with disabilities.
- School and agency personnel must be competent and willing to engage the family members as essential and co-equal partners in the youth's development and transition. Language, terminology and acronyms are a definite barrier to effective communication among all parties. A "we-they" dichotomy may emerge between the family and the school and agency personnel. Minimizing this dichotomy and strengthening the partnership will benefit all parties.
- School personnel who are responsible for the youth's Individual Education Plan (IEP) must work with the family unit and use the principles of a person/family-driven approach to planning and implementation. This may require "rethinking" how time is allocated for school personnel and reinforcing the engagement of the family.
- Frequent and personalized outreach and communication efforts are needed to ensure that families are prepared to make informed decisions. Educators and community service providers must be given the charge to engage the families and then provide the resources (time and knowledge) to ensure this engagement is productive for all. Above all, families must be encouraged to maintain high aspirations for their sons and daughters, allowing them the potential to become self-determined and empowered in their lives.

Lesson Four: Community perceptions and stigma about disability limit potential for integration

Lesson Four addresses the stigma of disability for youth and adults in our communities. Simply the distinction of Special Education from General Education creates a dichotomy of difference. We often use language that implies the youth is less capable and disability is discussed from the perspective of a deficit model. In education and other human services this sets up perceptions that lower expectations are appropriate for youth with disabilities, primarily in an effort to prevent disappointment and failure. The following points of discussion offer examples of unintentional but still stigmatizing perceptions that impede education, employment and community integration and ways to address them.

- The issue of labeling is problematic. The community uses labels to classify individuals and/or their capabilities. As an example, we have students in "special education" which signifies they are different and need special treatment. We use diagnostic labels to identify a class of individuals (i.e., they are on the Spectrum, he is a quad, the person is deaf or blind, etc.). These labels classify a person and places them in a group with the implication all individuals in the group have similar behaviors, abilities, and needs.

- Using labels create perceptions of an individual’s characteristics and capabilities. The labels are a shorthand method of identifying groups of individuals which negates their uniqueness. There is seldom the use of strength-based terminology associated with youth with a disabling condition. The focus is typically a deficit-based model, reinforced by funding that is attached to the identification of specific labels. Changing our focus to unique characteristics and addressing positive characteristics will, over time, change the narrative and community perceptions.
- There is a perception that a person with a disability must have supports paid by the systems and will have a difficulty meeting the expectations of the general community. There will always be challenges that impact the ability to be “normal”. Ensuring that the general community understands and is willing to support these accommodations is critical.
- Often times, we encourage employers to “hire the disabled” because it is the right thing to do. This approach negates the individual’s capabilities, uniqueness, and ability to contribute to the workforce. It results in the perpetuation of stereotypes and minimizes expectations that will prevent any failure or disappointment. Unfortunately, this attitude also prevents individuals from experiencing the dignity of risk, learning from their mistakes, and gaining resilience.

Lesson Five: Collaborative interagency and cross-organizational engagement are essential for increasing youth’s self-sufficiency

Lesson Five addresses the systems that we use to design and implement services and support. These systems are mandated at the Federal level and in each of our States and Territories. However, the mandates often result in both gaps and duplication of services. They create confusion for the youth and their families and over time create “organizational silos”. The following points of discussion offer ways to examine organizational mandates and the cross-discipline and cross-organizational efforts for the youth and their families.

- Each organization has its own legal mandate and policies and procedures that are based on Federal, State and/or local laws and regulations. The result is these mandates drive the interactions with youth and their families. These requirements need to be translated into common language, articulated with flexibility and not be the sole driver of the services and supports. There must be a balance between compliance with the legal mandate and the principles of individual development and growth.
- Often a youth will have multiple individualized plans depending on the nature of the services (e.g., IEP, ITP, IPE). Where possible, these multiple plans must be refined to reduce duplication, contradictions and conflicting policies. Agencies need to come together to address programming with a focus on the individual’s support needs to ensure a coordinated effort. This can be facilitated by cross-program planning and the collaborative delivery of services and supports. The principle of “one person – one plan” has often been discussed as a possible model for our systems, and should be based on a person-driven plan completed with the youth and family before the “official” plans are completed.

- Planning needs to include a focus on the “why” of independence and self-sufficiency not solely on the “how” to complete intermediate steps such as completion of the Individual Education Plan (IEP), the Individual Transition Plan (ITP), the Individual Plan for Employment (IPE), grade completion, physical development, etc.
- Our organizational practices and expectations are often “legacy systems” that have developed over time and have a comfort and familiarity with the administrators and staff. New policies and practices are difficult to implement and changing the culture and the legacies of the organization is extremely difficult. The changing of legacy systems requires shared values and targeted actions that are understood, reinforced and continuously explained and rewarded.
- There is a continuous and constant need for staff development and continuing education and training. There are often multiple implications and practices with each youth and the family members. The staff must be knowledgeable to individualize approaches and avoid using approaches that address “generic” issues and challenges.
- Policies and practices that support and reward collaboration across systems vary widely within and across states. Educators and adult system professionals often have limited knowledge about each other’s systems, which creates barriers for effective transition services. Cross-organizational training and programming is essential.
- Typically, human and educational systems are shaped at the Federal and/or State levels, but delivered by local entities (i.e., State Department of Education and the Local Education Agency, the Employment Development Department and the American Job Centers, the Healthcare Agency and the local health departments and private providers, etc.). Each agency has their own mandates, constituencies, language and acronyms. The mandates at the various levels are often contradictory and result in multiple messages being heard and understood by the youth and their families.
- Local partnership teams must take on the responsibility of improving services with youth with disabilities and their families. These teams should include representatives from education (K-12 and postsecondary education and training), community service agencies, the Department of Rehabilitation, the Regional Centers, American Job Centers, family members, advocacy groups, health care agencies and other community specific partners such as family resource centers and independent living centers.

Lesson Six: Organizational structures and resulting expectations present opportunities and challenges

Lesson Six discusses the lack of clarity and, in some instances, the contradictory legislation, definitions and eligibility or entitlement requirements. Often these organizational structures take on an importance that drive the scope and depth of transition services needed by the youth and family members. The following points of discussion offer consideration about organizational and legislative mandates that impact transition efforts.

- The Federal and State systems have varying definitions of disability and interpretations of their meaning, eligibility or entitlement requirements. As an example, the Social Security Administration, the Office of Special Education Programs and the Rehabilitation Services Administration in the US Department of Education, and the Administration on Developmental Disabilities in the US Department of Health and Human Services use different titles for and criteria for disability designations. The result is a lack of consistency across programs when categorizing disability classifications, creating confusion for families when they apply for and receive services from different organizations because of the variances in diagnostic classification.
- Qualifying for supports and services differs with the various Federal and State agencies. Often, there are economic indicators that trigger allowable expenses and income qualifications. As an example, concerns with SSI include confusing work incentives, overpayments, loss of benefits at age 18 and understanding the criteria for work and benefit retention. Understanding these external criteria and their application for youth and their families is critical for self-sufficiency and self-determination.
- Often healthcare and long-term medical supports are important considerations for the youth and the family. Considering the US healthcare policies and the lack of clarity, there is a constant concern that these supports will not be available in the future. There is an “existential fear” of healthcare and/or monthly financial supports ceasing to exist. This fear is real and frequently impacts decisions regarding an individual’s self-sufficiency and willingness to seek employment. Moving from medical care for youth to adult care systems is also an issue that needs to be addressed through the transition process.
- Data sharing across and between systems is often impossible. This is limited because of antiquated computer systems, legal requirements regarding data sharing agreements, security and confidentiality, different “languages” regarding the identification of data elements and significant costs and time to make data sharing changes.
- Often the youth and the family members must complete multiple steps to secure the entitlement for the services or meet the eligibility requirements. This often requires an extended period of time and extensive documentation⁴ citing why the youth is disabled and needs the services and supports. Once the youth qualifies for supports and services, they are often encouraged to become independent and self-sufficient. Yet, the safety of guaranteed SSI benefits may outweigh the potential of greater earnings. The contradiction causes a hesitancy to progress based on a fear of “relapse” or an inability to sustain self-sufficiency.

These six Lessons represent challenges and opportunities as we examine the systems and culture that impacts transition efforts with youth and family members. To increase the impact of our transition efforts and most importantly increase the opportunities for self-sufficiency for the

⁴ The California Department of Rehabilitation has recently implemented an expedited eligibility process that can result in a same day eligibility decision.

youth and their family members requires system and cultural changes. We must change the culture and expectations of our youth with disabilities and their family members, our supporting organizations, the educators and service providers, the administrators and the policy makers. To address these Lessons learned, we have identified six actions for consideration.

A call to action – shaping the vision, culture and actions in our future

*Change is not a rejection of our past and present actions and achievements;
Change is a response to our future opportunities and desired accomplishments.*

The Lessons learned regarding transition efforts for youth and their families through CaPROMISE are extensive and complex. Many of these Lessons have been known for years and resulted in targeted and incremental changes in practices, funding, legislation and/or regulations. As cited previously, there have been numerous legislative initiatives at the national level (i.e., IDEA, WIA, WIOA, Ticket to Work, etc.) and comparable initiatives in individual States. There have been many demonstration projects and research studies over the past 25 plus years that indicated and reinforced positive findings for youth and local and state “champions” who advocated progressive refinements in transition services. The challenge with all of these efforts has been achieving long-term sustainability and scalability through the (re)alignment of resources (i.e., personnel, finances, collaborative partnerships, and constant and consistent leadership and communications). The ability to change the expectations and cultural norms for youth and their families, education and rehabilitation personnel, community partners and postsecondary education personnel, and employers is challenging and fraught with large and small concerns. All of these individuals and their representative organizations must be engaged as collaborative partners if we are to change the cultural norms, the expectations of our systems and our public policies that enable youth and their families to create a new future of increased self-sufficiency.

We have identified six recommended actions that serve as foundational efforts to **change** the cultural norms surrounding transition efforts for youth and their families; **increase** the chances of sustainability and scalability that enable youth with disabilities to increase their opportunities for increased self-sufficiency; and **influence** current and future transition public policies. We address these actions first from the perspective of the youth and their families and the local communities. This focus is essential to engage the youth, families, local educators and community providers as the primary partners in cultural, policy and practice changes. We suggest a process of change from the youth and family up rather than the traditional method of driving change from the top down through the organizations to the youth and their families. Second, we address two actions at the State level and conclude with two recommended actions at the Federal level. Public policy and cultural change is complex, takes a focused and long-term commitment and will require regular reviews and refinements. All partners must have the political will to take the necessary risks and actions if true, meaningful, and substantial change is to occur.

Action 1: *Ensure the articulation of transition services and outcomes is clearly understood by all through written, visual, technological and spoken media.*

Discussion: The written and spoken message must espouse collaborative transition efforts that speak to one mission and goal – self-sufficiency and a quality of life based on youth’s and families’ interests and dreams. The actual transition efforts seldom demonstrate this message. What typically happens is the youth and families are directed to services based on disability, funding, and categories. Furthermore, the message from one program to the next is disparate and disconnected despite the fact these programs are mandated to provide transition services in partnership and in concert with each other and with youth and families.

To implement Action 1, all points of interface between the youth with a disability and their family members must be examined in the context of their expectations and comfort zone. This includes the materials provided to teachers and parents, information distributed by community partners, language and terms used by the respective State Departments and community partners, and technology related access to transition services. The use of various technologies such as websites, methods of communicating, etc. need to be aligned with the needs of youth and their family members. Social and economic factors play an important role in youth’s and families’ access to resources and must be considered in all programming. All points of contact need to be geared to the daily lives of the youth and their families and the understanding of what transition efforts mean to/for them. As an example, family members and the youth may not be available during traditional work hours (i.e., 8 to 5). Therefore, adjusting hours and locations for meetings may need to be changed to ensure access.

The outreach, coordination and delivery of services with the youth and their family members needs to be simplified. This requires structural changes, preparation and support of staff, and implementing services that are directed to the youth and their families. Virtually all interfaces need to be examined to ensure clarity and focus for the youth’s transition. In essence, the process must be demystified and transparent. These efforts must be created at the local level and supported by the State Departments. These interfaces need to be the “face” of all transition efforts. They must be presented to the local community in a way that resonates with their values and experiences. They will vary based on the local characteristics (i.e., cultural make-up of the community, rural/urban environments, local economic resources, and/or postsecondary education and employer needs and resources) of the youth and their families. The optics are not “one size fits all” for each community let alone the State. This Action requires constant examination and engaging youth and their families in shaping the optics, the understanding and the interface with community partners and resources. Ultimately, the family becomes more empowered to more effectively drive the services and supports in partnership with the professionals who are charged with this important responsibility.

Action 2: Identify community partners that are participating in the majority of these programs and merge local collaborative “program sites” that target career and employment outcomes.

Discussion: This Action focuses on the numerous transition efforts that are occurring in the local community. There are a number of initiatives in K-12 education that link career development to the traditional educational experiences. These include career pathways with a focus on STEM disciplines and a recognition that career and technical education is increasingly critical. While these efforts are available to most students, there is inadequate recognition or targeted efforts to include youth with disabilities in these programs. Further, there are programs currently addressing various aspects of transition services for youth with disabilities. In California, these include (a) the various WorkAbility programs in middle schools, high schools, community colleges and four-year universities; (b) CaPROMISE through DOR and supported by 18 LEAs; (c) California Career Innovations funded by the US Department of Education through DOR and involving multiple LEAs; (d) the implementation of pre-employment transition services, as mandated by WIOA, through DOR with community partners; (e) Disability Support Programs and Services through the community colleges and four-year universities; (e) paid internship resources through the Department of Developmental Disabilities, and (f) the Disability Employment Initiative through the US Department of Labor to the EDD and engaging specific One-Stop Centers.

To implement Action 2, programs must start with a person-centric focus, such as that designed by CaPROMISE, characterized by the youth and the family members driving the process. In this process, community partners are matched to the youth and families, based on the needs, interests, and dreams of the youth and families. To facilitate this match, a list of programs and services available in the schools and communities must be compiled and continuously updated. The list should not be limited to disability-related programs; rather it should be wide-ranging and include all programs and services that provide targeted support to achieve career and employment outcomes. The shift is targeting the specific initiatives for the youth and the family members based on their specific needs and expectations. From this determination, the services and resources can be braided to meet their unique needs.

What we learned is that having one person to serve as mentor and point of contact for the youth and the family was critical. Equally important, this person should be competent as a certified benefits planner and have “staff status” with the LEA and/or DOR. This professional will be the interface between the youth and the family members, State Departments and community partners. An effective interface requires access to a databank that can collect, store, and organize information that is relevant to youth and families and informs service providers and programs. The Data Management System currently used by CaPROMISE can serve as the system for data gathering and tracking across the multiple programs. Efforts to develop data sharing processes with State Departments can be accomplished through this collaborative action. This strategy needs to be flexible and expanded and reshaped as the needs and expectation of the youth and their family members change over time.

The strategy for Actions 1 and 2 can be combined and provided in a coordinated and viable model for significant system changes with transition efforts. The benefit to the youth and their families is much greater if the separate funding mechanisms can be blended to address their transition needs and resources. It will be the responsibility of the local providers to manage the various compliance requirements.

From the youth and family member perspective, developing workplace skills and knowledge at an early age may promote self-sufficiency in education and eventually in employment.

Action 3: Develop and implement, with equal representation of the authorizing organizations, the expected vision, mission, values, outcomes and framework for transition efforts with youth and their family members as the primary focus.

Discussion: This action addresses the multiple educational and organizational structures, the long tradition of developed public policies and the implementation of various transition-related programs and services. What has evolved over the past 25 plus years is a myriad of legislative mandates, programs and services that cover multiple aspects of the youth's and family's transitions from K-12 education to adult life. Attempting to "restructure" these efforts from a system-centric approach to a person-centric approach is problematic at best. Shaping transition policies and practices for the future requires the current State Departments and community providers to change policies, share resources, relinquish organizational control and reorient staff and recipients of services. The Federal initiative implemented through WIOA in 2014 provides the mandate. The expectation of WIOA is embedded in the title – *Innovation and Opportunity*- and will ideally be mirrored in the next reauthorization of IDEA. Implementation of policy and cultural changes must occur at the State level.

To implement Action 3, programs must craft a unified vision for transition efforts. This action requires stepping out of the silos of individual organizations and into a larger arena comprised of multiple organizations. Working backward from a unified vision and shared values, programs must jointly define the mission, outcomes and framework for transition efforts with youth and their family members. This model would be analogous to creating "public transition charters." A charter defines the functions of an organization and describes its rights, aims and principles. In this charter, the primary focus must be the youth and the family members. This charter's aim is to demonstrate, understand, and study the engagement of youth and their families, understand the essential structural and cultural changes and frame the competencies of personnel in a collaborative model for transition. This model will require a buy-in from the State Departments and their community partners (i.e., one-stop centers/American Job Centers, LEAs, Regional Centers and DOR District Offices). The contractual language (i.e., interagency agreements, memorandums of understanding, service contracts, program contracts, etc.) must focus on performance outcomes and allow local control of strategies and implementation efforts. There must be a "loosening" of fiscal requirements

to allow shared expenses, cost savings and agreement that funds can be accessed by partners to provide the full array of transition services to the youth with a disability and their family members.

From the perspective of the youth and family members, access and receipt of supports and services across the State Departments and community partners should be seamless.

Action 4: Ensure direct service staff have the latitude to provide youth and family specific services and outcomes while senior administrators ensure legal and fiscal mandates are met.

Discussion: This action addresses the engagement, development and ongoing education of the State Departments' and community partners' staff. Informing, engaging, educating and supporting staff is essential and must be continuous. While clearly articulating the vision, values and performance outcomes are essential, there must be a structure and plan to continuously engage all staff, including the educators responsible for preparing the students for transition. This person-driven approach to transition services changes the current paradigm. Educators and agency staff must start with understanding – fully – the expectations and needs of the youth and family members and from this understanding, access appropriate transition resources to be individually responsive. This will require staff to be knowledgeable of local resources and the availability of resources through the various State Departments and community partners.

To implement Action 4, cross training (within and across State and community partners) must be provided to all staff. Supervisors must be leaders, mentors and coaches for staff, not solely "compliance supervisors". There must be concurrence that multiple resources within and across the partners can be used for serving youth with disabilities and their family members. Staff, supervisors and administrators must have access to current information (i.e., reports, data, performance outcomes, etc.) that illustrate the progress and attainments as well as challenges regarding the youth's outcomes, service coordination, and State Department and community partner collaborations. Accessing information is not enough. They must take the time to understand the content of these materials and resources; use the information to identify strengths and gaps in program services, coordination, and operations; and take the necessary steps to build on the strengths, fill the gaps, and reshape the systems and culture.

There must be latitude (and possibly waivers) in meeting regulatory and contractual requirements and incentives need to be built into the system to support collaborative efforts. Senior administrators must examine ways to ensure legal and fiscal mandates are met while providing latitude in the provision of services and outcomes. These strategies are highly complex, but not insurmountable.

From a youth and family member perspective, a seamless transition delivery system reduces or eliminates the confusion, frustration and headaches associated with seeking, obtaining and sustaining services from multiple providers. This strategy requires time, ongoing dialogue, and refinements through all levels of the State Departments and the community partners.

Action 5: *As the six PROMISE research and demonstration efforts are completed, it is critical for the Federal partners to examine the results and determine which policies and regulatory requirements should be refined to increase impact and scalability in service delivery models.*

Discussion: This action focuses on the Federal partners. The funding for the six PROMISE projects is an excellent example of interagency and cross-organizational collaboration. Four Federal agencies – Education, Labor, Health and Human Services and the Social Security Administration – worked in a collaborative manner to create this initiative, which has spanned over 5 years and included fiscal support exceeding \$210 million dollars.

To implement Action 5, Federal partners must examine the evidence-based practices identified by the six PROMISE projects and explore the recommendations provided in light of current policies and regulatory requirements. Federal partners should consider potential refinements to these policies and regulations to increase impact and scalability, recognizing the unique needs and structures that vary within and across states. Examples of possible changes include supporting transition planning efforts for younger youth (i.e., at age 12 or younger), increasing the flexibility of WIOA especially related to regulatory criteria on the ages for providing pre-employment transition services, expanding these services to youth outside of the K-12 structure, and creating an alignment of WIOA transition efforts with IDEA legislation that supports a seamless transition process. The terms “*Innovation*” and “*Opportunity*” in WIOA need to be operationalized by granting greater flexibility for States.

Action 6: *As legislative reauthorization is considered with these various Federal agencies, we urge that the classification systems used for identifying the disabling conditions of the youth be aligned with common titles and definitions.*

Discussion: Disability classification systems contribute to the fragmentation of services and reinforces the silos in which individual agencies and programs exist. Each Federal agency has its own definition for disabling conditions, which causes confusion for parents and professionals. Differing disability labels and categories often results in differences in entitlements and eligibility requirements. From one agency/program to the next, youth, their family members and the service providers must continuously determine if the youth is eligible or entitled to the services.

To implement Action 6, Federal partners must jointly examine these classification systems and determine the purpose and utility of the disability categories. Collaborative reviews of the classification systems may uncover opportunities to modify, merge, or replace disability labels and categories with the goal of creating one classification system aligned with common titles and definitions.

Summation⁵

*It's important to remember that we cannot become what we need to be,
By remaining what we are.*

Max DePree

The goal of any transition effort must include successful performance outcomes for youth with disabilities and family members in postsecondary education and/or training and competitive integrated employment and sustainable careers. The six Lessons learned through CaPROMISE have been revealing, challenging and have shaped our learning over the past five years and changed our vision for the future. Embedded in each Lesson are key points that have emerged and challenged the provision of services and supports for the youth with disabilities. They have also demonstrated the creativity and innovation of the education and rehabilitation staff who translated their passion and commitment into positive developments for the youth and their families. They created mutually beneficial and trusting relationships that fostered self-determination, enabling youth and families to achieve maximum independence and a positive quality of life.

The six recommended actions serve as foundational steps in creating a culture of engagement and growth for the youth, their families and the educators, service providers, and administrators who address these transition challenges on a daily basis. Implementing these actions will change the trajectory for our youth with disabilities, their family members and most importantly the impact of our programs on their quality of life, career and employment outcomes. Moreover, creating a comprehensive transition model that is inclusive of all possible programs is functional and person-centric for youth with disabilities. Starting at age 14 (or preferably younger) allows time to maximize the existing and recommended resources, connect families to these resources, and enable families and youth to experience outcomes that will elevate expectations for life after high school.

This is a transformative process. **The efforts are not project-based, but must be based on a continuum of changes, refinements, engagement and cross-discipline and organizational collaborations.** The process reflects a substantive cultural and public policy change – for all of the right reasons: the youth with a disability and their family members! As Margaret Mead stated: *Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.*

⁵ Disclaimer: CaPROMISE is funded through a cooperative agreement with the U.S. Department of Education, Office of Special Education Programs (OSEP) Grant #H418P130003. The contents of this paper do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government.

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