NYS PROMISE

CASE MANAGEMENT

A Field Guide for Case Managers and Family Coaches

Version 3.0, April 2018

The NYS PROMISE project produced this document under a cooperative agreement with the U.S. Department of Education, Office of Special Education Programs associated with PR Award # H418P130011. Andrew Karhan, Thomas P. Golden, and Arun Karpur served as the Principal Investigators. The views expressed herein do not necessarily represent the positions or policies of the Department of Education or its federal partners. No official endorsement by the U.S. Department of Education of any product, commodity, service or enterprise mentioned in this publication is intended or should be inferred.

NYS PROMISE. (2018). *NYS PROMISE Case Management Field Guide Version 3.0*. Cornell University, Ithaca: NY. Carol Blessing, Ray Cebula, Thomas Golden, Adene Karhan, Valerie Malzer, Michelle Podolec and Sara Van Looy.

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Acknowledgements

The NYS PROMISE program is made possible by funding from the U.S. Department of Education (USDOE), the U.S. Social Security Administration, the U.S. Department of Health and Human Services (USDHHS), and the U.S. Department of Labor (USDOL). The NYS PROMISE staff would like to thank these agencies for their continued support, as we work together to improve outcomes for youth who receive Supplemental Security Income.

Table of Contents

Contents

Introduction

Case management services under NYS PROMISE are provided by a robust and diverse network of case managers and family coaches. Case managers work predominantly with youth in the research demonstration sites, while family coaches work exclusively with the families of intervention group youth enrolled in NYS PROMISE through regional Parent Training Centers. Regardless of the title of the practitioner, or their organizational placement, they provide similar critical care, coordination and access to the core services and supports provided under the NYS PROMISE intervention, as well as information and referral for other needed services and supports. In addition, they provide intermittent "light touch" data gathering on control group youth and families.

While "field guides" have traditionally been employed in the study of plants and fauna, they have increasingly been created to support practitioners in an array of professional fields as they face the obstacles and challenges that can arise while accomplishing specific tasks. The NYS PROMISE Case Management Field Guide was designed for the express purpose of assisting case managers and family coaches in navigating their day-to-day roles, functions, and expectations, while adhering to high quality standards, and managing the impact of their work on their own health and wellbeing. The aim is to ensure that all NYS PROMISE case managers and family coaches (case management practitioners) are equipped to perform their job in a manner that leads to the expected youth and family outcomes of the NYS PROMISE intervention—holding to a common measure of fidelity.

While the aim for each case management practitioner will employ different strategies, based on the heterogeneity of the NYS PROMISE population, they will draw from a common set of strategies to ensure consistency in delivery of services and supports. This field guide is presented in modules and is indexed to assist case management practitioners in easily accessing the information they need, when they need it. Following is a summary of the specific modules included in this field guide:

Module 1: Overview of Case Management

This module provides a definition of what is meant by case management services under the NYS PROMISE. It provides an overview of critical roles and functions in case management, as well as outlines principles and standards of practice—inclusive of a code of conduct and ethical standards for case management. A taxonomy for NYS PROMISE case management is included, along with a set of skills, knowledge and attitudes considered by NYS PROMISE case managers and family coaches to be most critical to their effectiveness in supporting successful outcomes for youth and families. The information presented provides important professional boundaries for NYS PROMISE case management practitioners, as well as standards for practice.

Module 2: Service Delivery

This module outlines core outcomes-based services and other supports available to NYS PROMISE intervention youth and families—inclusive of outcomes and quality standards by service. This includes services and supports in the focus areas of economic independence and advocacy, supported post-secondary education, pre-employment, work-based learning, employment, and coaching supports. It describes an online resource for connecting students and families to other state-based programs and resources based on their unique needs. This module establishes a clear set of services and supports that are available to support both students and their families in achieving their desired economic, employment and educational aspirations.

Module 3: Youth in Transition

This module reviews foundational legislation and core principles that support best practice in transition planning. It establishes the context for student and family involvement and explains the role and responsibility of special education in the transition planning process. The framework for this module is based on key legislation, including the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act as Amended (ADAAA). Additional topics include diploma and credentialing options available for students; techniques on integrating efforts from multiple stakeholders with schools, as well as supporting self-determination and self-advocacy.

Module 4: Self-Determination

This module introduces practitioners to the concept of self-determination. It explores the role that case management practitioners will play in supporting, training, and assessing self-determination in NYS PROMISE youth. Additional topics include the personal and cultural factors that may influence self-determination for youth and families, tools available for utilization with youth and families, and further resources available to assist with integrating self-determination into case management.

Module 5: Case Planning and Service Coordination

This module covers case planning and service coordination for youth and families enrolled in the NYS PROMISE. It reviews the development, monitoring and ongoing engagement expectations for service plans. The module also discusses the importance of developing and maintaining collaborative relationships to the case planning and service coordination process. Finally, there is an overview of how services are evaluated.

Module 6: Case Recording

This module briefly covers the data collection and management expectations for case management practitioners. Additional information on records and data management for NYS PROMISE are available in the guides *NYS PROMISE Implementation & Intervention* and *NYS PROMISE Policies & Procedures* on the Online Technical Assistance Center (OTAC) at www.nypromise.org/secure.

Module 7: Counseling Resources

Counseling is the heart of proactive case management for family coaches and case managers. This

module reviews the proactive activities practitioners can incorporate into their daily practice. We introduce critical youth and family touchpoints in the transition process. We also discuss communication issues and challenges, and explore how to build resilience to challenges. Finally, we explore some of the challenging family situations common to this audience, and how to respond to angry individuals.

Module 8: Crisis Management

This module provides tools to assist case management practitioners in proactively planning for, handling, and resolving crises that may arise over the course of a case. The module begins with strategies for attempting to predict and prevent crisis. However, not all crises can be averted, and the module also provides a planning process to ensure safety of youth and families being served. The module includes tools that have proven effective in managing crises, as well as a list of examples of life experiences that may precipitate a crisis in youth and their families. The strategies discussed offer case management practitioners important tools and approaches that they can employed to manage and potentially avoid crises.

Module 9: Engaging Families

It is critically important for successful outcomes that case management practitioners in NYS PROMISE actively engage the youth and their family as partners in the counseling and case management process. This module explores how case managers can incorporate family-centered principles in their planning. It reviews what families need out of the case management process, and the vital support and collaboration case managers can provide. It concludes with an exploration of cultural competency, what this means for case management practitioners, and how they can build professional development in this area into their career paths.

Module 10: Protection and Advocacy

This module offers an overview of Protection and Advocacy services, with a description of programs that may be helpful for NYS PROMISE students and families.

Module 11: Triaging Benefits and Entitlements to Support Career Development and Work

Navigating the systems of public benefits and entitlements can be challenging for NYS PROMISE youth and their families. Further complicating matters, case managers, educators and even community rehabilitation practitioners often have limited knowledge and understanding of how these programs work and how to support youth and families that receive them. This module assists case managers in understanding how they can help families and youth understand benefits and entitlements as short-term assets meant to support competitive or supported integrated employment in the community versus life-long supports that may lead to long-term poverty and reliance on these programs.

Module 12: Justice-Involved Youth

Many case management practitioners will find themselves called to assist youth and families during or after their involvement with the legal system. This module provides an overview of the juvenile justice system, define frequently used terms, and illustrate the issues faced by students with special education needs within the justice system.

Module 13: Community Participation

This module provides a definition of community inclusion and discusses its importance to people with disabilities. Case management practitioners are provided a set of guiding principles to center their practice around inclusion, with questions to help determine if they are fully supporting youth and families in achieving maximal opportunities for participation.

Module 14: Emerging Adulthood

This module presents the concept of "emerging adulthood" and discusses issues that may arise for case management practitioners, such as guardianship, alternatives to guardianship, and supported decision making.

Module 15: Closeout Process for PROMISE

This module discusses some of the issues that may arise as case managers undertake the process of closing out PROMISE and helping their youth and families prepare to move forward.

Module 1: Overview of Case Management

Introduction

This module provides a definition of what is meant by case management services under the NYS PROMISE. It provides an overview of critical roles and functions in case management, as well as outlining principles and standards of practice—inclusive of a code of conduct and ethical standards for case management. A taxonomy for NYS PROMISE case management is provided, along with a set of skills, knowledge and attitudes considered by NYS PROMISE case managers and family coaches to be most critical to their effectiveness in supporting successful outcomes for youth and families. The information presented provides important professional boundaries for NYS PROMISE case management practitioners, as well as standards for practice.

Definition of Case Management

NYS PROMISE case managers[1] and family coaches are varied professionals and pioneers of transition systems change—forging new territory for youth who receive Supplemental Security Income (SSI). These practitioners serve as leaders and innovators who open up new areas of thought, practice, research and development—positively impacting and improving student and family well-being and transition outcomes. NYS PROMISE case management and family coaching services are consumer-centric, collaborative processes of assessment, planning, facilitation and advocacy for options and services. These services are meant to meet the transition needs of a student and their family through clear communication and assignment of available resources to promote quality outcomes.

Case Management

Case management, as defined for NYS PROMISE, is a core intervention service that assists youth who receive Supplemental Security Income (SSI) and their families to gain access to needed services and supports that promote successful community living, learning and earning outcomes. The overall goal of the service is not only to help these targeted youth and their families access, participate in, and complete needed services, but that services are planned and executed in a timely, developmentally appropriate, and person-centered manner. Finally, case management practitioners also ensure that services and supports are coordinated among all stakeholder agencies and providers.

NYS PROMISE case management services address many complex and interrelated issues, including, but not limited to: health, education, employment, benefits, family issues, and others. Case management

[1] See the resource section for a sample job description of a NYS PROMISE Case Manager.

also helps to ensure service continuity—minimizing disruptions in therapeutic, educational and vocational services.[1,2]

Research has identified several strategies to improve case management coordination which are essential components of NYS PROMISE case management.[3] These include:

1. Student tracking and monitoring
2. Data access for service providers
3. Centralized database with assigned personnel responsible for data entry
4. Cross-training opportunities, cross-agency agreements, and frequent collaboration with local education agencies
5. Safety and Security

Family Coaching

As defined above, case management is a service provided both to intervention group youth who receive SSI and to their families. Family coaching is the vehicle through which case management is provided to families of intervention group youth. It is provided through regional Parent Training Centers, and can either be a 1:1 or small group intervention, but is always family-centered in nature and responsive to the family's unique needs and goals.

Control Group Considerations

Case management services are not provided to control group youth and families. However, case managers and family coaches with assigned control group participants will be required to complete data collection and reporting duties as outlined in the *NYS PROMISE Intervention and Implementation Guide* and the *NYS PROMISE Policies and Procedures Manual* (both online at www.nyspromise.org/secure).

[1] Levinson, E.M., & Palmer, E.J. (2005). P*reparing students with disabilities for school-to-work transition and post-school life*. National Association of School Psychologists.
[2] Blackorby, J., & Wagner, M. (1996). Longitudinal post-school outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*(5), 399-413.
[3] Levinson, E.M., & Palmer, E.J. (2005). P*reparing students with disabilities for school-to-work transition and post-school life*. National Association of School Psychologists.
National Evaluation and Technical Assistance Center. (2011). Improving educational outcomes for youth in the juvenile justice and child welfare systems through interagency community and collaboration. Washington DC: Department of Education and NETAC.
Gluckman, S. & Phelps, A. (2010). Electronic information exchange for children in foster care: A roadmap to improved outcomes. The Children's Partnership.

Case Management across the NYS PROMISE Continuum

As will be described below, case management is a central, core activity across the continuum of intervention services provided under the NYS PROMISE. It is a central coordinative and driving force in ensuring that services provided to youth and families in the intervention group are planned, executed, tracked and evaluated in a timely, developmentally appropriate, and person-centered manner.

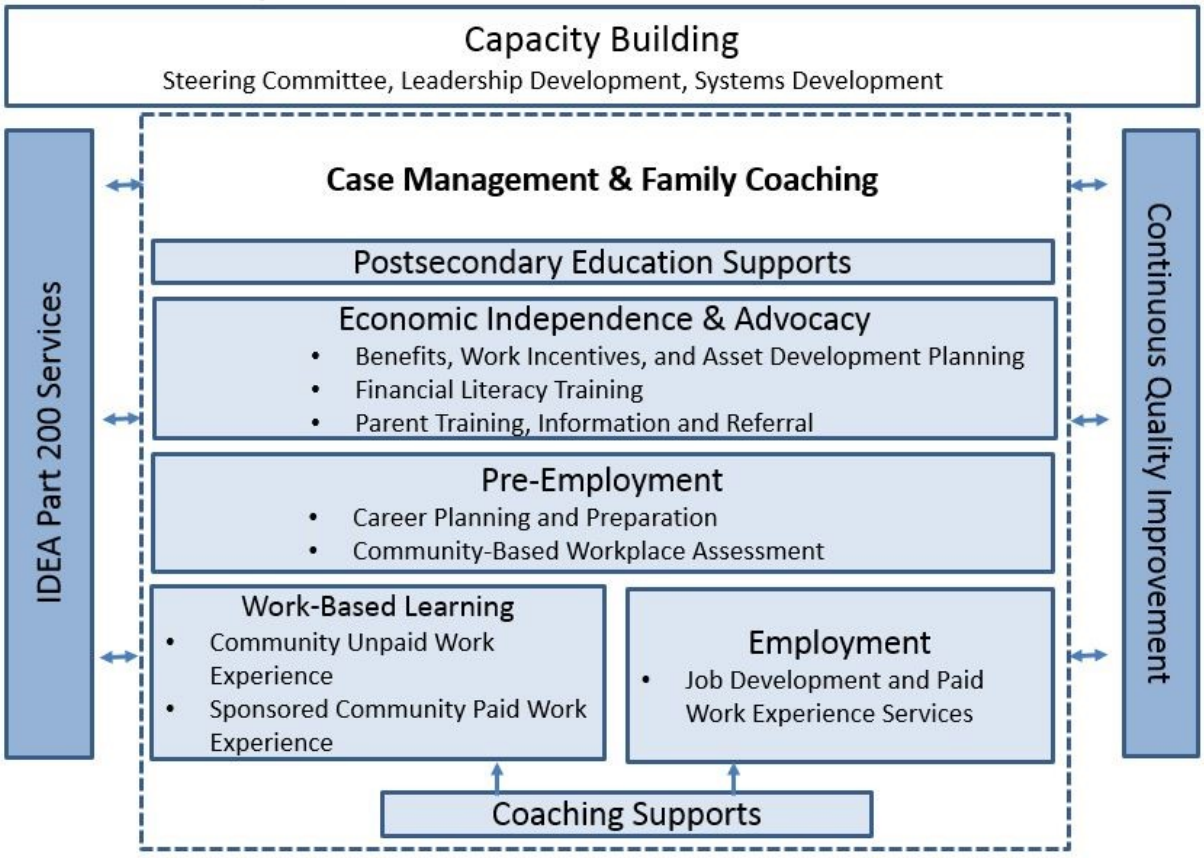

Figure 1.1. NYS PROMISE Continuum of Services

To support youth and/or family accountability and continuous engagement, a multi-pronged intervention case management process has emerged across the NYS PROMISE. This includes the following key areas:

1. Assessment activities
2. Case planning
3. Meeting basic needs
4. Crisis management
5. Education preparation
6. Employment preparation
7. Advocacy and self-sufficiency
8. Brokering of resources

This process is illustrated in the figure below.

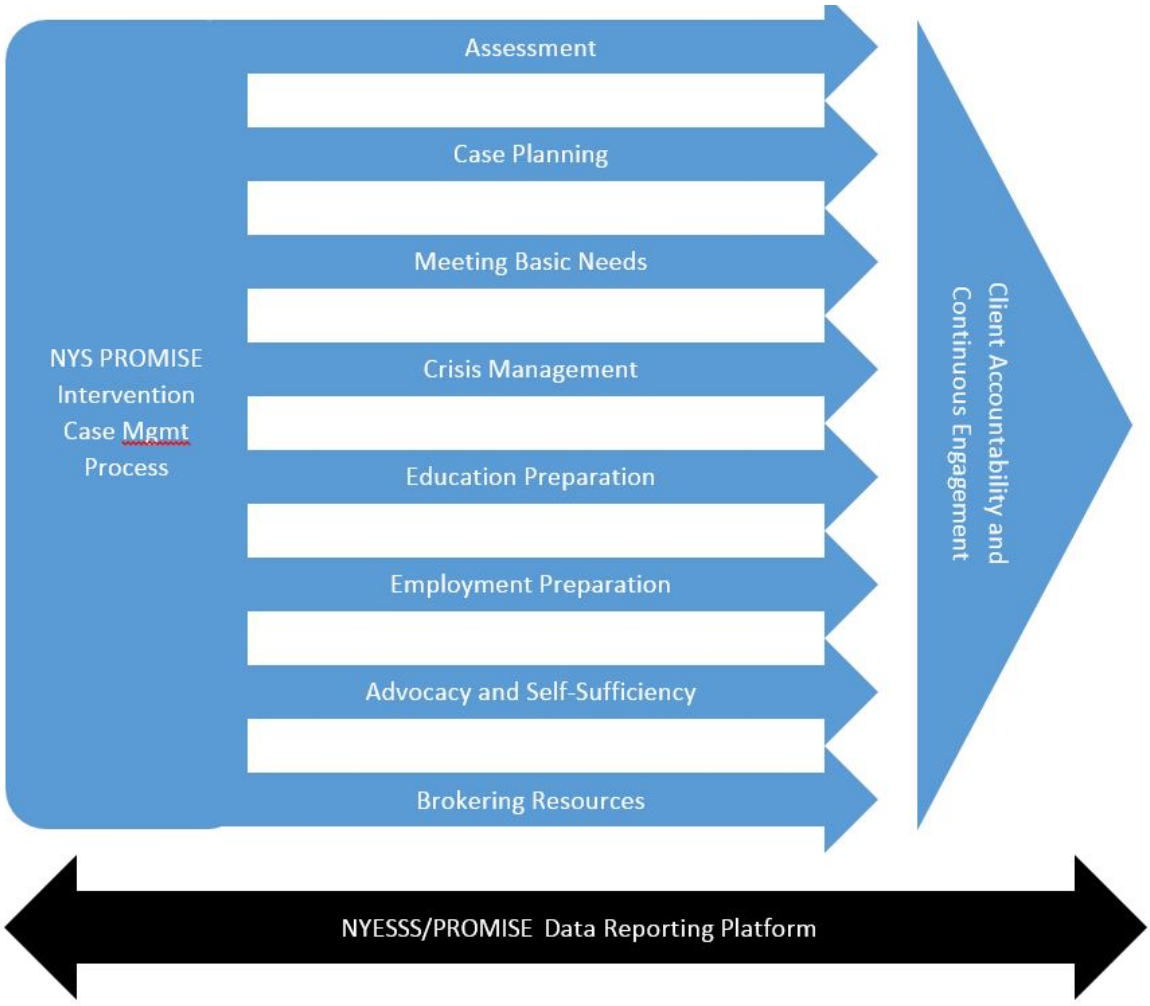

Figure 1.2. NYS PROMISE Data Reporting

Case Management Principles and Standards

A clear understanding of the limits and boundaries of the position and of provision of services is critical to the implementation of high quality case management services and supports Case management practitioners need to conscientiously provide services within local, state and federal laws, as well as general ethical practices—including intervention and implementation guidance for NYS PROMISE.

NYS Promise Service Delivery Principles

The NYS PROMISE principles for service delivery also govern case management. These include:

- **A person-centered perspective** on planning for and providing services. This tenet has a core assumption that all individuals are unique, have diverse interests, capacities, support needs, and circles of support, and that these markers guide the design, delivery, evaluation and customization of services.
- An **outcomes-based and future orientation** toward service design, program planning, service delivery, and impact evaluation. Intervention services are intended to support the movement of youth and their families toward preferred and desired outcomes based on their unique needs, preferences and support requirements.
- A **customized, accessible approach** to information, services, and supports. This tenet recognizes that individuals are unique in how they comprehend, understand and take action. They are also exposed to varying environmental factors that may impact their perceived needs and levels of engagement in service provision. This requires an intimate knowledge of the living contexts, unique capacities of and preferences of individuals regarding not only their culture, neighborhood and primary language, but also the types of reasonable accommodations that may be needed to maximize the benefits realized from services rendered.
- **Flexibility** in the scheduling and construct of intervention services. Given the diversity of the NYS PROMISE participants and their needs, it will be necessary to flexibly construct services to maximize the ability of participants to engage in planned activities, events, and services.
- The implementation of a **high quality, evidenced-based service orientation.** Services provided under the intervention have been developed based on evidence-based and/or best practices, and will hold to activities, outputs, and quality indicators as referenced in the *NYS PROMISE Intervention and Implementation Guide* (online at www.nyspromise.org/secure, pages 21-30).
- The **secure and confidential treatment** of personal information. Over the course of the NYS PROMISE intervention, participants, providers, and researchers will be privy to confidential information. Protocols for ensuring confidentiality will be practiced across all elements of service delivery. For additional information on NYS PROMISE security best practices, please see the *NYS PROMISE Security Protocol* (online at www.nyspromise.org/secure).
- **A focus on management through data**, to ensure comprehensive collection of intervention-related data and information. All providers and researchers across the intervention will demonstrate competency in entering data and using the New York Employment Services System

(NYESS). They will also demonstrate an understanding of the NYS PROMISE program, ethical research practices, and how this contributes to the fidelity of the intervention. Providers will engage in periodic reflections to assess their needs in improving quality of services as well as their delivery.

CCM Ethical Guidelines

The Commission for Case Manager Certification holds to a code of professional conduct for case management practitioners to protect the public interest. CCM certification is not required of NYS PROMISE case managers or family coaches, but its normative set of practice guidelines are consistent with the guiding principles of NYS PROMISE and provide framework for ethical, high quality case management care. The guidelines include eight primary principles:

- Principle 1:
  Case management practitioners place the public interest above their own at all times.
- Principle 2:
  Case management practitioners will respect the rights and inherent dignity of all of their clients.
- Principle 3:
  Case management practitioners will always maintain objectivity in their relationships with clients.
- Principle 4:
  Case management practitioners will act with integrity and fidelity with clients and others.
- Principle 5:
  Case management practitioners will maintain their competency at a level that ensures their clients will receive the highest quality of service.
- Principle 6:
  Case management practitioners will honor the integrity of the CCM designation and adhere to the requirements for its use.
- Principle 7:
  Case management practitioners will obey all laws and regulations.
- Principle 8:
  Case management practitioners will help maintain the integrity of the code.

The full issue brief highlighting practices under each of these principles is available online at https://ccmcertification.org/sites/default/files/downloads/2015/CCMC-Feb-IB.edits6-WEB_0.pdf.

NYS PROMISE Case Manager Critical Functions

This manual is intended to provide research-based information to address the needs of case managers and family coaches.

To discover the topics that were most important to practitioners in the field, the Yang-Tan Institute conducted a research study in the summer and fall of 2016. We wanted to understand how case management practitioners conceptualize their goals, and learn what they feel are the most important services and supports they need to achieve those goals.

We asked case managers and family coaches one question:
"For me to be effective in my job as a NYS PROMISE case manager or family coach, I need to be aware, know, or be able to do…"

Respondents

The 47 participants submitted over 130 responses. Yang-Tan researchers sorted the responses to remove duplicates and unrelated ideas.

Of people who responded, over three-quarters had 100% of their time allocated to NYS PROMISE, with close to 8% reporting having 90-95% of their time, and only 15% reporting having less than 50% of their time allocated to NYS PROMISE.

Respondents had an average of 6.3 years of experience in transition planning, but 65% had less than 5 years of experience in transition. Most were from New York City (54%), about a quarter were from Western New York (27%) and a fifth from the Capital Region (19%).

Developing a Concept Map

The goal of the study was to develop a "Concept Map." In concept mapping, a set of stakeholders develop a conceptual model that they can use for strategic planning, problem solving, and evaluation. This effort leads to the identification of key goals, objectives, and hypotheses.

Our concept mapping for Case Management Practitioners had three phases. First, participants were asked to respond to the focus question above. Second, Yang-Tan researchers reviewed the responses to remove duplicates and ideas unrelated to the prompt question and sorted the remaining responses into groups based on similarity. Finally, the ideas were rated on a scale of importance to the role of Case Manager and feasibility of implementation.

Grouping ideas that are conceptually similar allows researchers to create a concept cluster map. From this, key areas can be identified and relationships between areas can be expressed. Each cluster can be given a name that broadly represents the individual responses within that cluster. In this project, after the concepts were mapped and clustered, study participants were asked to name the thematic areas.

The cluster map in Figure 1.3 below shows the relationship of individual responses to the overall cluster map developed. All the answers to the prompt question could be grouped into seven main areas. The map indicates those areas, using relative size and position to indicate emphasis and relations.

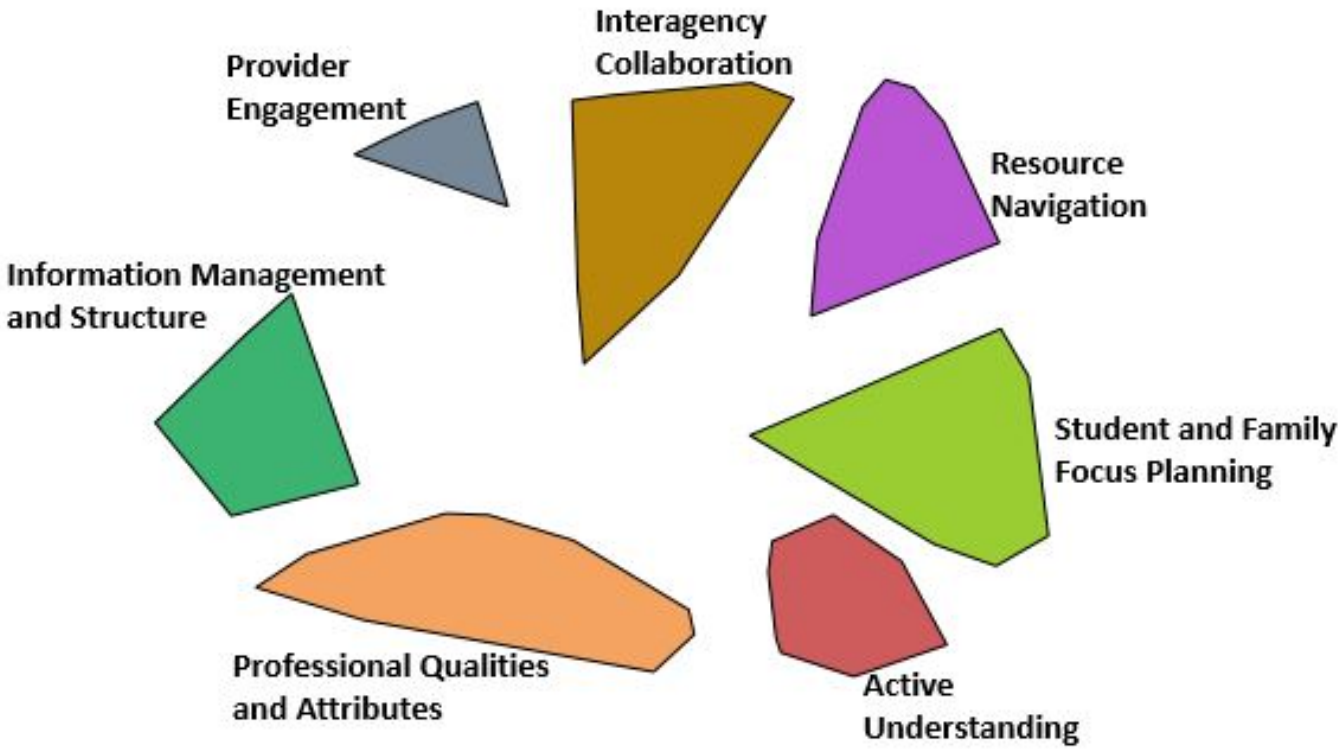

Figure 1.3. Fall 2016 Case Management Concept Map, Clusters

NYS PROMISE Taxonomy of Case Management Services

A "taxonomy" is a way of organizing thoughts into groups. The seven clusters of responses in Figure 1.3 above formed the basis of the NYS PROMISE *Taxonomy of Case Management*. The Taxonomy we present below consists of the seven categories of activities which were described and named by case managers and family coaches.

These were the seven categories of practices, polices, and procedures that NYS PROMISE case management practitioners told us were important for them to do their jobs effectively. While the rest of this Field Guide is organized by functional, rather than thematic, concerns, these seven topics have constantly informed our delivery of training and support to case management practitioners.

Student and Family Focused Planning

Practices, policies and procedures that use both strength- and need-based assessment information, environmental context, student and family self-advocacy and self-determination, and student and family future-oriented goals and objectives to inform individual service plan development. This includes the following critical elements and functions:

- Recognize critical touch points in a student's and family's life which require proactive supports.
- Help students and families express and manage their frustration.
- Address very basic needs of students and families like food, clothing and shelter.
- Help parents in seeing the potential of their student.
- Learn the needs of both students and families so as to be able to find the appropriate resources to assist.
- Identify incentives and motivators that trigger goal progress.
- Support the development of students and families over time.
- Have more options where case manager/family coach can meet with students and families.
- Identify and integrate natural supports into service planning for students and families.
- Using self-determination and motivational interviewing techniques to assist in setting priorities.
- Develop individualized service plans based on student and family priorities.
- Assist families with self-advocacy skills when they are faced with challenges to disability rights.
- Be aware of various obstacles in the local and regional context that students and families face in their individual lives.
- Assist families with how they can become better at advocating for themselves and their children, learning how to navigate through the system.
- Know the functional implications of disability on student and family engagement.
- Support development of individual service and support plans.

Active Understanding

Practices, policies and procedures that support understanding and empathy of student and family context and dynamic, flexibility to encourage student and family comfort, and surface unique cultural, linguistic and demographic assets and needs to build trust and rapport.

- Build trust with students and families.
- Be empathetic to the unique needs of students and families.
- Understand that people come from countless places and cultures with experiences that have taught and shaped them into the people they are now.
- Meet families where they are most comfortable.
- Be flexible with students and families who are disengaged from mainstream services.
- Invest time and effort to identify what motivates students and families.
- Understand the stages of change in regard to the student and families' goals.
- Build and maintain relationships with students and families to support communication, clarity, and participation.
- Be aware of family dynamics in order to refer to the most appropriate agencies/services.
- Address barriers to specific student and family goals with those I work with.
- Keeping an open and non-judgmental mind in relation to students and families negative reactions.
- Provide services and supports in a culturally and linguistically accessible way.
- Be aware of the range of cultural norms dealing with students and families from varying cultures.
- The broader environment or physical context's impact on students and families.
- The family dynamic and its impact on a student.
- Be aware of the impact of disability on family and caregivers.

Professional Qualities and Attributes

Practices, policies and procedures to promote quality and integrity of case management services, ethical parameters, practitioner skills, and boundaries to ensure practitioner work/life balance.

- Provide flexibility in the times and locations for meeting with students and families.
- Remember that the case manager/family coach is likely not a student's or family member's first priority.
- Maintain a neutral view while still being sensitive to needs.
- Be creative in interacting and communicating with students and families.
- Know when to step back and allow families to own their responsibilities.
- Be cognizant that people will disagree with my opinions and accept that they have a differing view.
- Maintain student and family confidentiality.
- Manage my own stress.
- Understand the relationship of Maslow's Hierarchy of Needs to crisis management.
- Follow through on commitments made.
- Know how to multi-task.
- Understand the limits and boundaries of case manager/family coach services and supports when working with students and families.
- Know how to exercise patience and ongoing tenacity
- Be proactive in dealing with crises and issues that arise that could pose obstacles to effective outcomes.
- Be able to think outside of the box, be creative.

Information Management and Structure

Practices, policies and procedures that relate to timely and effective delivery and documentation of case management-related services and support, and the structures and attributes of case management.

- Allow time in the work day to complete all required and requested activities in role as case manager/family coach.
- Be able to complete everything that is required for centralized data reporting.
- Be organized and timely in completing required reporting.
- Practice proactive case management.
- Document interactions with students and families through effective case noting.
- Obtain appropriate release of information.
- Be supported by administrators.
- Ensure access to a centralized management information system to support effective case reporting.

Provider Engagement

Practices, policies and procedures that facilitate involvement and collaboration with service providers as transition stakeholders, including articulation agreements regarding communication, roles and functions that support access to services and student and family achievement of goals, objectives, and adult outcomes.

- Communicate openly and frequently with provider agencies.
- Be aware of the communication of community providers with students and families.
- Build connection with service providers to ensure timely response to student and family needs.
- Maintain fluid and consistent relationships with providers so that we are on the same page and the support for one another is obvious to the student and families.
- Build and maintain a network of community providers to work with to meet student and family goals.
- Have open communication with fellow case managers/family coaches.
- Communicate through expressing and listening with service providers and parent centers regarding the needs and priorities of families.
- Be aware of the details of what case managers/family coaches are working on with the students and families.
- Obtain individual service plans to help with the referral process.

Interagency Collaboration

Practices, policies and procedures that facilitate involvement and collaboration with community organizations and systems, including articulation agreements regarding communication, roles and functions that support information and referral, student and family achievement, as well as system improvements.

- Use a guide to local area social services for information and referral.
- Have access to community based providers that can address housing, medical, legal, academic, vocational, or transition needs so that families can receive this information expeditiously.

- Provide information and referral to families through the appropriate channels.
- Emphasize the partnership between case managers/family coaches and parents as allies to support their child.
- Understand referral requirements and processes for each state agencies services and support.
- Be familiar with the agencies to which students and families are referred.
- Understand and integrate with the special education transition planning requirements.
- Integrate services and supports across the school and other service providers.
- Seek out additional formal and informal learning on how to engage students and families in productive and efficient case management practices.
- Understand case manager/family coach roles and responsibilities in the broader context of services and supports that a student or family may be receiving.

Resource Navigation

Practices, policies and procedures that support the student and family in maneuvering various public and private entitlements, benefits and programs to support greater economic, employment and education outlook.

- Know more about the state workforce development services and programs.
- Understand Medicaid and other state health care options.
- Understand how means-tested benefits are impacted by earnings.
- Know more about the various diploma options available to our students.
- Understand the portfolio of benefits and entitlements a student and family receive to better understand the impact of earnings and income on monthly budgets.
- Inform students and families with details about services they may be unaware of.
- Counseling.
- Receive specific coaching on how state disability agencies may benefit students and families.
- Help students and families navigate unfavorable disability benefit determinations and the appeals process.
- Support students and families in applying for the Medicaid Buy-In Program for Working People with Disabilities.
- Apply knowledge of the stages of adolescent development to appropriate and necessary services and reports
- Help students and families navigate the continuing disability review and redetermination processes.
- Access and utilize translation services as needed.

Consumers of NYS PROMISE Case Management

The primary consumers of case management services under the NYS PROMISE are transition-age youth who receive SSI, and their families. However, NYS PROMISE case managers and family coaches coordinate and interact with a diverse array of stakeholders. These include, but are not limited to:

- Extended family members of the primary youth
- Private community service providers the youth and/or family member may be involved with
- School personnel, including transition planning personnel
- Local, county, state and/or federal agency personnel
- Legal/judicial system representatives
- Immigration and naturalization representatives
- Others

Many of these stakeholders could also be considered consumers, depending on their interaction with the case manager / family coach. For example, a case management practitioner in their attempts to integrate goals, objectives and activities into the youth's IEP may need to provide essential information to the designated school representative. At the same time, a case management practitioner may also be interacting on behalf of the youth and/or their family in an appeal with the Social Security Administration. Most critical regardless of the stakeholder is the case management practitioner keeping their focus and priority on the needs and preferences of the youth and/or their family member they may be representing.

A Week in the Life of a Case Manager

Heather, a full-time Family Coach from the Capital Region, provided the following description of her typical weekly activities:

The first hour of each day for me is generally the same. I start most days browsing local agencies' Facebook pages for new resources for our families. I take about 30 minutes to find items of importance that range from free/low cost events, free/low cost programs, to job fairs or job listings. I then share them on our Facebook page as a resource for the families and the staff working in the program. I also use this time to get organized for my meetings that day and get together any information I may need to provide at meetings.

I have a notepad on my desk that has the days of the week listed on it, and that is where I write down specific tasks I need to accomplish each day. This is how I prioritize the items I need to get accomplished.

I work very closely with my Case Managers and we share Google Calendars so we can schedule meetings together for each other. We have divided the phone calls so that each person isn't calling everyone. I call to schedule bi-annual Case Management meetings with the Control Group, and my Case Managers call to schedule Quarterly Case Management meetings. We usually schedule the meetings in the families' homes, but sometimes we meet at school, or in the community. I call/email all of the Control families the first week of each month. I always make sure to update NYESS (and the RTA as necessary) as I go, so that the Case Managers have access to any changes and can see my activities if necessary. If phone numbers don't work, I immediately email my CMs to see if there is an updated phone number available in the school database. If there is, I update the record and make a call. If there isn't, I then mail a letter explaining that we need to meet. During these phone calls, I often reach parents/caregivers that want me to call back (this is where my weekly notepad comes in handy).

Case Managers get the Committee on Special Education (CSE) meeting schedules and put them on my calendar for the Intervention group. Sometimes we divide up the meetings by priority, because meetings can happen on the same day and/or same time.

Parents will invite me to attend Family Court Hearings, MSC Meetings, and CPS Meetings, but I may have one of those meetings each week.

Aletha, a full-time family coach from the Buffalo area, provided the following description of her typical weekly activities:

I allow my clients to form my schedule and leave it open for them to fill in. Some weeks I am not in the office at all because I am out at court and other places, and then I might have two days in a row when I am in the office reporting in NYESS. I found in the past when I gave families a specific window of availability, it was difficult for them to make themselves available. Instead, I try to make myself as accessible to families as possible, and then arrange my other responsibilities for the week around those

meetings. This means that at times, I work on weekends, because it is the only time that some of the families are available. When I work during these untraditional hours, I have an arrangement with my boss that allow me to take flex time off during the following week to make up for it. On Monday mornings, I attend a weekly staff meeting to discuss my case load with my supervisor and other staff. Throughout the week, whenever I have open blocks of time in my schedule, I log onto NYESS to record the work that I am doing in the field.

I find that I spend a great deal of time in court hearings with families. This includes housing court related to evictions and other housing issues, drug court, criminal court, and family court. Within the family court, for example, I have been providing support to a mother who is trying to regain custody of her children. I have been surprised to find that about 75% of my job has nothing to do with helping the kids find work. Instead, I am spending my time assisting families with many other issues such as housing, benefits, and various forms of family crisis. I feel very strongly about advocating for families as they navigate various systems within the community, because many families feel so overwhelmed and alone that they "shut down." I try to be there to help make that process a little bit less stressful for them.

Amelia, a full-time Case Manager from the Capital Region, provided the following description of her typical weekly activities:

Each week as a Case Manager is a bit different and it's one of the first things you need to embrace. Likewise, having three different schools to work at, I move offices each day. I have scheduled which days I go to which school and try to stick to it as much as possible. Scheduling this helps me to see students at that specific school when I'm already there, so that I can schedule to see students at other schools at other times. Many of our students attend alternative schools, where I don't have an office, and so I have to schedule times to meet with those students with their teachers or at home.

As a Case Manager I keep spreadsheets and notes of who has had their quarterly meetings from the intervention group and what we discussed the last time we met. Meanwhile, my Parent Network counterpart checks in on and schedules meetings with the control group. We found this to be particularly helpful as the intervention group needs to meet more frequently, and, as a result, requires more attention to their specific needs. Likewise, as PROMISE continues each year, our intervention families have opened up and now ask us to help with more things besides just the PROMISE services offered to them. Some of these other issues they ask for help with can range anywhere from help with transportation to help understanding where their child stands within the Juvenile Justice system. As a result, my weeks tend to vary considerably.

In a standard month, I will meet with the providers my students work with at least once. This meeting serves two purposes; first, I check in on what is being done, how the student is progressing, and what next steps may need to be taken, and second, I listen to the provider to understand any issues they are having working with the student, which I will then try to assist them with. Following my provider meetings, I attempt to correct any issues that may be taking place in the relationship between provider and student/family. As communication can be a huge barrier in providing services, I frequently contact parents to remind them that the provider is trying to contact them or will ask if they've spoken with the

provider recently. Often, this quick communication allows for the provider to get the contact they need to provide services.

The week of the 11th each month, I will receive an email from my providers telling me who they billed for and if the billing form is uploaded in Filenet. From there, I download and print the billing form, look it over, and then begin approving the billing. Following this, I will put all of the new forms in my binders for each student. Any questions I have I will email back to the provider to find out the answer before approving billing.

In terms of scheduling case management meetings, because the intervention group requires much more, I keep a spreadsheet of who has had meetings last quarter and who needs a meeting shortly. I typically look at my spreadsheet early in the month, so I can begin calling or emailing those families. Each family is a little different when scheduling meetings. Most families tend to want to meet at home, but others prefer school or another public location. Many of our parents receive their schedule for work the week of and, as a result, it becomes exceedingly difficult to plan meetings a week or two ahead of time, so I will schedule meetings for the following day or two days out. Therefore, our Google calendar is essential for us to make as many meetings happen as possible. After I schedule a meeting, if it's at school or public location, I contact the person who is in charge of reserving rooms and reserve a room. Often, I will let that school's transition department know, in case they want to meet with the student or parent. This goes both ways, as when I may need to speak with a student or parent and haven't been able to reach them, the transition department will let me know they're planning on seeing a student in PROMISE.

Similarly, when scheduling case management meetings, I speak with parents and they occasionally inform me of CSE meetings coming that they want me to go to, or want some information on how to advocate for something, which I then schedule in to meet. Every spring we are busy with CSE meetings, which I generally find out about from parents or from a notification on *IEP Direct* that alerts me that a student will be having a meeting. At one of the schools, I receive an email with a list of all the scheduled CSE meetings for the months of February, March, April, and May. I list these all on my Google calendar, which I then share with my Parent Network colleague, so she can attend the intervention group CSE meetings with me. Similarly, I like to try and check in with the student about how they feel they are doing with school, any PROMISE services, and anything they may want to talk about before the CSE meeting, so that it gets stated during the meeting.

Ultimately, I am rarely able to schedule my activities a week in advance, except for a couple of meetings here and there, a training, or court (when it's applicable). I keep a notebook that lists the days of the week, includes sticky notes, and a place where I keep business cards to give out. I use that as my main source of organization for what tasks need to be accomplished for the week, as the week may change at any time. Likewise, many days I will be informed, or find out myself, that a number is no longer working, or the student has moved and write it in my notebook. From there, I will look up if the student has a new number and if not, I contact the person at the school closest with them (as occasionally, the front offices don't have up-to-date information) to see if they have a new number. Also, when I see that a

family hasn't met with us in a while and I have continued contacting them, I will send them a letter stating they can still receive services if they'd like to and to try and contact us when they can in order to re-start the service. I tend to do this at the end of the quarter, so I can then record in NYESS whether we have new information or not.

Module 1: Resources

Sample NYS PROMISE Case Manager Position Description

Job Title: NYS PROMISE Case Manager

Position Summary:

The NYS PROMISE case manager is assigned to work within [insert school or department]. The purpose of the case manager is to act as a coordinator for the planning and referrals for services for youth served under NYS PROMISE and their families. Successful case managers will meet with their students and families on a quarterly basis in person and by phone to create an individualized service plan, monitor service referrals, evaluate service goals and outcomes, and plan for additional services and activities designed to support successful living/earning/learning outcomes for youth/families during the youth's transition to adulthood.

Duties include but are not limited to:

- Provide case management services and supports for students and families. Make home or in-school case management visits to youth and families, facilitating case management service coordination.
- Utilize the New York Employment Support System (NYESS) to initiate and monitor service referrals, update case management records, and authorize payment to service providers on an on-going basis.
- Utilize database applications as required to obtain, manage, and maintain documentation and effective case-notes and track case management efforts
- Organize mailings and make outreach phone calls to youth and families, local service providers, government agencies, non-profits and school administration
- Plan, facilitate and attend informational meetings and public events for youth and families
- Work with local community service providers and agencies to build partnerships that benefit youth and families
- Participate in all required professional development. In-state travel is required (2-4 days per year).
- Maintain youth/family confidentiality and comply with data security and HIPPA requirements, obtain appropriate release of information.
- Must be able to obtain New York State fingerprinting and criminal background check and Social Security Administration Security Clearance
- Flexible schedule that may include evenings and weekends, meetings at schools, public places, or in student/family homes.

Required Qualifications:

- Bachelor's degree in education, behavioral, social, health or mental health, public health/administration, family or youth counseling, social work

- Minimum one year experience conducting case management-related activities
- Strong communication, interpersonal and writing skills
- Highly organized, detail oriented multi-tasker with demonstrated experience working as a highly effective member of a diverse team
- Good attendance and punctuality

Preferred Qualifications:

- Three to five years of experience in transition planning for youth with disabilities or appropriate field and/or an equivalent combination of education and experience
- One to three years of experience providing benefits and work incentives planning and assistance
- Experience with self-determination and person-centered planning.
- One to three years of experience with federal regulations and guidelines related to the delivery of educational, transition, employment, and/or disability benefits services (to include but not limited to Supplemental Security Income (SSI), Medicaid and state health care options
- One to three years of experience in special education (Special education Certified) vocational rehabilitation, employment, transition and/or disability benefits field and working within the context of federally funded projects
- Knowledge of NYS diploma options
- Established network and knowledge of local community service providers and/or non-profit agencies

Preferred Characteristics:

- Demonstrated excellence in follow-through and tenacity with hard-to-reach populations
- Demonstrated ability to maintain neutrality, patience, and non-judgmental attitude in sensitive and stressful situations
- Pro-active and creative individual with the ability to think outside the box

Module 2: Service Delivery

Introduction

This module outlines core outcomes-based services and other supports available to NYS PROMISE intervention youth and families—inclusive of outcomes and quality standards by service. This includes services and supports in the focus areas of economic independence and advocacy, supported post-secondary education, pre-employment, work-based learning, employment, and coaching supports. An online resource for connecting students and families to other state-based programs and resources based on their unique needs is provided. This module provides the case management practitioner a clear set of services and supports that are available to support both students and their families in achieving their desired economic, employment and educational aspirations.

Pathway to Adult Success for Youth with SSI

The NYS PROMISE is based on a nationally-informed, systems-focused, and locally-based model of partnership—recognizing that partnerships and activities in the transition planning process are mirrored at the systems, organization, and individual level.

The NYS PROMISE approach for achieving higher postsecondary employment, educational and economic outcomes for youth ages 14-16 who receive SSI includes:

(a) Improving state, regional and local collaboration across SSI youth serving agencies and providers;
(b) Implementing outcomes-based payment systems for provider services;
(c) Building local and regional capacities in implementing best practices, conducting impact assessment and continuous quality improvement in transition to adulthood services for SSI youth; and
(d) Collecting high-quality evidence for studying impact of interagency collaboration, coordinated service delivery systems, participation in transition program activities, family and youth engagement in transition planning and training and technical assistance on postsecondary outcomes for SSI youth.

The intervention is being implemented across three diverse geographic areas (western NY, the capital region, and New York City). This intervention incorporates research-based practices such as:

- Age-appropriate transition skills assessment and career development activities
- Preparation for community living, including independent living skills, financial literacy and assistive technology training
- Work-based learning and paid employment
- Supported postsecondary education
- Individualized planning with students and their families including skills enhancement for families on transition planning, increasing expectations, student engagement, benefits, work incentive

and asset accumulation planning and assistance, youth and parent development through person-centered planning and citizen-centered leadership development

NYS PROMISE Intervention Services

The NYS PROMISE intervention has been designed to include a set of activities (collectively called the "intervention"), with the goal of generating educational, employment and financial outcomes for youth who receive SSI, and their families. It is important that these program activities are applied in a consistent way across all three NYS PROMISE regions, so that it is possible to determine whether or not the services the project provided to youth and families had an impact on outcomes.

There are three major categories of NYS PROMISE services:

- Case management and service coordination (provided by Research Demonstration Site [RDS] Case Managers)
- Parent support, including training and family coaching (provided by Parents Centers)
- Outcomes-based intervention services (provided by service provider organizations)

The following section briefly describes these three areas and then provides a detailed list of the possible services available through NYS PROMISE for each area.

Case Management and Service Coordination

For transitioning youth, emphasis on post-school planning is highly important.[1] Case management helps to ensure service continuity, which minimizes disruptions in therapeutic, educational and vocational services.[2] The goal of NYS PROMISE case management is to ensure that services provided to intervention group youth and their families are planned and executed in a timely, developmentally appropriate, and person-centered manner. It is expected that providers of those services communicate and share information across local transition stakeholders. Case management for youth receiving SSI can address many complex and interrelated issues, including: health, education, employment, benefits, and family issues.

Parent Training and Family Coaching

Parent/family information, participation, and coaching are key components of the NYS PROMISE intervention strategy. Research has identified inadequate family participation as one of the "five national challenges facing secondary education and transition services" for youth with disabilities.[3]

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[1]Levinson, E.M., & Palmer, E.J. (2005). P*reparing students with disabilities for school-to-work transition and post-school life*. National Association of School Psychologists.

[2] Blackorby, J., & Wagner, M. (1996). Longitudinal post-school outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*(5), 399-413.

[3] Johnson, D., Stodden, R., Emanuel, E., Luecking, R., & Mack, M. (2002). Current challenges facing secondary education and transition services: What research tells us. *Exceptional Children,* 68(4).

Effective transition planning depends not only on linking schools, vocational rehabilitation (VR) agencies and human service and community agencies, but also on overcoming a "lack of shared knowledge and vision" by youth, parents, and staff about post-school goals and resource needs.[1] The goals of NYS PROMISE include working with parents and families to engage them in planning for their child, as well as to enable the parents and families to gain knowledge, skills and abilities applicable to their own lives and continued development.

Outcomes-Based Intervention Services

Finally, NYS PROMISE has been structured to include a wide range of youth- and parent-focused intervention services. These services include support around education, finances and benefits, and work preparation and participation. These services were designed in alignment with research suggesting their potential to improve youth post-school outcomes related to employment, education and earnings. In addition, these services employ an outcomes-based payment scheme, in which service providers only receive payment for services once youth have achieved specified objectives. Research also suggests this sort of payment approach improves youth outcomes over the use of a fee-for-service payment structure.

State and Regional Disability Services Locator

To aid case management practitioners in providing additional information and referral based on student and family need, the NYS PROMISE has modified the Disability Services Locator originally developed under New York State's Comprehensive Employment Systems Grant – NY Makes Work Pay. The disability services portal was developed to ensure that any person with a disability can quickly and easily identify services and other supports in New York State that might support them in moving toward a better economic, education or employment outcome. The service calculator does not determine eligibility but will generate a report of various state agencies that may be able to provide services and supports to assist an individual with a disability in meeting their needs.

To use the online portal, go to http://paths.nyspromise.org\locator OR http://www.nymakesworkpay.org/rny-services.cfm.

The calculator takes less than 3 minutes and will automatically generate a report of agencies and organizations to consider, along with contact information for follow-up.

Family Coaching and Support

Each family enrolled in NYS PROMISE is assigned a family coach at a Regional Parent Training Center. The primary responsibilities of the Family Coach include:

1. Providing 1:1 family coaching to individual families

[1] Johnson, 2004.

2. Providing parent training on topics related to work and transition
3. Referring families to NYS PROMISE providers for Benefits and Work Incentives (BWI) and Financial Literacy Training (FLT)
4. Connecting families to community resources

Family coaching is a flexible service that allows family coaches to meet with parents (by phone or in person) to provide support and information related to benefits and entitlements, education and achievement, employment, finances, healthcare, housing, and transition planning. Most coaching is conducted with individual families, but it can also be provided in groups. Coaching activities often include:

- Providing assistance with filling out paperwork
- Preparing for transition planning meetings
- Accompanying parents to meetings
- Group mentoring/networking
- Assisting parents with decision-making.

Regional Parent Training Centers deliver training to families in small groups or in a one-on-one setting. Training topics utilize a standard curricula, and core topics include:

1. **The *Power of Know* (Effective Advocacy)**. Being an advocate doesn't mean you have to write big checks or cozy up to politicians. This training will help parents to better understand their youth's disability, become their family's best advocate and use their voice to make a difference. Join the Parent Center and share your story and experiences with other NYS PROMISE families.
2. ***Life Has Choices* (Transition Planning)**. There are many possibilities for NYS PROMISE children as they transition to adulthood. This training will help parents identify their youth's preferences, strengths and options for the future, along with the key tools, resources and supports needed to assist them in the journey.
3. ***What's In It For Me?* (Self-Determination and Family Action Planning)**. What's in it for me isn't always about what parents will get - it is also about how parents will feel. This training will enable parents to reflect and assess the entire family's interests, needs and goals. Parents will also have an opportunity to develop an action plan to connect with community based resources. Come learn about the many values of this important program.
4. ***Destination Next* (Rights and Work Incentives)**. Understanding the special education process and transition planning can be a challenge. The right resources and supports can help make it a little easier. This training will allow parents to explore their youth's options for living, learning and earning. They will also learn what benefits the Social Security Administration offers, especially work incentives.

Regional Parent Training Centers are responsible for making all referrals for families that are interested in receiving Benefits and Work Incentives (BWI) and Financial Literacy Training (FLT). These services are delivered through NYS PROMISE-approved providers. In addition, the Regional Parent Training Centers can help the family to connect to resources within the community related to the following areas:

- Benefits and Entitlements
- Childcare
- Citizenship/Immigration
- Education and Achievement
- Employment
- Financial Literacy
- Food and Nutrition
- Guardianship
- Healthcare
- Housing
- Legal Services
- Mental Health
- Parenting
- Recreation
- Transportation
- Utilities
- Substance Use/Addiction

NYS PROMISE Service Rubrics

This section describes the specific NYS PROMISE interventions in detail with regard to:

- **Program Activities**. The set of activities that must take place in order to qualify as a NYS PROMISE service.
- **Outputs**. The deliverables that result from the provision of a NYS PROMISE service, this may include a report, evidence of youth/parent engagement and understanding or other products.
- **Quality Indicators**. Specific characteristics of the service delivered that act as indicators of the service quality.
- **Outcomes**. The immediate or longer-term goals to which the service is intended to contribute.

Some or all of the items outlined in each rubric will be measured or monitored as a part of the program monitoring and fidelity. At minimum, all Program Activities and Outputs are monitored via the New York Employment Services System (NYESS).

NYS PROMISE Services: Definitions

Case Management: a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet a participant's needs. It is characterized by advocacy, communication, and resource management that are person-centered, developmentally

appropriate, timely, and responsive to individual needs leading to improved educational, employment and economic outcomes.

Parent Training, Information and Referral Services: services that support the involvement of parents in transition activities, providing them with information, resources and technical assistance to support development and attainment of financial, educational, and employment goals for themselves and their children.

Community Based Workplace Assessment (CBWA): an individualized strategy for assessment activities leading to a balanced, capacity-based, vocational profile—that must include development of work or community evaluation sites according to the interests and known employment factors of the student. This must also include selected observations of the person in other integrated community situations (e.g. school, home, etc.), as well as interviews with significant others who may know the person well, to aid in gaining a comprehensive, person-centered assessment of the individual's strengths, capabilities, needs, skills, and experiences. This assessment will give the student hands-on experience in an actual work or community site(s) allowing for direct observation by the evaluator.

Career Planning and Preparation (CPP): a set of activities that lead to the acquisition of specific soft skills by an individual. These services can be conducted individually or in a small group settings, resulting in an actionable career development plan for pursuing education and work opportunities leading to career-oriented employment.

Community Unpaid Training Experience (CUTE): an experience designed to provide a student with an employer-based (unpaid) training opportunity in accordance with restrictions imposed by the Fair Labor Standards Act. The vendor will provide job development services consistent with the student's interest and local labor opportunities, and will be responsible for setting up the work experience, monitoring and supporting the student, and making arrangements for required paperwork with the employer.

Sponsored Community Work Experience (SCWE): a set of individualized activities consistent with the student's career goals and locally available employment. This service will take place in integrated community-based work settings, and provide the student a paid internship, reimbursing the vendor at minimum wage, and not the prevailing wage if different, plus an administrative cost for payroll issues for up to 160 hours of paid work experience. This is a wage reimbursement mechanism when an employer is unable or unwilling to put the student on payroll. The vendor is responsible for withholding federal, state and local taxes—including FICA.

Job Development and Paid Work Experience (JDV+PWE): a set of individualized activities consistent with the student's career goals and locally available employment. This service will take place in integrated community-based work settings, and equip the student for entry level work in the student's field of interest. This service must include job development and involve the student learning the essential functions of the job to meet employer expectations.

Benefits, Work Incentives, and Asset Development Planning and Assistance (BWI): a service that allows youth to make informed choices concerning the range of public entitlements and benefits they receive or that are available to them, including the work incentives available to them as they participate in education, training and employment.

Financial Literacy Training (FLT): supports greater economic self-sufficiency and asset development. These services will lead to youth and their family members making better-informed decisions about their financial futures, and taking action to ensure greater economic self-sufficiency and financial well-being.

Coaching Supports (CS:) interventions that can be used with Community Unpaid Training Experience or Sponsored Community Training Experience as well as Job Development and Paid Work Experience to provide the individual student assistance and support on or off-the-job in activities on a short-term or long-term basis that are employment-related and needed to promote job development, adjustment and retention. Services duration will be determined by the RDS and provider depending upon the individual Youth' Individualized Education Plan.[1]

Supported Education (SEd): a set of individualized activities and supports consistent with the student's post-secondary educational goals. This service will take place in community –based settings and will assist the student in making informed educational choices regarding postsecondary education, navigating preparation for the post-secondary school environment and accessing additional information and resources.

[1] Coaching supports are an accompanying service provided based on student needs and to support the outcomes of one of the following prescribed services: Community Work Experience, Sponsored Community Training Experience as well as Job Development and Paid Work Experience.

Module 2: Resources

Service Rubrics: Case Management

Definition: Case management is a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet a participant's needs. It is characterized by advocacy, communication, and resource management that are person-centered, developmentally appropriate, timely and responsive to individual needs leading to improved educational, employment and economic outcomes.

Program Activities	Outputs (Deliverables)	Service Quality Indicators	Outcomes
Research Management (Intervention & Control Groups) • Access and collect student information on a quarterly basis for C/I groups in NYESS • Notify Cornell and PCs of youth who are relocating, communicate with new school to assist in transition • Interface with Cornell about: outreach and recruitment, case management, data entry, and service coordination • Collaborate with Parent Centers to identify potential dropouts and provide timely intervention to reduce participant dropout ***Case Management (Intervention Group)*** • Access student IEP information and participate in regular student IEP/planning meetings • Discuss youth service needs with youth, family, and other community stakeholders • Integrate short-term and long-term strategies for service delivery based	***Case Management (Intervention Group)*** • Measurable post-secondary goals are included in the IEP ○ Goals are clearly reflected in the IEP • Coordinated set of NYS PROMISE- and non-NYS PROMISE-sponsored activities are included in IEP ○ Activities are clearly outlined in the IEP • Developmentally appropriate and well-coordinated transition planning and services are provided to youth and family ○ As evidenced through IEP progress reports, and regular updates to the NYESS ***Partnership*** • Evidence of increased collaboration of RDS with service providers ○ Referrals for services initiated in a timely manner and tracked to verify student progress	• Youth are linked to NYS PROMISE interventions within one month of their assignment to intervention group ○ Documentation of case management and/or other NYS PROMISE intervention services within NYESS • Alignment of services provided and those in the student IEP ○ IEP incorporates specific NYS PROMISE intervention services youth are referred for through NYESS • Services are individualized, timely and meet the needs of youth and family ○ Software-based IEPs integrate customized goals, objectives and activities ○ Services articulated in the IEP flow from student performance levels and statements of need ○ Evidence of student/family satisfaction with case management services	• Timely and appropriate referral of youth for needed services • Youth and family participate in service coordination and service receipt • Youth are retained in school and in NYS PROMISE • Increased youth/family knowledge of resources and services available and how to access them • Increased understanding of the benefits of staying in school • Increased levels of empowerment and self-determination in youth and family • Youth/families have positive attitudes towards work and reduced perception of dependency on public welfare system • Youth and families are satisfied with case management and service coordination

Program Activities	Outputs (Deliverables)	Service Quality Indicators	Outcomes
on NYS PROMISE-sponsored and transition counterfactuals in the IEP • Early identification/integration of youth for return to school/drop-out reduction • Refer, monitor and verify services through NYESS to initiate outcomes-based payments • Coach youth and families on documentation requirements for accessing counterfactual services (e.g., VR, etc… • Conduct a minimum of quarterly check-ins with student and families to ensure their full engagement in services as well as seek information on their satisfaction with services received • Provide participants and families with information and technical assistance • Be available for troubleshooting for youth and families for services • Follow up with provider about services ***Partnership*** • Attend regional quarterly case management support meetings with Cornell (to reflect on quarterly data, formative evaluation reports and discuss any problems) • Participate in NYS PROMISE community teams meetings as convened regionally	• Documentation of regular meetings consisting of various transition stakeholders including both NYS PROMISE and counterfactual personnel ○ Timely approval for payment of services provided under the outcomes-based payment systems	• Case management is culturally sensitive, and is informed by youth and family choices, and their full participation ○ Evidence of student and family participation in planning events • Case manager develops respectful relationships with youth and families. ○ Communication with youth and families is clear and timely ○ Documentation in NYESS of families reaching out to case manager for support • Case management is responsive, accessible and proactive ○ Case noting and documentation in NYESS of family interactions	

Service Rubric: Parent Training, Coaching, Information and Referral Services

Definition: Parent Training, Coaching, Information and Referral Services will support the involvement of parents in transition activities—providing them with information, resources and technical assistance to support development and attainment of financial, educational, and employment goals for themselves, and their child.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Develop and Conduct Trainings
• Effective advocacy: The power of know
• Transition: life has choices
• What's in it for me?
• Destination next (work readiness & incentives)
 	
Family Coaching: Initiate family-focused technical assistance to the research participants
• Provide basic information on benefits, public entitlements and eligibility, etc…
• Assist people in filling out paperwork
• Accompany people to key meetings with agencies, as needed
 	
Train RDS staff and participating agencies in effective family collaboration
• Develop and deliver an interactive module on family engagement and collaboration for the required provider orientations and/or learning communities
• Consultation provided to local/regional participants (RDS and providers) individually or in team meetings and case conferences. Consultation may be in person or by phone
	Develop and Conduct Trainings
	• Training Curriculum including learning objectives and modules
	• Participant evaluation tools and quarterly reports
	• Marketing and recruitment for workshops
	• Training on participant tracking in NYESS
	
	Family Coaching
	• Intervention manual[1] on approved practices for family coaching including content materials
	• Plan for outreach and implementation of coaching
	• Reporting on family coaching in NYESS
	• Quarterly summary report of activities
	Train RDS staff and participating agencies
	• Training curriculum designed and vetted
	• Planning and delivery of training to stakeholders
	• Pre-/post- evaluation of participants with quarterly summative reports
	• TA and training information entered into NYESS and Cornell OTAT
		• Services are comprehensive, customized and targeted, goal-oriented, informed by individual planning and case management
		  ○ Family service plans are documented in NYESS
		• Logical progression in services with an outcomes focus
		  ○ Family service plans are updated on a quarterly basis
		• Trainings focus on skill development and empowerment
		  ○ Program evaluations are conducted to ascertain level of knowledge acquisition
		• Training uses simple language
		  ○ Reading does not exceed 6-7th grade language level
		• Provide reasonable accommodations to customize the content to individuals' needs based on their disabilities
		  ○ Possible documentation of needed accommodations could be included in student's IEP or 504 Plan
			• Increased knowledge of choices and opportunities, their/young person's strengths
			• Improved advocacy skills (versus adversarial)
			• Increased knowledge of rights
			• Increased outcomes-orientation toward transition planning
			• Increased expectations of youth postsecondary success in employment and education
			• Increased understanding of processes in education and adult serving agencies, their role within process (including advocacy)
			• Increased understanding of benefits and work incentives
			• Increased sense of competency in being able to advocate, participate

[1] Family Coaching Intervention Manual will guide and ensure consistent delivery of this service across the three Parent Centers.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Help families participate effectively in transition IEP meetings
• Small-group facilitated (up to 12 participants) practice sessions with materials focusing on key transition issues and building parent confidence
• Individual prep sessions for IEP meetings with transition focus
 	
Information and referral to support families on career development, employment, education, and financial literacy
• I&R includes making connections and following up to be sure that connections are made
• Use NYS PROMISE Community Teams to build out I&R Network
• Financial Literacy referral through NYESS
 	
Facilitate Group Mentoring/Networking with NYS PROMISE Families
• Topic or issue-specific small group meetings to share information, strategies, and build connections and relationships. May include guest presenters or speakers, especially members of the NYS PROMISE Community Team (see above)
• Meeting in convenient location for participants
• Frequency TBD according to demand
• Develop mentors and champions from among NYS PROMISE families to support other families
	• PCs attend RDS meetings
	
	Help families participate effectively in transition IEP meetings
	• Help session structure and materials delivered to Cornell and included in Coaching Intervention Manual
	• Planning calendar for group sessions
	• Groups conducted and reported in NYESS
	• Meetings held with parents before IEP meetings
	• Meetings held with parent after IEP meeting
	
	Information and referral to support families on career development, employment, education, and financial literacy
	• Regional resource directory on services and information on providers for employment, education, and financial literacy services developed and available.
	• NYESS parent tracking for I&R for families
	Facilitate Group Mentoring/Networking with NYS PROMISE Families.
	• Team members identified and roles and responsibility developed for group mentoring
	• Archived meeting minutes
	• Topical discussions meetings organized quarterly
		• Privacy and confidentiality are maintained
		  ○ Classroom protocol for maintaining confidentiality of student personal and financial information
		  ○ Security protocol form archiving student information and files
		• Flexible service availability
		  ○ Coursework offered at various times based on learner preference including evenings, weekends, group, one-on-one
			• Increased access to employability/job-related services
			• Increased family goal attainment

Service Rubric: Outcomes-Based Intervention Services

Community Based Workplace Assessment (CBWA)

Definition: an individualized strategy for assessment activities leading to a balanced capacity-based vocational profile—that must include development of work or community evaluation sites according to the interests and known employment factors of the student. This must also include selected observations of the person in other integrated community situations (e.g. school, home, etc…), as well as interviews with significant others who may know the person well, to aid in gaining a comprehensive, person-centered assessment of the individual's strengths, capabilities, needs, skills, and experiences. This assessment will give the student hands-on experience in an actual work or community site(s) allowing for direct observation by the evaluator.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes
Must include the following: • **360 Assessment** • **Life and Social Skill Observation** • **Work or Community Site Development** • **Work Skill Observation** Could include: • **Discovery/Engagement**	**1. Vocational Assessment Profile Report containing:** • Purpose and proposed employment goals • Skills, attributes and capacities • Interests and preferences • Priorities, values and ideals • Travel and mobility skills • Supports needed • Networks and resources (including natural supports and community connections) • An action plan to be incorporated into the IEP for further movement toward full employment	• Assessment report includes qualitative interviews and inputs from the worksite employers, youth, family and school teacher or guidance counselor to assess functional capacities and interests and preferences ○ Documentation of input including person, date, and information solicited • Observations of the youth are conducted across multiple integrated work settings based on student interest and need ○ Documentation regarding work sites, dates, and number of hours of observation • Group planning session to review above report, summarize findings and discuss next steps ○ Inclusive of the student, their family, the evaluator, school personnel, the	• Actionable employment goals are identified • Personal attributes, capacities, skills, interests and preferences are identified to enable person-centered planning and strength-based approach in transition planning • A plan for employment, work-related skills training, mobility, and travel supports are included in the IEP

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes
	• Specific guidance to aid the student, their family, educators, and other providers in mapping a road to work. • Recommendations for potential reasonable accommodations in the workplace based on job interests of the student and their needs for support **2. Group planning session to review above report and discuss next steps:** • Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders	provider, and other stakeholders • FLSA compliance ○ No more than 90 hours of unpaid assessment per employer, per student ○ Meet criteria as listed at http://www.dol.gov/whd/FOH/ch64/64c08.htm	

Career Planning and Preparation (CPP)

Definition: A set of activities that lead to the acquisition of specific soft skills by an individual. These services can be conducted individually or in a small group settings resulting in an actionable career development plan for pursuing education and work opportunities leading to career-oriented employment.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Based on student need, this must include instruction regarding:
 	
• **Advocacy:**
• **Community Mobility Training**
• **Disability Self-Awareness**
• **Health Management**
• **Identification of Motivators**
• **Job Interview Practice**
• **Resume Writing**
• **Work and Social Conduct**
• **Work-Related Daily Living Skills**
 	
Could include:
 	
• **Business Tours**
• **Discovery/Engagement**
• **Screening Assessment**
	1. Final services report, to include:
	
	• Type of services provided
	  ○ Checklist of learning objectives
	  ○ Description of actual services rendered/curriculum used
	• Summary of the individual's progress in skills leading to improved employability
	  ○ Checklist of activities engaged in and skills acquired
	• Action Plan: Actionable goals and objectives for subsequent employment, educational and related-services for youth's progression towards employment goals. Self-determination and self-awareness assessment summary
	
	2. Group planning session to review above report and discuss next steps:
	
	  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
		• Youth demonstrates higher level of self-determination and self-awareness
		  ○ Student can define their desired employment aspirations, steps to get there, and needs for support
		  ○ Student can request reasonable accommodations needed
		• Youth demonstrates appropriate work and social conduct
		  ○ Documentation of appropriate behaviors and conduct
		• Youth understands workplace cultures and values relationships for seeking job opportunities, mentoring and career planning
		  ○ Student can articulate preferred aspects of desirable work cultures
		  ○ Student can articulate a plan for continued employment development
		• Youth demonstrates process of skills matching as a way to seek jobs leading to sustained engagement in work
		  ○ Student can identify jobs and career paths in sync with their capacities
		• Youth understands transportation options and is aware of community resources to access work
		  ○ Student is able to independently navigate to and from work
		• Youth understands the importance of wellness and healthy lifestyle
		  ○ Student can articulate strategies for maintaining work/life balance
		• Group planning session to review above report, summarize findings and discuss next steps
		  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
			• Youth is equipped with an actionable career development plan for pursuing education and work opportunities leading to career-oriented employment

Community Unpaid Training Experience (CUTE)

Definition: An experience designed to provide a student an employer-based (unpaid) training opportunity in accordance with restrictions imposed by the Fair Labor Standards Act. The vendor will provide job development services consistent with the student's interest and local labor opportunities, and will be responsible for setting up the work experience, monitoring and supporting the student, and making arrangements for required paperwork with the employer.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Must include the following:
 	
• **Monitoring**
• **Site Development**
• **Work Skill Observation**
 	
Could Include:
 	
• **Community Mobility Training**
• **Interview Support**
• **Screening Assessment**
 	
*This service can be used with Coaching Supports if collaboratively determined necessary by both the RDS and provider.
	1. Develop and place the student
	
	2. Prepare and submit a report indicating:
	
	• Type of services provided
	  ○ Dates, locations, hours, etc…
	• Summary of the student's training experience progress
	  ○ Inclusive of employer, supervisor, and job coach assessments
	• Action plan including additional skills training, education and work opportunities for supporting employment goals for the youth
	  ○ Specific goals and objectives for further inclusion in the IEP
	
	3. Group planning session to review above report and discuss next steps:
	
	Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
		• Unpaid training experience is based on student interests
		  ○ Past documentation in assessments and IEP regarding jobs of interest
		• Work experience in settings providing exposure to real-life work situations, in integrated competitive settings and in industry sectors leading to sustained full-time work (e.g., work in food services often leads to part-time work opportunities with lower pay)
		  ○ Documentation of employer location, employment hiring outlook, and range of job opportunities
		• Student progress is evident in the report
		  ○ Marked improvement in student performance is documented
		• Employer and youth voices included in shaping the report
		  ○ Assessment and evaluative data included in report
		• Youth and parent are satisfied with services
		  ○ Exit evaluation to gather perceptions and satisfaction of student with experience
		• FLSA compliance
		  ○ No more than 120 hours of unpaid experience per employer, per student
		  ○ Meet criteria as listed at: http://www.dol.gov/whd/FOH/ch64/64c08.htm
		• Group planning session to review above report, summarize findings and discuss next steps
		  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
			• The youth gains training experience in real-life work settings, exposure to the rewards and stresses of specific workplace contexts
			• Student can articulate next steps in career pursuits
			• Goals and objectives supporting youth next steps are articulated and integrated into the IEP

Sponsored Community Work Experience (SCWE)

Definition: A set of individualized activities consistent with the student's career goals and locally available employment. This service will take place in integrated community-based work settings, and provide the student a paid internship, reimbursing the vendor at minimum wage, and not the prevailing wage if different, plus an administrative cost for payroll issues for up to 160 hours of paid work experience. This is a wage reimbursement mechanism when an employer is unable or unwilling to put the student on payroll. The vendor is responsible for withholding federal, state and local taxes—including FICA.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Must include the following:
 	
• **Monitoring Site**
• **Development**
 	
*This service can be used with Coaching Supports if collaboratively determined necessary by both the RDS and provider.
	1. Student will have a sponsored internship experience for a maximum of 120 hours.
	
	2. Prepare and submit a report, including:
	
	• Copies of pay stubs for hours worked
	• Data relating to the experience of the individual
	• Documentation of the student's ability to meet the essential functions of the job and employer's expectations
	• Action plan including additional skills training, education and work opportunities for supporting employment goals for the youth
	
	3. Group planning session to review above report and discuss next steps:
	
	• Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
		• Sponsored work experience is based on student interests
		  ○ Past documentation in assessments and IEP regarding jobs of interest
		• Work experience in settings providing exposure to real-life work situations, in integrated competitive settings and in industry sectors leading to sustained full-time work (e.g., work in food services often leads to part-time work opportunities with lower pay)
		  ○ Documentation of employer location, employment hiring outlook, and range of job opportunities
		• Student progress is evident in the report
		  ○ Marked improvement in student performance is documented
		• Employer and youth voices included in shaping the report
		  ○ Assessment and evaluative data included in report
		• Youth and parent are satisfied with services
		  ○ Exit evaluation to gather perceptions and satisfaction of student with experience
		• Group planning session to review above report, summarize findings and discuss next steps
		  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
			• Youth has a real-life experience of work and understands rewards of work
			• Youth has a positive attitude towards work
			• Student can articulate next steps in career pursuits
			• Goals and objectives supporting youth next steps are articulated and written into the IEP

Job Development and Paid Work Experience (JDV+PWE)

Definition: A set of individualized activities consistent with the student's career goals and locally available employment. This service will take place in integrated community-based work settings, and equip the student for entry level work in the student's field of interest. This service must include job development and the student learning the essential functions of the job to meet employer expectations.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Must include the following:
 	
• **Job Development**
• **Work Site Monitoring**
 	
*This service can be used with Coaching Supports if collaboratively determined necessary by both the RDS and provider
	1. Student has real paid work experience at or above minimum wage for 60 calendar days with outcomes being documented at 5 days (Tier 1), 30 days (Tier 2), and 60 days (Tier 3)
	
	2. Prepare and submit a report to the designated school, to include:
	
	• Description of work
	  ○ At a minimum this should include role and responsibility, average number of hours worked per week, average hourly wages earned, types of workplace accommodations provided
	• Employer feedback and assessment
	  ○ Supervisor summary of performance report
	• Documentation of the student's ability to meet the essential functions of the job and employer expectations.
	  ○ Summary of student performance through job coach or supervisor observation
	
	3. Group planning session to review above report and discuss next steps:
	
	• Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
		• Full-time work in competitive setting at or above minimum wage
		  ○ Documentation of prevailing wage for job student placed in
		• Work should align with career goals and youth interests
		  ○ As evidenced by student's stated preferences in past assessments and the IEP
		• Workplace supervision and mentoring available/provided
		  ○ Documentation of supervisor mentor input and performance assessment
		• Workplace accommodations provided
		  ○ Summary of accommodation dialogue and output
		• Youth works in integrated settings providing opportunities of networking and building social capital
		• FLSA compliance
		  ○ Nonagricultural occupations youth employment provisions as specified in http://www.dol.gov/whd/regs/compliance/whdfs43.pdf
		  ○ Agricultural occupations child labor requirements as specified in http://www.dol.gov/whd/regs/compliance/childlabor102.pdf
		• Employer tax incentives completed
		  ○ Work Opportunity Tax Credit, Barrier Removal Tax Deduction, etc…
		• Group planning session to review above report, summarize findings and discuss next steps
		  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
			• Student has acquired work readiness skills associated with their specific career area of interest
			• Youth engages in paid work settings with feedback from supervisors/mentors
			• Youth develops a career path for securing meaningful work
			• Youth utilizes work-incentives to off-set wages earned
			• Overall increase in family's earnings
			• Youth identifies additional training or skills development needs and enrolls in post-secondary programs

Benefits, Work Incentives, and Asset Development Planning and Assistance (BWI)

Definition: A service that allows youth to make informed choices concerning the range of public entitlements and benefits they receive or that are available to them, including the work incentives available to them as they participate in education, training and employment.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Based on referral, must include:
 	
• **Comprehensive Benefits Analysis**
• **General Benefits Overview**
• **Work Incentives Plan**
 	
Could include:
 	
• **Asset Accumulation Plan**
• **Ongoing Benefits Coaching**
	1. Signed information releases with youth and their families to allow sharing of benefits information with the RDS
	
	• Must be a copy in the student's file
	
	2. Prepare and submit a report to the RDS, to include:
	
	• Benefits analysis and work incentives and asset accumulation plan
	• Action plan for next steps
	
	3. Provide counseling to the student and/or family:
	
	• Review benefits and earnings scenarios to support informed decision making
	• Case noting of counseling sessions
		• Benefits Planning Query (BPQY) requested
		  ○ Record and copy in file
		• Release of information
		  ○ Signed releases in file
		• Consumer intake form completed
		  ○ Maintained in file
		• Group planning session to review above report, summarize findings and discuss next steps
		  ○ Inclusive of the student, their family, the evaluator, school personnel, the provider, and other stakeholders
			• A work incentive and asset accumulation plan is integrated into the IEP
			• Youth utilize work incentive programs
			• Youth whose earnings exceed 1619(b) thresholds enroll in Medicaid Buy-In (MBIWPD)
			• Youth decrease dependence on benefits
			• Youth accumulate assets
			• Youth understand benefits and various work incentives to make career choices

Financial Literacy Training (FLT)

Definition: Financial Literacy Training will support greater economic self-sufficiency and asset development. These services will lead to youth and their family members making better informed decisions about their financial future, and taking action to ensure their greater economic self-sufficiency and financial well-being.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Services can be offered individually or in small group settings; they may be offered in a one-time setting or over multiple sessions, face-to-face, or in an online format.
 	
To minimally include:
• **Asset Accumulation Plan**
• **Banking**
• **Budgeting**
• **Consumer credit**
• **Financial Planning**
• **Managing financial records**
	1. Prepare and submit a report that includes:
	• Outline of the curriculum used
	  ○ i.e., description of course content and learning objectives
	• Evidence of client participation and engagement
	  ○ i.e., list of days and times of all scheduled classes and dates/times clients attended
	• Achievements of the student/family
	  ○ i.e., description of extent to which the student/family member achieved individual learning objectives; and/or results of course examinations
	• Plan for next steps; such as further training or refresher courses, etc…
	  ○ i.e., specific goals, objectives, timelines, etc… for supporting further development
	
	2. Evidence that this report and plan were discussed and provided to the student/family.
	• Documentation of debrief/meeting with the student/family to discuss progress
	  ○ i.e., meeting notation/case notes including date, time, attendees
		• Training uses simple language
		  ○ Reading does not exceed 6-7th grade language level
		• Provide reasonable accommodations to customize the content to individuals' needs based on their disabilities.
		  ○ Possible documentation of needed accommodations provided in the report
		• Privacy and confidentiality are maintained
		  ○ Classroom protocol for maintaining confidentiality of student personal and financial information
		  ○ Security protocol form archiving student information and files
		• Flexible service availability
		  ○ Coursework offered at various times based on learner preference including evenings, weekends, group, and one-on-one.
		• Curriculum is valid and reliable
		  ○ Materials used are based on prior testing and align with minimum standards articulated under "Program Activities"
		• Information delivered in family's primary language.
		  ○ Language translation is available (both spoken and written)
		• Evidence of evaluation
		  ○ Indices of learner performance are measured—which may include pre, post assessments, satisfaction surveys, and follow-up impact assessments
		• Next steps are identified
		  ○ A plan is developed for needed next steps in further enhancing financial literacy skills and putting knowledge into practice
			• Increase in parent/student content knowledge
			• Change in parent/student attitudes and behavior towards:
			  ○ Savings
			  ○ Spending
			  ○ Managing debt – rent, utilities and food; vehicle and student loans; other personal loans
			  ○ Managing credit – credit cards, debit cards, prepaid cards, credit report and score
			  ○ Financial security planning

Coaching Supports (CS)[1]

Definition: This service includes interventions that can be used with Community Unpaid Training Experience, Sponsored Community Training Experience as well as Job Development and Paid Work Experience to provide the individual student assistance and support on or off-the-job in activities on a short-term or long-term basis that are employment-related and needed to promote job development, adjustment and retention. Services duration will be determined by the RDS and provider depending upon the individual Youth' Individualized Education Plan.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes

Activities are based on student needs and preferences, and may include, but not be limited to:
 	
• **Community Mobility Training**
• **Job Coaching**
• **Life/Social Skills Training**
• **Meeting with Team/Family**
• **Meeting with Employer**
• **Monitoring**
• **Work and Social Conduct**
• **Work Performance Behavior Intervention**
• **Work-Related Daily Living Skills**
	1. The expected outcome is that youth will receive coaching supports on or off the job site in order to perform the essential functions of the position to the employer's satisfaction.
	
	2. Prepare and submit a report to the designated RDS, to include:
	
	• Evidence of the need for the services
	  ○ Documentation of the hours and the nature of the services delivered to the student
	• Description of student progress
	  ○ Documentation of performance baseline and progress made
	
	Authorizations and reporting will occur on a monthly basis, and will be jointly determined between the RDS and the local provider.
		• Youth needs are respected and their needs and preferences inform customization of coaching supports
		  ○ As evidenced by student's stated preferences in past assessments and the IEP
		• Job orientation and training support plan developed
		  ○ Plan details who, what, where, when, and how measured
		  ○ Natural supports are identified
		  ○ Contact log of interface with employer, supervisor, and/or mentor
			• Student received coaching supports on or off the job site resulting in their ability to support the attainment of outcomes in the accompanying primary service.

[1] Coaching supports are an accompanying service provided based on student needs and to support the outcomes of one of the following prescribed services: Community Work Experience, Sponsored Community Training Experience as well as Job Development and Paid Work Experience.

Supported Education (SEd)

Definition: A set of individualized activities and supports consistent with the student's post-secondary educational goals. This service will take place in community –based settings and will assist the student in making informed educational choices regarding postsecondary education, navigating preparation for the post-secondary school environment and accessing additional information and resources.

Program Activities	Outputs (Deliverables)	Quality Indicators	Outcomes
Activities are based on student needs and preferences, and must include, but is not limited to: • Educational Assessment Could include**:** • Advocacy for Accommodations • Campus Orientation • Certification and Licensure Support • Class Registration • Communication Skills • Course Identification and Recommendations • Educational Counseling and Guidance • Financial Planning – Loans • Financial Planning – Scholarships • General Education – Organization • General Education – Study Skills • General Education – Time • Management • Meeting with Educational Faculty • Meeting with Team/Family • Monitoring • Planning and Goal Setting • Social Skills/Networking • Touring of Educational Facilities	**1. The expected outcome is that the student will receive supported education services on or off campus** **2. Prepare and submit a report** to the designated RDS, to include: • Evidence of the need for the services ○ Documentation of the hours and the nature of the services delivered to the student • Description of student progress ○ Documentation of performance baseline and progress made Authorizations and reporting will occur on a monthly basis, and will be jointly determined between the RDS and the local provider.	• Youth demonstrates higher level of self-determination and self-awareness ○ Student can define their desired educational aspirations, steps to get there, and needs for support ○ Student can request accommodations needed • Youth demonstrates appropriate social conduct • Student can articulate a plan for continued educational development • Youth understands educational cultures and values relationships for seeking educational opportunities and career planning • Student can identify jobs and career paths in sync with their capacities	• Student received educational supports resulting in their ability to achieve their post-secondary educational goal

Module 3: Youth in Transition

Introduction

This module reviews foundational legislation and core principles that support best practice in transition planning. It establishes the context for student and family involvement and explains the role and responsibility of special education in the transition planning process. The framework for this module is based on key legislation found in the Individuals with Disabilities Education Act (IDEA), including core responsibilities for developing and implementing the Individualized Education Program, (IEP); laws that protect the rights of students with disabilities to be free from discrimination as promulgated in Section 504 the Rehabilitation Act of 1973 and in the Americans with Disabilities Act (ADAAA). Additional topics include diploma and credentialing options available for students; techniques on integrating efforts from multiple stakeholders with schools, as well as supporting self-determination and self-advocacy.

Students and Schools – Partners in the Transition Process

One of the most important things to think about, plan for and take action towards throughout a student's high school years is what they will be doing after school comes to an end. Who will the student become as an adult? How will they earn a living? What contribution will they make to their community? Where will they live? What supports are needed to ensure a successful transition? These and other equally critical questions about the future frame the transition planning process for students and their transition planning team.

The transition process offers the student and the family the opportunity to take an active role in directing the planning and implementation of activities that are based on the student's vision of a desirable future. It is vital that they are equipped with the information and resources that will assist them in understanding their rights for a free and appropriate public education (FAPE) and the role that they, school personnel, community agencies and others, play in ensuring that relevant and concrete action is taken to guide and prepare the student to successfully achieve his or her goals.

Special Education: IDEA

The Individuals with Disabilities Education Act of 2004 (IDEA), is a federal law that requires schools to serve the educational needs of eligible students with disabilities.[1] One of the fundamental functions of the IDEA is to protect the rights of students with disabilities and to ensure access to a free and appropriate public education in the least restricted environment, (LRE). LRE requirements ensure that students with disabilities have, to the greatest extent possible, equal access to educational opportunities alongside students who do not have disabilities.

[1] http://www.p12.nysed.gov/specialed/lawsregs/

IDEA provides financial support for state and local school districts. However to receive funding, school districts must comply with six main principles set out by IDEA:

1. Every child, regardless of the presence of a disability, is entitled to a free and appropriate public education (FAPE).
2. When a school professional believes that a student between the ages of 3 and 21 may have a disability that has substantial impact on the student's learning or behavior, the student is entitled to an evaluation in all areas related to the suspected disability.
3. If the student is determined to have a disability that has an impact on learning or behavior, the student is entitled to receive an Individualized Education Plan (IEP). The purpose of the IEP is to lay out a series of specific actions and steps, based on a comprehensive assessment, through which educational providers, parents and the student themselves identify and pursue relevant educational goals.
4. The education program, curriculum and relevant services must be provided in the least restrictive environment, (LRE) to ensure that whenever possible, the student has access and opportunity to learn alongside non-disabled students in typical or mainstream classroom settings and experiences.
5. The student and the parents are considered part of the IEP team and as such, input from the student and their parents must be solicited and taken into account in the education process.
6. If/when a parent feels that an IEP is inappropriate for their child, or that their child is not receiving needed services, they have the right under IDEA to challenge their child's treatment (due process).

IDEA is composed of four key components, summarized in the table below.

IDEA Component	**Purpose**
Part A	This section defines the terms used within the Act as well as providing for the creation of the Office of Special Education Programs, which is responsible for administering and carrying out the terms of IDEA.
Part B	This section lays out the educational guidelines for school children 3-21 years of age. IDEA provides financial support for state and local school districts since states must, by law, educate children with disabilities.
Part C	This portion of IDEA provides guidelines concerning the funding and services to be provides to children from birth through 2 years of age. Families are entitled to several services through Part C of IDEA.
Part D	This section describes national activities to be undertaken to improve the education of children with disabilities. These activities include grants to improve the education and transitional services provided to students with disabilities. In addition this section provides resources to support programs, projects and activities which contribute positive results for children with disabilities.

New York State has its own version of the IDEA, under Regulations of the Commission on Education, known as Part 200, (http://www.p12.nysed.gov/specialed/lawsregs/part200.htm).

By definition, Special Education is a range of services and related programs that are specifically designed to meet the unique needs of students with disabilities aged three to twenty-two. To qualify for special education services, a child must have one of thirteen identified disabilities and the disability must adversely affect educational performance.

The identified disabilities are:

- Autism
- Blindness
- Deafness
- Emotional Disturbance
- Hearing Impairment
- Intellectual Disability
- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impaired
- Specific Learning Disability
- Speech or Language Impairment
- Traumatic Brain Injury
- Visual Impairment

There are no special education classifications within the IEP that include specific mental health diagnosis. When the primary diagnosis that impacts a child's academic performance is related to a mental health condition (anxiety, depression, bipolar disorder, etc.) the student is typically classified for special education services under the Other Health Impaired (OHI), Emotional Disturbance (ED) category, or through a co-occurring learning disability.

Special education services can be provided in separate education programs, within general education programs or a combination of the two. Services can include specific programs tailored to meeting the needs of the student; access to specialists such as speech therapy, counseling, etc.; and/or modifications in educational programming, curriculum and teaching methodologies.

Co-Occurring Mental Health in Youth

At one point, the general consensus among society and professionals in the field of mental health was that individuals with intellectual disabilities either did not experience mental health conditions, or that they could not benefit from treatment of mental health issues due to cognitive deficits.[1] In 1983, Steve

[1] Burke, T. (2013). *Dual diagnosis: Overview of therapeutic approaches for individuals with co-occurring intellectual/developmental disabilities and mental illness for direct support staff & professionals working in the*

Reiss coined the term **"diagnostic overshadowing"** to describe the tendency for professionals to overlook mental health symptoms in individuals with co-occurring disorders, because the intellectual deficits are more obvious than the underlying mental health symptoms. Research now shows that nearly 1 in 3 individuals with intellectual and/developmental disorders (ID/DD) also meet the criteria for mental health disorders. In fact, individuals with intellectual disabilities suffer from mood disorders at a rate of more than double that of the general population. There are a variety of factors that contribute to higher rates of mental health conditions within the population of those with intellectual disorders, including: low levels of social support, poorly developed social skills, low socioeconomic levels, increased level of family stress, increased likelihood of central nervous system damage, increase in likelihood of experiencing early trauma and abuse, and decreased opportunities to learn adaptive coping skills.

One major barrier facing individuals with co-occurring disorders is that providers in the community lack the necessary skills and training in assessing, diagnosing and treating individuals with both mental health and ID/DD. Individuals may be turned away from mental health providers due to IQ thresholds or a disability diagnosis, and providers of ID/DD services may refuse treatment to individuals with significant behaviors or MH diagnosis.[1] Both MH and DD services are often limited in who they can serve based on funding streams, and as a result, individuals with dual diagnosis may be bounced back and forth from one provider to another. The resulting frustration causes a serious risk to the ability individuals to follow through in obtaining appropriate services. In addition, many regions experience gaps in community services that are essential for individuals with mental health conditions and their families such as respite care, crisis behavioral support, home-based behavioral intervention, and afterschool care. Inadequate services contribute to inappropriate hospitalizations, restricted, living situations, homelessness, interrupted education, and incarceration in individuals with co-occurring disorders.[2]

Similar to the field of developmental disabilities, the field of mental health has begun to shift from a focus on medical diagnosis and treatment of deficits to a focus on community integration and overall quality of life across all domains. The President's New Freedom Commission on Mental Health defines the recovery process for individuals with mental health as "a process in which people are able to live, work, learn, and participate fully in their communities."[3] Community integration within this context is viewed as a multidimensional construct that encompasses both objective factors (such as activities outside the home and interactions with neighbors) and subjective factors (feelings about the meaningfulness of social connections, attitudes about one's sense of belonging, etc.). As a result of

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Developmental Disability System (white paper). Retrieved February 8, 2018 from Ohio Mental Illness/Developmental Disability Coordinating Center of Excellence at http://mha.ohio.gov/Portals/0/assets/Initiatives/CentersOfExcellence/201312-dual-diagnosi-white-paper.pdf

[1] Jacobstein, D. M., Stark, D. R., & Laygo, R. M. (2007). Creating responsive systems for children with co-occurring developmental and emotional disorders. *Mental Health Aspects of Developmental Disabilities, 10*(3), 91.

[2] Davis, M., Jivanjee, P., & Koroloff, N. (2010). *Paving the way: Meeting transition needs of young people with developmental disabilities and serious mental health conditions.* Portland, OR: Research and Training Center on Family Support and Children's Mental Health.

[3] Jivanjee, P., Kruzich, J., & Gordon, L. J. (2008). Community integration of transition-age individuals: Views of young with mental health disorders. *The Journal of Behavioral Health Services & Research, 35*(4), 402-418. 10.1007/s11414-007-9062-6

stigma within society, fragmented and limited services, and other factors, youth with mental health conditions and dual diagnosis are at risk of becoming "disconnected youth", existing on the fringe of community, without work, stable housing, and supportive relationships. Youth who are transitioning from the school system to the adult community and systems are particularly vulnerable to becoming disenfranchised and discontinuing treatment. Access to accurate information about their diagnosis, support from a network of family, friends, teachers, employers, and service providers, and opportunities to gain greater control over their own lives contributes to a greater sense of well-being in individuals with DD and MH diagnosis.

IDEA and the Individualized Education Plan (IEP)

An IEP is an *Individualized Education Program*. There are three core elements of an IEP: a current and comprehensive assessment of the student; a statement of measurable annual goals, including short-term benchmarks relevant to assisting the student in meeting the goals and a statement of the special education and related services that are necessary to meet the student's needs.

In addition, the IEP must include an explanation of how the student's progress toward the goals will be tracked and reported. A statement of how and how often the student will (or will not) participate in mainstream general education programs is required in the IEP as well as a description of and rationale for any modifications or adaptations that will be used.

No later than the student's 15th birthday, the IEP must include a statement for transition planning from school to post-school life. Transitional goals and services focus on instruction and support services needed to help the student move from the school environment and into a job, vocational program, post-secondary education and/or other programs designed to promote age-appropriate, functional independent living.

Services and Supports

Under the IDEA, there are a variety of services and supports available to students with disabilities. These can include the following:

1. *Special Education*- Instruction that is specifically designed to meet the individual needs of a child with a disability.
2. *Related Services*- Extra help that a student may need to access education such as speech and occupational therapy, counseling services, medical services, transportation, etc. The IEP team will identify any needed services and include them in the IEP. These services can be provided by the school, or the school may contract with a private provider, public agency, or another school district to provide the service.
3. *Supplementary aids and services*- Includes other supports and services that the student will need in order to have equal access to education, such as adapted equipment, a 1:1 aide, assistive technology, training (for the student, school staff, or parents), etc.

4. *Accommodations and modifications*- Supports or changes that can be made to help support the unique learning needs of the student. Accommodations and modifications are most often made in scheduling (e.g., providing extra time to complete assignments and tests), setting (e.g., taking a test in an alternate location), materials (e.g., providing copies of lecture notes), instruction (e.g., reducing the reading level of an assignment), and student response (e.g., allowing answers to a test to be dictated verbally).
5. *Program modifications of supports for school staff*- Support available to those who work with the student to help meet the needs of the child (e.g., training related to a specific reading program that the child uses).

Transition and IDEA

Transition services are firmly situated within the IDEA. IDEA is the national special education law, which requires schools to provide to students a coordinated set of activities to promote a successful transition from high school to postsecondary education or employment, and independent living. Transition services are intended to be based on the student's strengths, as well as their preferences and interests.

The process must focus on improving the academic and functional achievement of the student to facilitate movement from school to life after school and the course of study must be meaningful to the student's future plans and motivate the student to complete his or her education.

What is a Transition Plan?

A transition plan is required for students age 15, or earlier if appropriate, enrolled in special education who have an Individualized Education Program (IEP).[1] It is the section of the IEP that outlines transition goals and services which target individualized post-secondary results relative to living, learning and earning and identify the objectives that need to be accomplished during the school year to assist the student in achieving the post-high school goals.

The plan is a results-oriented process that takes into account the student's strengths, abilities, preferences, interests and support needs as the basis for establishing educational and experiential programs and services.

Here is a brief description of the core elements for transition planning:

Development of appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills. These goals should reflect the student's strengths, preferences, and interests. In determining such goals, the IEP team (including the student) must determine what instruction and educational experiences will help prepare the student for a successful transition from secondary education to post-

[1] Stanberry, K. (2015). *Transition planning for students with IEPs. Learn how this part of the IEP allows a teen in special education to outline goals that will help him achieve his post-high school plans*. Retrieved from http://www.greatschools.org/gk/author/kristinstanberry/

secondary life. Age-appropriate transition assessments might include such things as interest inventories and other assessment tools that can help identify an individual's special talents.

Development of a statement of the transition services, including courses of study, needed to assist the student in reaching those goals. The statement of transition services should relate directly to the student's self-determined postsecondary goals. The activities contained in the statement of transition services should:

- Define every activity that must occur
- Identify who has primary responsibility for each activity
- Specify the dates that each activity will begin and end

What are Transition Services?

Transition services in high school for students who have an IEP are made available through the school special education program and general education programs.[1] They can include any or all of the following areas:

Instruction designed or provided to build the skills necessary to reach post-secondary goals. Instruction could include general or special education courses to meet academic requirements, advanced placement courses, career and technical education or remedial services.

Related Services needed for students to access integrated work, education and living environments. They may include occupational and physical therapy, speech therapy, rehabilitative counseling services, travel training, and other professional supports.

Community Experiences should include services that are needed for students to access integrated work, education and living environments. They may include occupational and physical therapy, speech therapy, rehabilitative counseling services, travel training, and other professional supports.

Employment and Other Post-School Living Objectives focus on the development of work-related behaviors, job seeking and keeping skills, career exploration and actual employment, such as career planning, job shadowing, job training, or supported employment.

Acquisition of Daily Living Skills - daily living skills are the skills involved in caring for oneself on a daily basis and are considered an important component of independent living. Services may include such activities as dressing, grooming, hygiene, self-care skills, house chores, shopping, and control or management of finances.

Functional Vocational Assessment – in some cases vocational assessments conducted at school may not provide enough information to allow the student to make an informed decision about vocational or

[1] Advocates for Children. (2013). *Helping students with disabilities move from school to adulthood.* (AFC'S Guide to Transition Services. http://www.advocatesforchildren.org/sites/default/files/library/transition_guide.pdf?pt=1

career-based interests. To supplement traditional assessment processes, additional assessments can be conducted such as situational assessments, community-based assessments, assistive technology evaluations or aptitude tests, to generate more insight and information about the student's needs, preferences, and interests.

Who is on the Transition Team?

IDEA requires that in addition to the student, parents, and school personnel, other agency representatives are invited to participate in the transition planning process as needed and driven by the student's goals and support needs. Beginning with the first IEP at age 16, (or younger if deemed appropriate), the student must be invited along with representatives of any other agency that is likely to be responsible for providing or paying for transition services.

Outside agency representatives who could be invited to the IEP meeting may include but are not limited to:

- Rehabilitation counselor, including vocational rehabilitation counselors
- Community-based social worker
- Employment agency staff, such as vocational evaluator, job coach or placement specialists
- Independent living center staff
- Disability support staff from a postsecondary educational or technical school
- Person knowledgeable about assistive technology
- Person knowledgeable about financial benefits such as Supplemental Security Income (SSI) and Medicaid or Medical Assistance (MA)
- Personal care or health care providers, including mental health care providers
- Probation officer or teacher from a juvenile justice center
- Agency transportation staff

In addition, families may invite an advocate from an advocacy organization to assist them with interpreting information and follow-up.

Section 504 of the Rehabilitation Act of 1973

Some students who are found ineligible for special education services by the school district under the IDEA standard of disability may qualify for accommodations and supports under the broader definition of disability set forth by the Section 504 Rehabilitation Act. The U.S. Department of Education, Office of Civil Rights is responsible for enforcing section 504 of the Rehabilitation Act of 1973.[1] Section 504 is an anti-discrimination, civil rights statute that requires the needs of students with disabilities to be met as adequately as the needs of the non-disabled are met.

[1] Extrapolated from Durheim, M. (2015). *A parent's guide to section 504 in public schools*. http://www.greatschools.org/gk/articles/section-504-2/

Section 504 states that "No otherwise qualified individual with a disability in the United States, as defined in section 706(8) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance…" [29 U.S.C. §794(a), 34 C.F.R. §104.4(a)].

Although every state must comply with the federal statute, compliance varies from state to state.

Definition of Disability Under Section 504

In order to meet the criteria to be considered an individual with a disability under Section 504, an individual must:

1. Have a physical or mental impairment that substantially limits a major life activity.
2. Have a record of such impairment.
3. Be regarded as having such an impairment.

Major life activities can include (but are not limited to):

caring for oneself	-performing tasks
-seeing	-speaking
-hearing	-breathing
-learning	-eating
-reading	-sleeping
-walking	-concentrating
-thinking	-communicating

Key Points to Note:

- A student may have a disability and be eligible for Section 504 services even if the disability does not limit the major life activity of learning.
- A student may have a disability and be eligible for Section 504 services, including modifications, even if the student earns good grades.

Please note: All youth who receive SSI, regardless of whether they have a 504 plan or an IEP, are presumed to be eligible for transition services through ACCES-VR. For more information about these transition services visit the following link to *A Transition Guide: To Postsecondary Education and Employment for Students and Youth with Disabilities*, a 2017 publication by Wrightslaw.com http://www.wrightslaw.com/law/osers/transition.postsecondary.guide.2017.pdf

Evaluation and Documentation Under Section 504

Under Section 504, if a school district believes that a student may have an unidentified disability, the district must conduct an evaluation in a timely manner. Either the school staff or the parents can request an evaluation. It is recommended that a student's need for Section 504 services be documented in a written plan. This helps to avoid misunderstandings or confusion about the services that are being made available to the student. Section 504 and School Behavior

A school district must evaluate a student if there is a reason to believe that a student has a disability even if the student only exhibits behavioral (and not academic) challenges. This is determined by comparing the student's behavior to the behavior of peers without a disability and assessing whether the behavior is related to a disability.

In December of 2016 the U.S. Department of Education published *Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools,* a guidance document for parents and professionals. This document can be downloaded here: https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf.

Special Education in NY State

New York State has an array of resources to support transition planning for youth with disabilities.[1] A brief description of these resources, and links to additional information follows.

NYS Transition Services Professional Development Center

The Transition Services PDSC was established by the NYSED, Office of Special Education, and awarded to Cornell University's Yang-Tan Institute. The Transition Services PDSC provides ongoing professional development support to the State's Transition Specialists within the Regional Special Education Technical Assistance Support Centers (RSE-TASC). Through the RSE-TASC transition specialists, school districts can access technical assistance and professional development on a variety of topics related to effective transition planning and services, including but not limited to:

- Individualized education program (IEP) development relating to transition planning; student exit summaries
- Transition assessments; work-based learning
- Self-advocacy/self-determination; and partnering with community agencies

The Transition Services PDSC also maintains TransitionSource (www.transitionsource.org), an online resource and planning center, designed to support educational programs and agencies across New York State, to advance the post-school outcomes of secondary education students with disabilities. The website provides tools to assist with:

- Finding just the right web and agency resources to support your efforts Strategic planning and progress development for secondary transition program development
- Interactive features for online discussions, document and media sharing among members
- Email messaging to other users of the website
- Data collection tools to chart and report progress toward meeting organizational goals

You can learn more about transition in New York State by visiting
http://www.p12.nysed.gov/specialed/techassist/rsetasc/tslist.htm

[1] 2015 Cornell University NYS Consortium for Advancement of Supported Employment

NYSED-sponsored Regional Special Education Technical Assistance Support Centers

The NYSED supports ten Regional Special Education Technical Assistance Support Centers (RSE-TASC). Each center employs Regional Transition Specialists. To contact your RSE-TASC, please use the following directory:

REGION 1 – Long Island
Eastern Suffolk BOCES
Sherwood Corporate Center
15 Andrea Drive
Holbrook, NY 11741
(631) 218-4197
Fax: (631)218-4146

REGION 2 – Lower Hudson
Putnam-Northern Westchester BOCES
200 BOCES Drive
Yorktown Heights, NY 10598
(914) 248-2290
Fax: (914) 248-2288

REGION 3 – Mid-Hudson
Dutchess BOCES
900 Dutchess Turnpike
Poughkeepsie, NY 12603
(845) 486-4840 Ext. 3023
Fax: (845) 483-3648

REGION 4 – Capital District/North Country
Capital Region BOCES
900 Watervliet Shaker Road
Albany, NY 12205
(518) 464-3938, 464-5128
Fax: (518) 464-3975

REGION 5 – Central
Jefferson-Lewis-Hamilton-Herkimer Oneida BOCES
Arsenal Street Road
20104 NYS Route 3
Watertown, NY 13601
(315)269-2275
Fax: (315)779-7109
1-800-356-4356

REGION 6 – Mid-State
Onondaga-Cortland-Madison BOCES
6075 East Molloy Road
PO Box 4774
Syracuse, NY 13221
315-433-2645
Fax: 315-431-8495

REGION 7 – Mid-South
Greater Southern Tier BOCES
459 Philo Road
Elmira NY 14903
Located at Broome-Delaware-Tioga BOCES
435 Glennwood Road
Binghamton, NY 13905
(607)766-3769

REGION 8 – Mid-West
Monroe 1 BOCES
15 Linden Park
Rochester, NY 14625
(585) 249-7025
Fax: (585) 218-6267

REGION 9 – West
Erie I BOCES
355 Harlem Road
West Seneca, NY 14224
(716) 821-7540
Fax: (716) 821-7556

REGION 10 – New York City
New York City Department of Education
Queens Plaza North
Long Island City, NY 11101
(718) 391-6648
Fax: (718) 391-6887

Full list available:
http://www.p12.nysed.gov/specialed/techassist/rsetasc/locations.htm

NYS Degree and Credential Options[1]

The following chart was obtained directly from the New York State Department of Education website.[2] The chart was developed to outline the diploma and credential requirements in effect at the time this field guide was published.

The chart is intended to provide an overview of the requirements and identify the student populations that have access to each type of diploma and non-diploma high school exiting credential. In addition, website links are provided to offer specific regulatory requirements and more detailed information regarding the requirements for each diploma or credential. Links to download worksheets and guides for students, parents, and counselors can be found in the "Resources" section of this module.

Diploma Type (Available to)	Requirements
Regents (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 English language arts (ELA), 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 Language other than English (LOTE), 2 Physical Education, 3½ Electives • Assessment: 5 required Regents exams with a score of 65 or better as follows: 1 Math, 1 Science, ELA, Global History and Geography, US History and Government http://www.p12.nysed.gov/part100/pages/1005.html#regentsdiploma
Regents (through appeal) (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. • Assessment: 4 required Regents exams with a score of 65 or better and 1 Regents exam with a score of 62-64 for which an appeal is granted by the local district per Commissioner's Regulation section 100.5(d)(7) as follows: 1 Math, 1 Science, ELA, Global History and Geography, US History and Government http://www.p12.nysed.gov/part100/pages/1005.html#regpasscore
Regents with Honors (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives • Assessment: 5 required Regents exams with a computed average score of 90 or better as follows: 1 Math, 1 Science, ELA, Global History and Geography, US History and Government http://www.p12.nysed.gov/part100/pages/1005.html#diplomaHonors

[1] http://www.p12.nysed.gov/specialed/diploma-credentials.html
[2] *Diploma/Credential Requirements (Revised February, 2017):*
http://www.p12.nysed.gov/ciai/gradreq/Documents/CurrentDiplomaCredentialSummary.pdf

Diploma Type (Available to)	Requirements
Regents with Advanced Designation (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. In addition, a student must earn an additional 2 units of credit in LOTE or a 5 unit sequence in the Arts or Career and Technical Education (CTE). These credits can be included in the 22 required credits. • Assessment: 8 required Regents exams with a score of 65 or better as follows: 3 Math, 2 Science, ELA, Global History and Geography, US History and Government; and either a locally developed Checkpoint B LOTE examination or a 5 unit sequence in the Arts or CTE http://www.p12.nysed.gov/part100/pages/1005.html#regentsAD
Regents with Advanced Designation with an annotation that denotes Mastery in Math (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. In addition, a student must earn an additional 2 units of credit in LOTE or a 5 unit sequence in the Arts or CTE. These credits can be included in the 22 required credits. • Assessment: Meets all assessment requirements for the Regents with Advanced Designation (see above) and, in addition, scores 85 or better on each of 3 Regents Examinations in Mathematics See section 100.5(b)(7)(x) http://www.p12.nysed.gov/part100/pages/1005.html#regentsAD
Regents with Advanced Designation with an annotation that denotes Mastery in Science (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. In addition, a student must earn an additional 2 units of credit in LOTE or a 5 unit sequence in the Arts or CTE. These credits can be included in the 22 required credits. • Assessment: Meets all assessment requirements for the Regents with Advanced Designation (see above) and, in addition, scores 85 or better on each of 3 Regents Examinations in Science See section 100.5(b)(7)(x) http://www.p12.nysed.gov/part100/pages/1005.html#regentsAD

Diploma Type (Available to)	Requirements
Regents with Advanced Designation with Honors (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. In addition, a student must earn an additional 2 units of credit in LOTE or a 5 unit sequence in the Arts or CTE. These credits can be included in the 22 required credits. • Assessment: 8 required Regents exams with a computed average score of 90 or better as follows: 3 Math, 2 Science, ELA, Global History and Geography, US History and Government; and either a locally developed Checkpoint B LOTE examination with a score of 65 or a 5 unit sequence in the Arts or CTE http://www.p12.nysed.gov/part100/pages/1005.html#diplomaHonors
Local (Available to Students with disabilities with an IEP or Section 504 Accommodation plan)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. • Assessment: Low Pass Safety Net Option1: 5 required Regents exams with a score of 55 or better as follows: 1 Math, 1 Science, 1 ELA, 1 Global History and Geography, 1 US History and Government; http://www.p12.nysed.gov/part100/pages/1005.html#assessment, or; • Regents Competency Test (RCT) Safety Net Option for students entering grade 9 prior to September 2011: Passing score on corresponding RCT if student does not achieve a score of 55 or higher on the Regents examination http://www.p12.nysed.gov/specialed/publications/localdiplomaoptions-may2011.htm; or • Compensatory Safety Net Option: Scores between 45-54 on one or more of the five required Regents exams, other than the ELA or mathematics exam, but compensates the low score with a score of 65 or higher on another required Regents exam. Note: a score of at least 55 must be earned on both the ELA and mathematics exams. A score of 65 or higher on a single examination may not be used to compensate for more than one examination for which a score of 45-54 is earned. http://www.p12.nysed.gov/specialed/publications/safetynet-compensatoryoption.html

Diploma Type (Available to)	Requirements
Local Diploma (through Appeal) (available to all student populations)	• Credit: 22 units of credit distributed as follows: 4 ELA, 4 Social Studies, 3 Science, 3 Mathematics, ½ Health, 1 Arts, 1 LOTE, 2 Physical Education, 3 ½ Electives. • Assessment: 3 required Regents exams with a score of 65 or better and 2 Regents exams with a score of 62-64 for which an appeal is granted by the local district per Commissioner's Regulation section 100.5(d)(7) as follows: 1 Math, 1 Science, ELA, Global History and Geography, US History and Government http://www.p12.nysed.gov/part100/pages/1005.html#regpasscore
Local Diploma, Regents Diploma, Regents Diploma with Advanced Designation (with or without Honors), with a Career and Technical education Endorsement (available to all student populations)	• Credit: Completes all credit requirements as listed above for specific diploma types and completes an approved CTE program • Assessment: Achieves a passing score on State assessments as listed above for specific diploma types and successfully completes the technical assessment designated for the particular approved CTE program which the student has completed. http://www.p12.nysed.gov/part100/pages/1005.html#carteched

Credential Type	Requirements
Career Development and Occupational Studies (CDOS) Commencement Credential (Available to Students with disabilities other than those who are assessed using the NYS Alternate Assessment (NYSSA))	• Completes a career plan; demonstrates attainment of the commencement level CDOS learning standards in the area of career exploration and development, integrated learning and universal foundation skills; satisfactorily completes the equivalent of 2 units of study (216 hours) in CTE coursework and work-based learning (including at least 54 hours of work-based learning); and has at least 1 completed employability profile; OR • Student meets criteria for a national work readiness credential. Credential may be a supplement to a regular diploma, or, if the student is unable to meet diploma standards, the credential may be awarded as the student's exiting credential provided the student has attended school for not less than 12 years, excluding Kindergarten. http://www.regents.nysed.gov/meetings/2013Meetings/April2013/413p12accesa1Revised.pdf
Skills and Achievement Commencement	• All students with severe disabilities who attend school for not less than 12 years, excluding Kindergarten graduate with this credential which must be accompanied by a summary of the student's levels

Credential Type	Requirements
(Available to Credential Students with severe disabilities that are assessed using NYSAA)	of achievement in academic and career development and occupational studies. http://www.p12.nysed.gov/specialed/publications/SACCmemo.htm http://www.p12.nysed.gov/part100/pages/1006.html

Regents Appeal Process

According to the New York State Education Department (www.nysed.gov) students within New York state may appeal their Regents Exam if their score is within three points of passing (62-64) and they:www.nysed.gov) students within New York state may appeal their Regents Exam if their score is within three points of passing (62-64) and they:

1. Have taken the Regents Exam under appeal at least twice;
2. Present evidence that they have utilized academic help provided by their school in the subject tested under appeal;
3. Have an attendance rate of 95%;
4. Pass the course for which the appeal is being sought;
5. Are recommended for the appeal by their teacher or Department chairperson.

Career and Technical Education

New York State Education Department Approved Career and Technical Educational programs (CTE) help prepare youth for the world of employment and higher education while satisfying many of the New York State Regents Diploma requirements. Within New York State, there are over 1,100 Career and Technical Education providers, serving over one million students in school districts, BOCES, and postsecondary institutions. CTE studies are organized in the following areas of content:[1]

- Agricultural education
- Business and Marketing education
- Family and Consumer Sciences education
- Health and Occupations education
- Technology education
- Trade, Technical and Industrial education

[1] NYSED CTE: Career & Technical Education. Retrieved from http://www.p12.nysed.gov/cte/

The following are some examples from the Capital Region BOCES website of how students benefited from CTE courses:[1]

- Increased likelihood of acceptance to college.
- Helped define their career path.
- Gained skills and trades that can be used to help pay for college.
- Obtained "hands-on" learning.
- Competed in a competitive job market after high school graduation.

In order to graduate from a CTE program in New York State, students must:[2]

- Pass five required Regents examinations or alternatives approved by the State Assessment Panel; [3]
- Complete a minimum of 22 units of credit;
- Complete a minimum of 14.5 units of credit in academic core requirements; and
- Complete a maximum of one unit of credit in English, mathematics, science, economics, and government through either a full integrated* program with documentation of academic core requirements, specialized career and technical education courses, or a combination of the two approaches

There is no extra cost to parents or students for youth to attend CTE programs, because the cost is covered by the school district. Students may be required to purchase tools, supplies, and uniforms at their own expense.

The following links provide information about CTE programs for each region represented by NYS PROMISE:

Capital Region BOCES: http://www.capitalregionboces.org/CareerTech/aboutusfaq.cfm
http://www.capitalregionboces.org/CareerTech/aboutusfaq.cfm

New York City: http://schools.nyc.gov/NR/rdonlyres/B25967DA-0B9D-4027-8D61-FAFB3C3D6AB6/202143/CTEDedicatedSchoolList_1617.pdf

Western New York:
https://www.e1b.org/Portals/0/Files%20by%20Division/Career%20and%20Tech%20Ed/Programs/CTE%20Course%20Catalog%202017-2018.pdf

[1] Capital Region BOCES. *Why CTE? Students offer their own responses.* Retrieved from http://www.capitalregionboces.org/CareerTech/news/2016-17/2017_February/02.24.17_CTE_month_testimonial.cfm
[2] NYC Department of Education. *Who is a CTE Student?* http://schools.nyc.gov/ChoicesEnrollment/SpecialPrograms/CTE/ParentsandStudents/CTE+FAQ.htm
[3] NYSED. (2016). *Multiple pathways to graduation*. http://www.p12.nysed.gov/ciai/multiple-pathways/

TASC High School Equivalency Diploma (Previously GED)

What is the TASC?

Starting January 2, 2014, the Test Assessing Secondary Completion (TASC) replaced the GED as the primary pathway to the New York State High School Equivalency Diploma. It is made up of a series of 5 tests that are taken over approximately 9 hours (usually given over 1-2 days). The results of the exam are received 5-6 weeks after the exam completion. There is no cost involved in taking the TASC exam for individuals who reside in NYS.

The ELA and Math tests included in the exam are now aligned with the Common Core Learning Standards, and these exams are considered to be more rigorous than those that were previously included in the GED exam. However, in order to help compensate for the increased difficulty, the number of correct questions required to pass the TASC are lower than the number that were required by the GED. Any of the five exam sections that are not passed can be retaken by the individual after 60 days.

What are the age requirements involved in taking the TASC exam?

1. Students who are 16 must wait until June 30th of the school year in which they turn 18 to take the test, **AND:**
    - Must be enrolled in an Alternative to High School Equivalency Prep (AHSEP) program
      OR
    - Must provide proof of acceptance to the US Armed Forces, a college or University, or an accredited post-secondary institution.
2. Students who are 17-18 must wait until 1 year has passed since they were legally able to leave high school and were last enrolled **OR:**
    - Be a member of a high school class that has already graduated
      OR
    - Enrolled in an ASHEP program
      OR
    - Applied to the US Armed Forces, a college or university or accredited post-secondary institution
      OR
    - Have participated in the Job Corps training
      OR
    - Be a resident confined to a narcotics addiction control center, the NYS Office of Children and Family Services facility, a jail or corrections facility, or a patient in a hospital in the state or county of New York.
      OR
    - Be an adjudicated youth under the direction of a prison, jail, detention center, parole or probation officer
      OR
    - Have been home schooled

Testing Accommodations for TASC

Students with a diagnosed disability can apply for accommodations, but will need appropriate documentation of their diagnosis from a doctor along with documentation supporting the need for accommodations. For more information about applying for accommodations, go to http://www.tasctest.com/special-needs-accommodations.html.

Preparing for TASC

Free TASC programs are provided within most local communities. Registered TASC preparation programs can be found at http://www.acces.nysed.gov/hse-prep-programs-maps.

There are also free sample tests and on-line media resources available to help prepare students for taking the TASC exam at http://www.tasctest.com/resources.html.

Requirements for Military Enlistment

Enlisting in the military has become increasingly more competitive, and the military will not accept the Career Development (CDOS) or Skills and Achievement Commencement Credential (SACC). Active duty requirements include (with very few exceptions) a high school diploma. It is recommended that those who receive a high school equivalency test (such as the TASC) complete 15 or more hours of college-level courses from an accredited institution. Those applying for an officer (management) position will most likely need a minimum of a 4-year-college degree. Many officers have a minimum of a master's degree, and the application process is very competitive.

More information about military enlistment can be found at http://www.military.com or http://www.armyenlist.com.

All five branches of the military require the following:

- Must be a US citizen or resident alien (with I-551)
- Must be at least 17 years of age (those who are 17 need parental consent)
- Must (with few exceptions) have a high school diploma
- Must pass a medical exam

Applicants of all branches must also pass the Armed Services Vocational Aptitude Battery (ASVAB). This is a 3-hour test that was developed and is maintained by the Department of Defense. The four critical areas of the test that impact enlistment most significantly are Arithmetic Reasoning, Word Knowledge, Paragraph Comprehension, and Math Knowledge. These four areas make up the Armed Forces Qualifying Test (AFQT) portion, and each branch of the military designates a cut-off point for the AFQT score. The scores on the other areas of the test will be utilized to determine how qualified the applicant is for certain military occupational specialties and enlistment bonuses.

Each branch varies slightly in age requirements and AFQT score requirements. The following chart provides an overview of these requirements:

Army	• Ages 17-34 • AFQT minimum of 31
Navy	• Ages 17-34 • AFQT minimum of 50
Air Force	• Ages 17-27 • AFQT minimum of 50
Marines	• Ages 17-29 • AFQT minimum of 32 • Must also meet exacting physical, mental, and moral standards.
Coast Guard	• Ages 17-39 • AFQT minimum of 45 • Willingness to serve on or around water

High School Drop-Outs

If a student has dropped out of high school, they may be able to re-enroll if they are under 18 (with no IEP) or until the age of 21 (with an IEP) under the IDEA.

Consult with the student's school district to determine eligibility for re-enrollment.

The ADA Amendments Act of 2008 (ADAAA) Expands Rights Under the Americans with Disabilities Act

Title II of the 1990 Americans with Disabilities Act prohibits discrimination against individuals with disabilities in state and local government services, programs, and activities, including public schools, regardless of whether they receive Federal financial assistance. When the ADA was passed, Section 504 from the Rehabilitation Act of 1973 was expanded to include any public or private institution. Subpart E of the Rehabilitation Act requires an institution to be prepared to make reasonable academic adjustments and accommodations to allow students with disabilities full participation in the same programs and activities available to students without disabilities.

The ADA Amendments Act of 2008 (ADAAA) was enacted on September 25, 2008, and became effective on January 1, 2009, (www.ada.gov). The law made a number of significant changes to the definition of "disability" under the Americans with Disabilities Act (ADA) in response to several Supreme Court decisions that had narrowly interpreted the Americans with Disabilities Act's (ADA) definition of disability. The ADAAA is designed to ensure that it is easier for individuals seeking the protection of the ADA to establish that they have a disability that falls within the meaning of the statute.

The ADAAA further clarifies and reinforces the statutes associated with Section 504.

Student and Schools

Transitions are about change. For many people, especially adolescents, change can be scary. Transition from the structured, predictable routine of high school into the adult world can pose daunting challenges for all young people. The process of transition is even more difficult for many youth with disabilities and require unique strategies to enable each student to learn and effectively use the skills of self-determination and self-advocacy to direct his or transition planning program.

The Individuals with Disabilities Education Act emphasizes student participation in the Individualized Education Program (IEP) to develop an outcome oriented focus in transition planning. To this end, the school is required to invite the student and the family to participate in the IEP and transition planning process.

The preferences and interests of the student must be taken into account even if the student chooses to not attend the meeting. Therefore a critical task for the NYS PROMISE case manager and/or family coach is to prepare students and families for the leadership role they will play in the transition process. Students and families must be made aware of and understand transition policies and practices and their rights within them.

Core areas that students and parents should be given the opportunity to actively engage, contribute and ideally, lead the transition process include:

- **My Future**: Identifying transition goals in the areas of living, learning and earning
- **Getting There**: Helping to link post-secondary goals to IEP/transition goals
- **Good Support/Assistance**: Identification of impairment-related support needs and preferences to maximize skill acquisition and application

The clearer the student and family can be around these key areas, the easier it will be for the school to understand what is needed in the IEP that will facilitate a smooth and successful transition process.

Thinking About the Future Aids Planning in the Present

Helping students and family members think through critical questions across and within life domain areas is essential to making informed and self-determined choices about the transition process. See the *Life Domains* resource at the end of this module for a table of life domain areas and questions that might be useful to supporting the student and family in framing the transition discussion.

Understanding Transition Planning Rights and Regulations

Being familiar with the basic elements of transition planning regulation and rights goes a long way in equipping students and families with the information they need to participate with confidence in the transition process. Assisting them in obtaining a working understanding of the IDEA, Part 200 of the New

York State law relative to the IDEA, Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) will create solid ground for good advocacy and negotiation.

The NYS PROMISE offers a great on-line resource that covers this material in an easy to use, accessible format. Other resources are available as well.

Integrating Planning Efforts with Schools and Other Providers

Service planning is a requirement for all publicly-funded services as it provides rationale, justification and therefore, accountability for the authorization and implementation of specific activities and expenditure of resources. Transition best practices, as well as IDEA mandates, require students work with a variety of people during the educational planning process--school psychologists, general educators, special educators, school administrators, community agency personnel, and their parents/guardians. Students who access and utilize services and supports from a variety of resources will have distinct planning requirements associated with each source. If care is not taken, this can result in fragmentation of services or even service conflicts.

It is useful to understand the different planning processes that a student may encounter during his or her high school experience.

The Individualized Education Program (IEP)

The IEP is a written document generated in the school setting, setting out in detail the nature of the student's educational needs, the services to be provided and specific goals for the student. They must be measurable and relate to meeting each of the student's educational needs that result from the disability, including those which will enable the student to be involved and progressing in the general curriculum.

Individualized Plan for Employment (IPE)

The IPE outlines the vocational rehabilitation (VR) services needed to achieve a specified employment outcome. The plan is developed between the person and the VR agency. Individuals and their VR counselor and/or authorized community service provider staff work together to establish their employment goals and identify the services that are necessary for the student to achieve and maintain their goals. Goals must be considered realistic and measurable and relate to the student's vocational support needs that result from the disability, including those which will enable the student to be employed in community-based, integrated settings.

Individualized Service Plan (ISP)

The ISP is the written articulation of the support needs, activities, and resources required for the individual to achieve personal goals in specific life domain areas. The plan is developed via disability service agencies and serves to articulate decisions and agreements made during a person-centered

process of planning and information gathering that, in theory, paints a picture of a desired future around which resources, including the assistance required to mitigate the impact of the disability, are used to maximize the potential of the person to engage fully in community living, learning and earning opportunities. Goals in the ISP must be concrete and measurable.

Common Threads between the IEP, IPE and ISP

Every student who is eligible for special education may not be eligible for vocational rehabilitation services; every student who is eligible for vocational rehabilitation may not be eligible for special education; and every student who is eligible for long term supports and services through home and community based programs may not be eligible for vocational rehabilitation. Therefore, the coordination and provision of transition services will vary from student to student, depending upon their eligibility status under IDEA and/or the Rehabilitation Act, which makes the coordination of these programs and services essential.

Devlieger and Trach[1] found that interagency collaboration and support for individual students in transition and their families is a factor so important that when done well, it facilitates achievement of transition goals, and when done poorly, it limits or impedes those goals.

While each of the planning processes described above are generated through different avenues, (school, state rehabilitation, and community based service organizations), they share some commonalities. Each requires the following components.

- An assessment of current levels of functioning, strengths, needs, interests and preferences of the individual.
- An individualized approach to assessment and planning, including responsiveness to cultural considerations and accessibility.
- A strength-based bias in developing a comprehensive, positive and balanced profile of the person.
- Long-term and short-term goals that are directly linked to the assessment process and include concrete, measurable outcomes with related activities to benchmark objectives.
- Provision of appropriate and timely support and assistance, including necessary accommodations that maximize the person's full potential to actively engage and participate.
- Charting and monitoring of progress made toward achievement of the goal and to revise the plan accordingly.

Such a close connection between planning approaches provides the case management practitioner a wealth of opportunity to be a valuable resource for integrated planning between providers, schools, the family, the student and the community.

- Advocate for student and family directed, culturally competent services and supports.

[1] Devlieger, P., & Trach, J. (1999). Meditation as a transition process: The impact on post-school employment outcomes. *Exceptional Children 65*, 507-523.

- Facilitate coordination, communication and collaboration among all key stakeholders.
- Organize and synthesize multiple plans under a single set of goals that direct resources from responsible agency/school through objectives and activities that appropriately respond to and support the goal(s).
- Link resources between providers to maximize efficiency and eliminate redundancy.
- Navigating between systems, including the community-at-large to ensure seamless coordination. Establish and maintain a strong interagency network.
- Bring the outside in. School staff rarely have a chance to get out to learn about innovation and best practice in the service world. Offer to bring in resources and information, training and technical assistance.
- Monitor, track and report progress and outcomes. Highlight successes so that partners see the fruit of their labor.
- Assist in conflict negotiate and resolution to avoid a break in communication and collaboration.

Justice-Involved Youth and Education Rights

According to the Individuals with Disabilities Education Act (IDEA), all students, including those involved in the juvenile justice system, are guaranteed the right to a free, appropriate, public education (FAPE). An in-depth discussion of the juvenile justice system and issues that Case Managers may encounter when working with youth who have been involved with the system is included in Module 12.

Module 3: Resources

Transition Planning Rights: Resources for Students and Families

NYS PROMISE Learning Center
http://paths.nyspromise.org/

Disability.gov page on Transition Planning
https://www.disability.gov/resource/disability-govs-guide-student-transition-planning/

Center for Parent Information and Resources
http://www.parentcenterhub.org/

New York State Education Department
http://www.p12.nysed.gov/specialed/transition/sandf.htm

Special Education in Plain Language
A publication of the New York State Special Education Task Force
https://www.nyspecialedtaskforce.org/publications.html

Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities
U.S. Department of Education Office for Civil Rights
http://www2.ed.gov/about/offices/list/ocr/transition.html

Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools
U.S. Department of Education
https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf

Part 100 Regulations: NYS Department of Education
http://www.p12.nysed.gov/part100/pages/1005.html

This page offers links to all the New York State regulations on general, Regents, and local diplomas as well as alternatives to diplomas. The language is legal and there are no charts or plain-language explanations.

Diploma Requirements Worksheet
NYC Department of Education
http://schools.nyc.gov/NR/rdonlyres/4C9C416B-88DF-4413-992B-E967D1F46D18/0/Acpolicydiplomaworksheet.pdf

This two-page worksheet helps students track credits earned and exam scores achieved.

Credit Requirements: General Education
NYC Department of Education
http://schools.nyc.gov/NR/rdonlyres/215FF06B-DCA3-442B-89DF-18E674DC867E/0/Acpolicygened.pdf

This colorful, 18-page guide describes the credit and examination requirements for general education students to earn a Regents and Advanced Regents Diploma. It breaks the requirements down by year of entry into 9th grade. For each year it features a "Look ahead" section that guides 9th graders towards

thinking about classes they can take and tests they need to pass to support their college and career readiness. It is organized so that if it is printed double-sided, it creates one-sheet handouts for students of different ages.

Credit Requirements: Students with Disabilities
NYC Department of Education
http://schools.nyc.gov/NR/rdonlyres/531C5296-BC35-43E0-BD29-2D7E29BAB2C7/0/AcpolicySWDGradCards201617.pdf

This colorful, 18-page guide describes the credit and examination requirements for students with disabilities to earn a Local and Regents Diploma or Advanced Regents Diploma, and also describes CDOS requirements. It breaks the requirements down by year of entry into 9th grade. For each year it features a "Look ahead" section that guides 9th graders towards thinking about classes they can take and tests they need to pass to support their college and career readiness, and it is organized

College and Career Prep

College Planning Handbook
http://schools.nyc.gov/NR/rdonlyres/9BD47E57-EF8E-4BDA-95E3-893BDA0FBC94/0/CollegeHandbook52912.pdf

This extensive guide to planning for postsecondary education was produced by the New York City Department of Education. It describes the difference between high school and college, lists the types of college options available to students, and discusses how to search for a school that matches interests and needs. It also provides and overview of the application process and financial aid options.

Other Resources to Prepare Youth for Transition

*Cents and Sensibility: A Guide to Money Management for People with Disabilities*http://www.nasddds.org/uploads/documents/Financial_Education_Booklet.pdf

This 60 page booklet can be completed independently by youth or with adult assistance. Walks through steps towards creating a budget, establishing credit, and borrowing and saving money.

http://www.lifecoursetools.com/learning-materials/

Series of tools developed by families to help youth and families envision and plan for the future. Includes 20-page daily life and employment guide and a 4-page guide that assists parents and professionals in talking with youth about transition-related decisions that help to share their future.

http://www.pacer.org/transition/resource-library/publications/NPC-33.pdf

This is a document published by the Pacer Center that provides a list of important paperwork that transitioning adults should obtain.

Life Domains

Life Domain	Questions to Answer	Long-Term Goal(s)	Short-Term Goal(s)
Health	• What health and medical needs are priorities right now? • Are there health and medical needs that require on-going support? • What condition must be present that will support this person to live a healthy lifestyle?		
Living Arrangements	• Where will this person live after leaving high school? • Where does this person want to live? Is it different than what the family wants? • What supports will need to be in place to maximize a good living situation?		
Finances/Money	• Where will money come from? • How will finances be managed? • Who will manage them? • What assistance might be needed to manage finances?		
Friends/Social Relationships	• Where or how will opportunities to make friends and establish social connections be available?		
Transportation	• What transportation requirements will be needed? • What assistance or support for transportation will be required?		
Continuing Education/Post-Secondary	• Is there interest in continuing educational pursuits beyond high school? • Trade school? • College?		

Employment	• Are there plans for finding a job? • What kind of employment might be of interest?		
Leisure Time	• How will leisure time be spent? • What hobbies, talents and/or interests might direct leisure activities?		
Community Participation	• Are there particular clubs, groups or associations that have similar interests? • How will this person make a contribution to civic life? • Are there opportunities for (or interest in) volunteering? Where? • What spiritual and/or cultural activities are available and of interest?		
Legal/Advocacy	• How will this person make decisions in his or her life? • Does he or she need support in decision-making? Who will help them?		

Module 4: Self-Determination

Introduction

In this module, case management practitioners will be introduced to the concept of self-determination. The module explores the role that case management practitioners will play in supporting, training, and assessing self-determination in NYS PROMISE youth. Additional topics include the personal and cultural factors that may influence self-determination for youth and families, tools available for utilization with youth and families, and further resources available to assist with integrating self-determination into case management.

Self-Determination in the Field of Intellectual and Developmental Disability

Self-determination is a concept that evolved in the field of personality psychology in the 1940's, and later became a catalyst for challenging the way society views individuals with intellectual and developmental disabilities.[1] Self-determination involves the determination of one's own fate, without coercion, and is viewed as a fundamental human right.[2] It is a lifelong process by which someone controls his/her own life—by making choices and decisions based on their own preferences and interests, monitoring and regulating their own actions, and being goal-oriented and self-directing.[3] Self-determination for individuals with disabilities includes an acknowledgement of their right and capacity to have control over and direct their own lives.[4] In addition to being defined as a conceptual model or perspective for viewing personal choice, self-determination involves a set of skills and behaviors that can be taught to youth in order to help them achieve more positive outcomes. Research strongly links self-determination to more favorable employment, college, independent living, and community engagement outcomes.[5] Yet, research also shows that individuals with intellectual and developmental disabilities have far fewer opportunities to make choices and express preferences in their lives than their peers

[1] Olney, M. F. (2001). Communication strategies of adults with severe disabilities: Supporting self-determination. *Rehabilitation Counseling Bulletin*, 44(2), 87-94.

[2] McDonald, M., Davis, K., & Mahar, N. (2016). When funding meets practice: The fate of contemporary therapeutic approaches and self-determination in a consumer-centred disability funding scheme: M. McDonald et al. *Journal of Policy and Practice in Intellectual Disabilities, 13*(4), 277-286. doi:10.1111/jppi.12195

[3] Deci, E.L. & Ryan, R.M (1985). *Intrinsic motivation and self-determination in human behavior*. New York, NY; Plenum.
Deci, E.L. & Ryan, R.M (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11, pp. 227-268.

[4] Wehmeyer, M. L. (2004), Self-determination and the empowerment of people with disabilities, *American Rehabilitation, 28*(1), 22-29.

[5] Carter, E. W., Lane, K. L., Cooney, M., Weir, K., Moss, C. K., and Machalicek. (2013). Self-Determination among transition-age youth with autism or intellectual disability: Parent Perspectives. Research *& Practice for Persons with Severe Disabilities*, 38(3), 129-138.

without disabilities.[1] There are many individuals who have the capacity to exercise choice and decision-making over their own lives who remain under restrictive substitute decision-making arrangements (e.g., guardianship).

Within the construct of self-determination theory, it is acknowledged that human behavior is complex and is motivated by a multitude of factors. Some behaviors are motivated by intrinsic value that is associated with an activity or event, and others are motivated by external factors, such as tangible rewards. Research has shown that compared to those motivated by external factors, individuals that engage in more self-determined behavior motivated by internal interests and values tend to experience higher levels of creativity, enhanced self-esteem, greater goal persistence, and better overall well-being.[2] Intrinsically motivated behavior is linked to three primary psychological needs: competence, autonomy, and relatedness.[3] **Autonomy** involves an individual acting volitionally with a sense of choice; **Relatedness** is the feeling that one is connected with others, both giving and receiving love; **Competence** is the perception of one's self as a causal agent who is capable of affecting change.

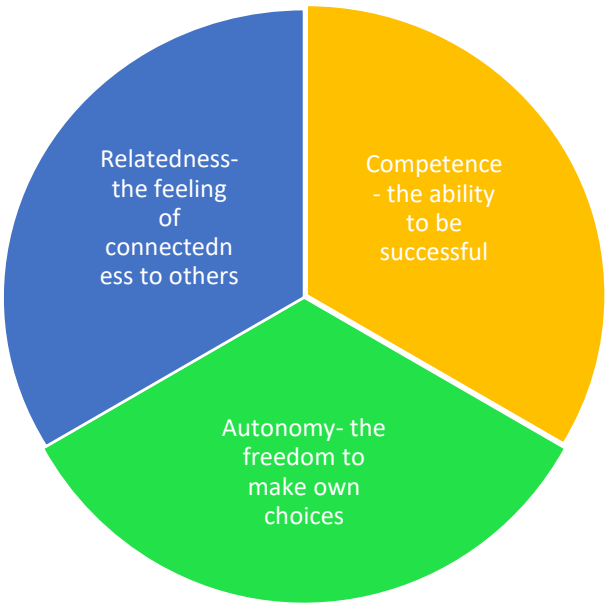

Figure 4.1. Intrinsically Motivated Behavior

[1] Wehmyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities*, 51(5), 399-411.

[2] Fitzgerald, S., Chan, F., Deiches, J., Umucu, E., Hsu, S., Lee, H., . . . Iwanaga, K. (2015). Assessing self-determined work motivation in people with severe mental illness: A factor-analytic approach. *Australian Journal of Rehabilitation Counselling, 21*(2), 123-136. doi:10.1017/jrc.2015.12

[3] Deci, E.L. & Ryan, R.M (1985). *Intrinsic motivation and self-determination in human behavior*. New York, NY; Plenum.

Deci, E.L. & Ryan, R.M (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11, pp. 227-268.

Self-determination is a process that evolves throughout the lifespan, and adults can help youth build skills over time that enable them to gradually prepare for assuming full responsibility of their own decision-making as an adult. Turning over the control of decision-making to a young adult can be scary for parents, especially with children with intellectual and developmental disabilities.[1] Some parents restrict decision-making opportunities for their child because they believe that they (the parents) know better than the child what is in their child's best interest. However, from a developmental perspective, adolescence is a time in the life cycle that is characterized by identity exploration and risk-taking, and allowing adolescents to experience both the positive and negative outcomes of their decisions while still experiencing the safety net of living in their parents' household is a crucial step in the growth process.[2] Throughout the transition from school to the adult world, it is important to provide opportunities for individuals with disabilities to acquire new skills that will help to improve their ability to make decisions and plan for their future. Within the context of healthy and supportive adult-child relationships, self-determination is not about suddenly giving a young person absolute control of all of his/her life decisions, but a process of movement over time from a relationship of dependence (on parent or caregiver) to interdependence and eventually (in many cases) to complete independence.[3] The self-determined student is able to set realistic goals, make decisions, see options, solve problems, act as his/her own self-advocate, and understand the supports he/she needs to achieve success.[4] Recent studies show that students with disabilities who are provided more knowledge about transition planning and transition goals demonstrate a higher level of self-determination.[5]

One of the stated goals of the NYS PROMISE project is to promote, develop and assess the self-determination and independent living skills of the young people involved in the project. Promoting self-determination for people with disabilities is also mandated and supported by federal disability policy and legislation (see Module 3 for more information).

Self-Determination in Individuals with More Severe Disabilities

Self-determination is important for individuals from all cultures and of all ability levels. Even individuals with the most severe disabilities are able to make choices about their own lives, with assistance. According to Shogren, a renowned expert in the field of self-determination, self-determination should

[1] Curryer, B., Stancliffe, R. J., & Dew, A. (2015). *Self-Determination:* Adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability*, 40(4), 394-399.
[2] Curryer, B., Stancliffe, R. J., & Dew, A. (2015). *Self-Determination:* Adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability*, 40(4), 394-399.
[3] McDonald, M., Davis, K., & Mahar, N. (2016). When funding meets practice: The fate of contemporary therapeutic approaches and self-determination in a consumer-centered disability funding scheme: M. McDonald et al. Journal of Policy and Practice in Intellectual Disabilities, 13(4), 277-286. doi:10.1111/jppi.12195
[4] McGuire, J. (2010). Promoting self-determination. In J. McDonnell & M. L. Hardman Successful transition programs: Pathways for students with intellectual and developmental disabilities (pp. 101-114). Thousand Oaks, CA: SAGE Publications Ltd. doi: 10.4135/9781452275024.n6
[5] Wehmyer, M. L., & Abery, B. H. (2013). Self-determination and choice. Intellectual and Developmental Disabilities, 51(5), 399-411.

not be confused with a specific prescriptive outcome, such as living along or having a job.[1] Instead, the focus should be on supporting individuals in intentionally making choices that will cause things to happen in their own lives to improve their desired quality of life outcomes. When an individual has difficulty communicating his/her preferences, others who know the individual well should do their best to take into account the interests, values, and preferences of the individual when making decisions on his/her behalf. Proponents of self-determination believe that all individuals are constantly interacting with their environment, regardless of their ability to communicate with words. For example, individuals with difficulty communicating verbally make preferences and choices known through eye gaze and touch, which may be overlooked by the untrained eye.[2]

Beamer and Brookes (2001) emphasize the fundamental human right of all individuals to engage in self-direction, regardless of level of abilities:

> *The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices (p.4).*[3]

Professionals that work with individuals with more significant disabilities must learn to be sensitized "listeners."[4] The sensitized listener considers the knowledge, environment, time and location when attempting to interpret communication of the individual with the disability. This active listening role requires professionals to collaborate, seek feedback and obtain clarification from the individual with the disability rather than assuming that he/she as a professional "knows" what the individual wants.

The following chart (adapted from Olney, 2001) shows the role that the sensitized listener plays with high verbal communicators vs. low verbal communicators in interpreting communication:

[1] Shogren, K. A. (2013). *Self-determination and transition planning*. Baltimore, MD: Paul H. Brookes Publishing Co.
[2] Olney, M. G. (2001). Communication strategies of adults with severe disabilities: Supporting self-determination. *Rehabilitation Counseling Bulletin,* 44(2), 87-94.
[3] Beamer, S., & Brookes, M. (2001). M*aking decisions. Best practice and new ideas for supporting people with high support needs to make decisions.* London: Values into Action.
[4] Olney, M. G. (2001). Communication strategies of adults with severe disabilities: Supporting self-determination. *Rehabilitation Counseling Bulletin,* 44(2), 87-94.

Sensitive "Listener"	High Verbal Communicator	Low Verbal Communicator
• Considers the context of communication. • Attends to the meaning expressed rather than just the expressions themselves; Suspends attitude of "knowing." • Knows that careful listening yields invaluable insights and information. • Attends to time and place when interpreting communication. • Views non-vocal interactions as valuable sources of communication.	• Expresses thoughts and feelings primarily through verbal means. • Expresses emotions through body language, facial expression, and words. • Assumes others will listen and understand. • Indicates preferences verbally. • Communicates ideas verbally.	• Expresses thoughts and feelings using a combination of verbal and non-verbal strategies. • Expresses emotions through body language, facial expressions, and actions. • May assume others will not listen or understand. • Indicates preferences through schedules, time, place, and movement. • Communicates ideas through shared experiences and knowledge.

Self-Determination in the Field of Mental Health

Although the concept of choice and self-determination conflict with the traditional medical model that has been historically prevalent within the mental health system, there has been a significant peer-led movement within the mental health community over the last century to replace the medical model with a model of shared decision-making.[1] Under the medical model, physicians and clinicians are viewed as the experts who provide information and make decisions regarding client/patient care, with the service participant maintaining a more passive role. In recent years, the paradigm has begun to shift to a more patient/client centered approach in which the physician or clinician views the individual more holistically, and power and responsibility are shared, with a focus on building a trusting therapeutic alliance. A study that was released in 2007 found that when individuals experiencing depression engaged in the act of shared decision-making, they demonstrated an increased overall understanding of their own health and a higher rate of compliance with mental health treatment.

The paradigm shift towards self-determination has coincided with the shift to a more recovery-focused approach. Recovery within this context is defined as the ability for individuals to live, work, learn, and participate fully in their community, and live productive and fulfilling lives while adjusting to a disability that encompasses just a part of their overall being.[2] The Substance Abuse and Mental Health Services Administration (SAMHSA) defines recovery as "a process of change through which individuals improve

[1] Olson, L. M. (2012). Self-determination and mental illness. *Mental Health Special Interest Section Quarterly / American Occupational Therapy Association, 35*(1), 1.
[2] Corrigan, P. W., Angell, B., Davidson, L., Marcus, S. C., Salzer, M. S., Kottsieper, P., . Stanhope, V. (2012). From adherence to self-determination: Evoluton of a treatment paradigm for people with serious mental illnesses. *Psychiatric Services, 63*(2), 169-173. doi:10.1176/appi.ps.201100065.

their health and wellness, live a self-directed life and strive to reach their full potential" (p.3).[1] Within the self-determined and recovery-oriented approach to mental health, services look beyond symptom reduction, and instead focus on promoting psychological well-being and overall quality of life.[2] Hope, empowerment, informed choice, and respect are embedded in all interventions. Within the context of the mental health system, self-determination can be promoted in decision-making and choices related to housing, therapy, employment, and community integration.[3]

Supported Decision-Making

The Right to Make and Act on One's Own Decisions

In 2007, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) brought the issue of "legal capacity" to the forefront in the field of disability. Historically, legal capacity has been viewed as inseparable from mental capacity, which has often led to the practice of deeming individuals with developmental and psychosocial disabilities legally incapable of making their own decisions. Within the CRPD, people with disabilities are granted legal capacity for rights and capacity to act on an equal basis with others in society. The CRPD also asserts that individual states have an ethical duty and responsibility to provide persons with disabilities access to the supports necessary to fully exercise their decision-making right. This also requires that states provide safeguards to prevent others from ignoring preferences and decisions of the individual with the disability.[4] The UNCRPD document is considered a major paradigm shift in the field of disability and mental health because it challenges the legal system to move away from evaluating individuals in terms of "capacity" (a deficit-based approach founded on the outdated medical view of disability) and implies that supports should be provided to individuals with deficits in order to enable the individuals to exercise their legal capacity on an equal basis with others.[5] As a human rights document, the UNCRPD is an abstract legal document that does not provide specific definitions of support. However, it serves as a framework that guides social and legal structures towards greater equality for all individuals, without making judgements about one's "capacity."[6]

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[1] SAMHSA. (2012). *SAMSHSA's working definition of recovery*. Report No. PEP12-RECDEF. Rockville, MD: SAMHSA.

[2] Fitzgerald, S., Chan, F., Deiches, J., Umucu, E., Hsu, S., Lee, H., . . . Iwanaga, K. (2015). Assessing self-determined work motivation in people with severe mental illness: A factor-analytic approach. *Australian Journal of Rehabilitation Counselling, 21*(2), 123-136. doi:10.1017/jrc.2015.12

[3] Stanhope, V., Barrenger, S. L., Salzer, M. S., & Marcus, S. C. (2013). Examining the relationship between choice, therapeutic alliance and outcomes in mental health services. *Journal of Personalized Medicine, 3*(3), 191-202. doi:10.3390/jpm3030191

[4] Gooding, P. (2015). Navigating the 'flashing amber lights' of the right to legal capacity in the United Nations convention on the rights of persons with disabilities: Responding to major concerns. *Human Rights Law Review, 15*(1), 45-71. 10.1093/hrlr/ngu045

[5] Morrissey, F. (2012). The United Nations convention on the rights of persons with disabilities: A new approach to decision-making in mental health law. *European Journal of Health Law, 19*(5), 423-440. 10.1163/15718093-12341237

[6] Gooding, P., Arstein-Kerslake, A., & Flynn, E. (2015). Assistive technology as support for the exercise of legal capacity. *International Review of Law, Computers & Technology, 29*(2-3), 245-265. 10.1080/13600869.2015.1055665

Supported decision-making is a process that supports people with disabilities to retain their decision-making capacity by choosing trusted supporters to help them make choices. A person using SDM selects advisors, such as friends, family members, or professionals, to help them through the decision-making process. Although the SDM model has a solid theoretic framework, the application of SDM will look different for everyone. As such, supporters commit to assisting the person with a disability understand, consider, and communicate decisions using experiential learning and other tools to make his or her own informed decisions.

Examples of these tools might be:

- Plain language materials or information in visual or audio form
- Extra time to discuss choices
- Creating lists of pros and cons
- Role-playing activities to help the person understand choices
- Bringing a supporter into important appointments to take notes and help the person remember and discuss her options
- Opening a joint bank account to manage financial decisions together
- Exposure to environments, options and opportunities to broaden/expand the person's experiential base
- Assisting the person to connect with others who can demonstrate something to the person

In situations in which SDM is not a viable option, a **Facilitated Decision-Making model (FDM)** has been proposed.[1] The FDM model can be applied in situations in which an individual with a disability is unable to communicate decisions and preferences and does not have an adequate support system in place. Within the FDM model, a person who is familiar with the individual with the disability makes decisions on his/her behalf, and the appointed decision-maker is bound to accommodate the individual based on any previously gained knowledge of the individual's expressed wishes. This process does not involve categorizing the individual with a disability as "legally incapable," and the individual can revoke the decisions at any time if he/she regains the ability to express his/her desires.

Resources on Supported Decision Making from the American Civil Liberties Union and other organizations are available – see the *Resources* section for links.

Shared Decision-Making in Mental Health Care

Advocates in the mental health field have begun to look at some of the specific challenges that arise in treating mental health conditions in which the capacity to make decisions is compromised. *Shared decision-making* recognizes that in crisis situations (such as relapses or negative reactions to medication) individuals experience a reduced decision-making capacity. Under the shared decision-making model, individuals with mental health diagnosis meet with their physician/health care provider(s) in advance to

[1] Morrissey, F. (2012). The United Nations convention on the rights of persons with disabilities: A new approach to decision-making in mental health law. *European Journal of Health Law, 19*(5), 423-440. 10.1163/15718093-12341237

discuss their future wishes for mental health treatment during times of crisis. This allows the individual and their health care providers to engage in discussion and exchange information at a time when the individual is able to fully engage in making decisions for himself/herself, so that the individual can express his/her wishes during times of mental health crisis.

While there are currently no legal mandates within New York State for implementing advanced directives regarding mental health decisions, case managers can engage in discussions with individuals with significant mental health diagnosis (depression, bipolar disorder, schizophrenia, etc.) about communicating their wishes to health care providers about preferences for treatment. For example, the individual may have experienced negative reactions to or have preferences about medications that might be administered during times of mental health crisis.

Role of the Case Management Practitioner in Supporting Self-Determination

Proponents of the ecological perspective recognize that all individuals within the community share a role in building self-determination within individuals with disabilities. Research supports the idea that individuals with intellectual disabilities can become more self-determined when exposed adequate supports, learning opportunities, and experiences from people in their lives.[1] The ecological perspective asserts that self-determination occurs as a result of a lifelong interplay between individuals and their environment. A recent study found that the absence of staff during free time led to increased choice-making by participants with disabilities, and it was hypothesized that they felt more free to choose their preferences when they did not need to ask permission from staff to engage in the activity.

Family members have different responses to the concept of self-determination. Some families have concerns about their child's vulnerability and offer limited opportunities for the child to be actively involved in making decisions about their future. The areas in which parents have the most difficulty allowing their child to make decisions are the more complex issues such as living arrangements, health care decisions, and money management[2]. Case managers can play an integral role in helping to facilitate conversations between parents and youth about the benefits of self-determination. Self-determination should be integrated into regular case management interventions with youth and their families. As described in Module 1, case management involves:

- Assessment activities
- Case planning
- Meeting of basic needs
- Crisis management

[1] Wong, P. K. S., & Wong, D. F. K. (2008). Enhancing staff attitudes, knowledge and skills in supporting the self-determination of adults with intellectual disability in residential settings in Hong Kong: A pretest–posttest comparison group design. Journal of Intellectual Disability Research, 52(3), 230-243. doi:10.1111/j.1365-2788.2007.01014.x

[2] Curryer, B., Stancliffe, R.J., & Dew, A. (2015). Self-determination in adults with intellectual disability and their family. Journal of Intellectual and developmental Disability, 40(4), 394-399.

- Education preparation
- Employment preparation
- Advocacy and self-sufficiency
- Brokering of resources

Practitioners should build opportunities for NYS PROMISE youth to meet these needs by providing opportunities during case management to:

- discuss preferences
- identify options
- examine potential outcomes (positive and negative)
- set goals
- outline intermediary steps
- identify supports

The following model of self-determination is adapted from a model that was proposed by Hoffmanand Field and can be used as a template for structure case management conversations with youth[1]:

Figure 4.2.Model for Self-Determination

[1] Hoffman, A., & Field, S. (2006). *Steps to self-determination.* (2nd ed.). Austin, TX: PRO-ED.

According to Wehmer (2007).[1] self-determination education should focus on teaching the following skills:

- choice-making
- decision-making
- problem-solving
- goal-setting and attainment
- independence, risk-taking and safety
- self-observation, evaluation, reinforcement
- Self-instruction
- Self-advocacy and leadership

The following chart provides some specific examples of self-determination skills that can be taught to youth throughout the employment process[2]:

Category	Related Activity/Skill
Preparing for work	• Getting ready • Getting dressed • Getting to work
Managing time	• Being on time • Structuring work day • Balancing work and personal time
Managing job duties	• Completing forms • Finding information • Dressing for work • Planning which job to do first
Communication skills	• Talking with boss • Talking with co-workers • Talking with customers • Asking questions
Managing Money	• Reading pay stubs • Banking skills • Budgeting

[1] Wehmeyer, M. L. (2007). *Promoting self-determination in students with developmental disabilities.* New York, NY; The Guilford Press.
[2] Wehmer, M. L. (2007). *Promoting self-determination in students with developmental disabilities.* New York, NY: The Guilford Press.

Case management practitioners can provide additional support for youth growth in the realm of self-determination by:

- Supporting a person-centered perspective on planning for and providing services
- Integrating self-determination into the transition to adulthood planning for youth by utilizing tools like the **NYS PROMISE Your Path to Success** toolkit at paths.nyspromise.org, academic calendar, and **NYS PROMISE Paths** skill sheets
- Providing referrals for families to the Parent Center core training (see Module 2 for a description of the trainings provided) and utilizing **NYS PROMISE Parent Binder** tools

Additional information on how case managers can integrate self-determination theory and processes into the case management process are detailed in *Module 5: Case Planning and Service Coordination*.

Cultural Differences in Self-Determination

How self-determination is expressed will vary between individuals, cultures, religions, genders, ages and regions. Self-determination may also vary between domains, with individuals expressing strong preferences in one area of their life and relying more upon the opinions of trusted friends and family in others. There is no one right approach or result for self-determination, practitioners may need to be flexible on what self-determination looks like for each individual. Case managers should respect the individual and personal characteristics that impact student self-determination including; youth's gender, racial/ethnic identity, disability, and family income.[1]

Autonomy, or the freedom to make choices, is very different from individualism, or the habit of being independent. In the United States, mainstream culture tends to value **individualism** or being independent and self-reliant and making decisions on one's own. Examples of individualistic goals may include milestones like; graduating from school with honors, moving away for college or work to gain a prestigious position, living away from the family home, and living a financially independent life with one's own spouse and children. However there are also many cultural groups within the United States that are more **collectivistic**, where individuals make decisions based on what is best for family, community, or society first. In a collectivistic culture, milestones may include supporting younger siblings or elderly family members, living at home until marriage, contributing earned money to communal finances, and maintaining very close ties or the same household with a multi-generational or extended family throughout an entire lifetime. Neither individualism nor collectivism as a philosophical approach is preferred by NYS PROMISE, however the project does aim to improve the student's autonomy and ability to participate actively in choice-making, increasing the student's self-determination capacity as they transition to adulthood.

Practitioners will likely encounter a range of approaches to choice-making for individuals within their practice with NYS PROMISE youth and families. Family and cultural philosophies can lead to very

[1] Shogren, K., & Shaw, L. (2016). The impact of personal factors on self-determination and early adulthood outcome constructs in youth with disabilities. *Journal of Disability Policy Studies*, 2016, online ahead of print.

different understandings and visions of self-determination, and case managers should take care to discuss with families and youth their individual and family expectations as a part of regular meetings.

Beliefs that families hold about individuals with disabilities can be culturally specific.[1] [2] These beliefs may impact how a family or individual views the cause of the disability as well as their decisions about the treatment process. For example, in some cultures, a child's disability is believed to be the result of a curse upon the family, while in other cultures, children with disabilities are viewed as individuals with special powers and abilities. When working with families, it is important to understand how the family members view the disability within the context of their culture.

Tips for Providing Culturally Sensitive Care[3]

1. Spend extra time working on the development of trusting relationships with the family.
2. As the family to explain their cultural beliefs surrounding disability.
3. Offer to serve as a cultural broker or advocate for the family when interacting with medical professionals and other professionals.
4. Talk with the family about their feelings about leaving their previous culture and losses that they have experienced.

Self-Determination Assessment

The services and training case management practitioners provide to youth and families are important in improving the youth and their family's assessment of self-determination. Case management interventions, trainings, and experiences youth have while enrolled in NYS PROMISE will help build and grow additional skills in finding supports in local communities for engaging in community living, learning and earning. NYS PROMISE will measure how youth and the parents enrolled in the project assess the youth's self-determination and independent living skills over time through surveys, activities in NYESS, and focus groups.

During case management interventions, practitioners will help youth and their families to set milestones, determine goals, and refer the youth and family for activities with service providers. Using the tools provided in the resource section of this Module, case managers will support post-secondary pathways, and chart progress over time.

Self-determination will be measured in the following life domains:

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[1] Boston, Q., Dunlap, P. N., Ethridge, G., Barnes, E., Dowden, A. R., & Euring, M. J. (2015). Cultural beliefs and disability: Implications for rehabilitation counselors. *International Journal of Advanced Counselling, 37*, 367-374.
[2] Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies, 21*, 311-319.
[3] Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability & Rehabilitation, 34*(23), 2007-2017.

- Employment
- Education
- Community Living
- Self-determination
- Health
- Finance
- Community Participation

Tools to Support Post-Secondary Pathways

NYS PROMISE has created seven worksheets for use by case management practitioners. These worksheets are to be used during regular case management meetings with intervention group youth. The worksheets address the seven domains of self-determination, and provide the opportunity for case management practitioners to discuss and outline goals and milestones for transition with the youth and their parent.

Figure 4.3 Community Living Worksheet

Figure 4.4 Community Participation Worksheet

Figure 4.5 Education Worksheet

Figure 4.6 Finances Worksheet

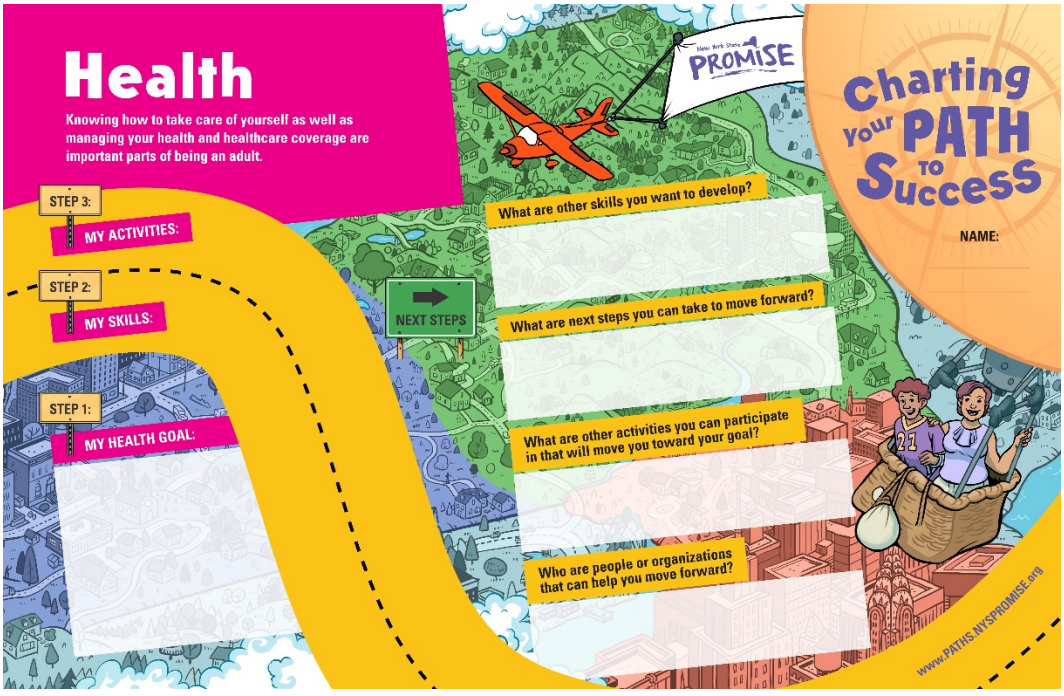

Figure 4.7 Health Worksheet

Figure 4.8 Self-Determination Worksheet

Figure 4.9 Work Worksheet

Module 4: Resources

See *Case Managers Field Guide, Module 13: Community Participation*, for a checklist on community inclusion.

Fostering Self-Determination Among Children and Youth with Disabilities. A guidebook written for parents by parents that gives tips for building self-determination and self-advocacy skills in youth.
http://interwork.sdsu.edu/sp/takecharge/files/2013/05/FosteringSelfDetermination.pdf

National Gateway to Self-Determination
http://www.ngsd.org/

The Path to Independence: Mobile Apps to Support Transition Age Youth. Contains a list of the most up-to-date mobile apps to assist with finding and getting a job, exploring careers and colleges, supporting independent living and executive function skills, and more.
http://www.pacer.org/transition/resource-library/publications/NPC-59.pdf

Promoting Self-Determination: A Practice Guide
http://ngsd.org/sites/default/files/promoting_self-determination_a_practice_guide.pdf

The Road to Work*:* 28-page workbook published by Youth4Advocacy that is filled with activities for youth to complete related to self-advocacy in the work world. Includes worksheets and activities that focus on identifying career interests, looking for jobs, writing resumes, preparing for interviews, and understanding your rights as a worker.

http://www.self-advocate.org/library/pdfs/RoadtoWork.pdf

Books

Deci, E. & Ryan, R. (2002). *Handbook of self-determination research*. Rochester, NY: University of Rochester Press.

Shogren, K. A. (2013). *Self-determination and transition planning.* Baltimore, MD: Brookes Publishing.

Module 5: Case Planning and Service Coordination

Introduction

This module covers case planning and service coordination for youth and families enrolled in the NYS PROMISE. NYS PROMISE case management and service coordination is described, as well as planning techniques. We review the development, monitoring and ongoing engagement expectations for service plans. The module discusses the importance of developing and maintaining collaborative relationships to the case planning and service coordination process. Finally, we review how services are evaluated.

Case Management and Service Coordination

Case management meetings are the foundational service provided by NYS PROMISE to enrolled youth and their families. Case management meetings occur whenever the youth, parent, case manager and/or family coach meet, whether in-person, online or by phone.

Case management practitioners will meet with youth and families on a regular basis. Practitioners will record in NYESS every attempt to contact youth and families. Additional guidance on case management activities can be found in the *NYS PROMISE Policies and Procedures Manual* as well as the *NYS PROMISE Intervention and Implementation Guide* available at www.nyspromise.org/secure.

Planning Techniques in Case Management

Planning is the primary activity that case management practitioners will be performing with youth and families. Planning techniques utilized by case managers may include:

- Motivational Interviewing
- Strength-Based Assessments
- Prioritizing Needs

Once a service plan is created, case management practitioners will provide appropriate service referrals and coordination to support the youth and family's plans. Service plans are expected to evolve over time, and the planning techniques discussed below should be regular and on-going activities case managers utilize during the regular case management meetings and planning sessions.

Motivational Interviewing

Motivational interviewing (MI) is a collaborative, person-centered counseling approach that has been adopted by human service professionals to help guide individuals through the process of changing unhealthy behavior.[1] The premise of MI is that individuals are often ambivalent about change, meaning

[1] Miller, W. R. & Rollnick, S. (2013) *Motivational interviewing: Helping people change*. (3rd Edition). NY: The Guilford Press.

that they can identify both reasons for changing behavior and reasons for maintaining their current behavior. Ambivalence involves wanting two incompatible things. The goal of MI is to engage individuals in a dialogue that promotes self-reflection and helps them identify their own reasons for change, drawing on their own internal motivation and strengths. MI is a model of communication that has been proven to be effective in working with individuals who are hesitant and guarded in their relationships with professionals, because the focus is on listening to the individual's story and highlighting strengths rather than forcing unwanted changes on the individual.

Professionals in the field of human services often have a strong "righting reflex," or desire to convince or persuade others to do what they think is right by providing information and arguments for change. Motivational interviewing involves a less forceful approach, because research has shown that if an individual in a state of ambivalence is pushed to change too quickly, the individual may feel angry, defensive, uncomfortable or powerless.

The Spirit of Motivational Interviewing

Motivational Interviewing (MI) is a style of interacting with individuals that sets a tone of empathy and compassion. It is a partnership and a commitment to walk "with" a person on his/her journey towards change.

The spirit of MI is based on acceptance, and that acceptance can be broken into four parts:

1. Valuing the inherent worth and potential of every human being.
2. Providing accurate empathy by taking an interest in and making an effort to understand life through the other person's eyes.
3. Supporting autonomy by honoring the person's right for self-direction.
4. Affirming the individual by communicating and acknowledging the person's strengths and efforts.

In contrast to the common approach in the human service profession of focusing on problem behavior, the spirit of MI involves a focus on strengths. The MI philosophy asserts that individuals hold the wisdom and strengths to come up with their own reasons for change and overcome their ambivalence. The goal of the case management practitioner in the MI relationship is to evoke or "bring out" the individual's own internal motivations for change and then assist the individual in creating a plan of action. Sometimes after individuals work through their feelings of ambivalence, they make changes on their own with very little need for assistance from practitioners.

Four Processes of Motivational Interviewing

There are four central processes that contribute to the flow of MI and help move an individual through the change process.

1. **Engaging**- the process of forming a positive working relationship and connection.
2. **Focusing**- identifying a direction for change goals
3. **Evoking**- helping the individual to identify and express reasons for change

4. **Planning**-developing a commitment to change and coming up with an action plan

Questions for Each Stage of the Motivational Interviewing Process	
Engaging	• How comfortable is the person talking to me? • How supportive and helpful am I being? • Do I understand the person's perspective and concerns? • How comfortable do I feel in this conversation? • Does this feel like a collaborative partnership?
Focusing	• What goals for change does this person have? • Do I have different aspirations for change than the client has for himself/herself? • Are we working together with common goals? • Do I have a clear since of where we are headed in the future? • Does this feel more like dancing or wrestling?
Evoking	• What are the person's reasons for change? • Is the reluctance more about confidence or importance of the change? • Am I steering the person too far or too fast in a particular direction? • Is the righting reflex pulling me to be the one arguing for change?
Planning	• What would be a reasonable next step toward change? • What would help this person to move forward? • Am I remembering to evoke rather than prescribe a plan? • Am I offering needed information or advice with permission? • Am I retaining a sense of quiet curiosity about what will work best for this person?

Principal Skills of Motivational Interviewing

There are some essential skills that can be utilized in all four processes of MI. These skills include:

Asking open-ended questions that invite the individual to elaborate and reflect on their reasons for change. Example: "Tell me more about your reasons for wanting to find a job."

Affirming the resources, strengths and wisdom that reside within the individual. Example: "In order to get where you are today, you have developed a lot of successful strategies for helping your son. What things have you learned that help him at home?"

Reflective statements that help clarify whether you are understanding the individual's thoughts and feelings correctly. Example: "It sounds like your negative experiences with school as a child cause you to feel nervous when you attend meetings for your daughter."

Summarizing what has been discussed during conversations. Example: "Before we wrap up our meeting, I just want to go over what we talked about and make sure we are all clear about where we are going from here. You would like your son to work on finding a job, but you are still concerned about how this will impact your family's finances. You will continue talking with your son at home about what kind of work he might be interested in learning more about and we will make a referral to a provider agency to begin taking your son out into the community to try out different jobs. It sounds like it would also be a good idea for you to attend our next training on benefits, so I will send you the information about that training."

Developing discrepancy between the individual's current behavior and goal and values. Example: "It sounds like you really want your daughter to graduate from high school with a Regents Diploma, but it has been difficult for you to maintain a morning routine that helps her to get to school. "

Stages of Change

As individuals move from ambivalence to actively carrying out change in their lives, they move through a series of steps:

1. **Pre-contemplation** - Individual perceives no benefits to change and many costs
2. **Contemplation -** Individual sees both costs and benefits to change, but believes the costs outweigh the benefits
3. **Determination** - Individual identifies both costs and benefits and believe the benefits of change outweigh the costs; Begin to explore options for change
4. **Action** - Continue to believe there are more benefits than costs to change and actively work towards change
5. **Maintenance** - Individual maintains change over time

See the *Snapshot on Motivational Interviewing Techniques* at the end of this module.

Strength-Based Assessment: Assessing Strengths and Needs across Life Domains

Strengths-based assessment[1] is the intentional search and discovery of the inherent strengths of a person or a family in order to recognize and to build upon them. It is an empowering alternative to traditional approaches that are often based on an unbalanced power structure: the professional as the expert authority and the student and/or family as a problem to be resolved. Instead, strength-based approaches presume that the student and the family have much to work with and to learn from and this information will serve as a powerful tool for advancing positive and productive strategies and objectives.

Strength-based assessment and strength-based practices:

[1] (Chapin, 1995; Early & GlenMaye, 2000; Kisthardt, 1992; Miley, O'Melia & DuBois, 2001; Poertner & Ronnau, 1992; Rapp, 1992; Saleebey, 1992c; Sullivan & Rapp, 1994; Weick et al., 1989)

- Avoid the use of stigmatizing language or terminology that families use on themselves and eventually identify with, accept, and feel helpless to change.
- Are solution-focused rather than problem-focused.
- Generate hope by focusing on what is or has been historically successful for the student, or the family, thereby exposing precedent successes as the groundwork for realistic expectations.
- Develop inventories (often for the first time in the student's experience), identifying the positive building blocks that already exist in his/her environment that can serve as the foundation for growth and change.
- Promote self-determination, autonomy and self-direction because it raises the student to the level of expert in regards to what has worked, what does not work, and what might work in their situation.
- Engage and invest students and families in processes where they feel they are an integral factor to success.

The following are seven important principles of the strengths perspective gleaned from an article called *What is the Strengths Perspective?*[1]

1. People are recognized as having many strengths and have the capacity to continue to learn, grow and change.
2. The focus of intervention is on the strengths and aspirations of the people we work with.
3. Communities and social environments are seen as being full of resources.
4. Service providers collaborate with the people they work with.
5. Interventions are based on self-determination.
6. There is a commitment to empowerment.
7. Problems are seen as the result of interactions between individuals, organizations or structures rather than deficits within individuals, organizations or structures.

People gain more from experience when they are empowered to take charge. This is vitally important for youth as they move from student status to adult status. Putting young people in the driver's seat of their own future often leads to:

- Clearer sense of direction and motivation to pursue goals
- An awareness of what being self-determined means
- Greater family/social network investment and involvement
- Improved social status in the community (as college student; employee; volunteer vs. client/consumer)
- Increased competence and self-esteem
- Enhanced perception, recognition and acceptance of capacities, strengths and potential
- Strengthened skill and experience as contributing members of society
- Broader job/continuing education choices, and therefore better job/post-secondary education fit
- Better overall transition planning goals and outcomes

[1] Stuart, G. (2012). *What is the strengths perspective?* Blog post on *Sustaining Community*. (https://sustainingcommunity.wordpress.com/2012/05/30/what-is-the-strengths-perspective/)

Conducting a Strengths Conversation (Youth and Family)

There are many ways to approach gathering information from a strengths-based perspective including actual assessment tools that range from facilitated to self-conducted processes. There are on-line strengths assessments, free of charge as well as fee-based services. These can be great resources to get students and families into thinking about the strengths that they have, especially if a focus on positive qualities, attributes, and experiences is a new perspective.

Person-centered planning processes, which are well-known in the community service provider sector, are by their very nature built on the foundation of a strengths-based perspective. For example, *A Framework for Planning*[1] has been used extensively as a formal facilitated process for transition planning with youth and their families because it explicitly produces a positive profile of the student from which transition goals can be identified and needs assessed within the context of the goals, especially with regard to employment, post-secondary education goals, community participation and contribution.

One of the best strategies for beginning to surface and gather information about the strengths, capacities and even the potential of a person or family, is through informal conversation. "Tell me about what you are most proud of or what you admire about…" is often a highly effective start to learning about someone's strength. The stories that emerge within the context of this kind of question often provide opportunities to dive deeper because of clues that are naturally embedded throughout the story.

Tips for conducting a strengths-based conversation

Since facilitating a conversation that yields positive, strengths-based information may be different for the student and the family, it is important to set the stage for the conversation. Let people know in advance that the focus of the conversation will be on finding what's "right" with the student. This doesn't mean avoiding all reference to the impact of disability but rather a rearranging of the emphasis of the conversation.

The person conducting the assessment must also be prepared to start and engage people in a conversation that is geared toward identifying strengths, attributes, interests, capacities, preferences, abilities and in surfacing the kind of support that the person needs and wants. In this context, this conversation moves away from an interview-style (professional asks questions and writes down answers) to a discussion that uses open-ended questions and reflective listening.

Providing the student or the family resources to complete in advance of the conversation offers them a chance to begin thinking about how they would answer particular questions so that they are better prepared to actively participate in the discussion. Asking the student to return these resources in advance of the conversation can be a strategy that lends insight into the degree of receptivity, readiness, or understanding a student or family has about identifying strengths.

[1] Blessing, C., & Ferrell, C. (2012). *A framework for planning.*

At all times, conducting a strengths-based conversation should be a positive, hopeful, and constructive process. Explore creative, non-intrusive recording methods to capture important details of the conversation to avoid inadvertently derailing the focus from the student/family-focused process to a paper-centered process.

The assessment is best conducted in an informal, conversational and genuine manner, rather than a structured interview. It is best conducted whenever possible on the student's own territory and in places where they and their family feels comfortable, rather than in formal service or institutional settings.

The assessment should be developed at each individual's pace and comfort level, and adapt to change. Because it is customized to meet the preferences and needs of the student and the family, some assessments will be completed relatively quickly, and can reasonably be reviewed on a regular basis e.g. every six-months. Some assessments will take many months or years to build up, and therefore may not fit a regular review cycle. However, the IEP and transition plan requires a comprehensive assessment so the information gathered from these conversations can and should be included where ever and whenever possible.

Important notes about the use of questions as a strategy to engage conversation.

- Questions are to be used merely as guideposts for discovering and surfacing interesting information about the person – when used well, questions should lead to new, deeper questions
- Questions are not required and should never be used to supplant an "agenda"
- Questions should always be conveyed with respect for the person
- The person always has the right to decide what questions to answer – or not
- Questions are asked in the spirit of discovery and seen through the lens of capacity
- Responses to questions must reflect the speaker's intent rather than the listener's translation

Categorizing strengths

Strengths can be identified as intellectual, emotional, creative and character strengths. Universal examples of strengths may include such attributes as:

- Courage
- Interpersonal communication
- Insight
- Optimism
- Integrity
- Honesty
- Resilience
- Perseverance
- Reliability
- Focus
- Sincerity

- Humor
- Flexibility
- Adaptability
- Warmth
- Generosity
- Creativity
- Open-mindedness

To Discover:	**Ask:**
Interests	• What is one thing that you love to do that time flies by when you are doing it? • What gives you energy to keep moving, even when you feel tired or sad?
Talents	• What are you most proud of being able to do? • What is one skill that you have that you could teach to someone else?
Purpose in Life	• What are some things that you do that you know make other people happy? • What matters the most to you in your life?
Attributes	• What nice words have other people said about you to describe you? • What do you think is your best quality?
Resources	• What are some places that you like to spend time when you are not in school? • Who are the people that you spend time with?
Priorities	• If you could only have one goal for your life RIGHT NOW, what would it be? Why? • What is most important to you right now to do in school? Why?

Sometimes questions can be the least effective strategy to use to conduct a strengths-based assessment. Inviting people to share stories through memory or experience based on a particular focus point can often get people unstuck when questions don't seem to be working well. Drawing or writing may also be good tools for assisting people in expressing themselves in positive, productive and strength-yielding ways. Remember: strength assessment and discovery is not a one-time interview process or a prescribed approach. It is a method for authentic, collaborative relationship-building that brings out and builds upon the best in everyone.

Assessing strengths and needs across life domains

Quite often, goals are established with the idea of eliminating or remediating a real or perceived deficit. Deficit-based planning or needs-only based planning sends a powerful message that the person or the family is the problem that needs to be fixed. This may inadvertently reinforce the story that the student or the family has come to tell about itself and thus, believe to be true.

The intention behind conducting a strength and needs assessment is to engage youth and families in a process for creating a profile that accurately reflects the student's personal and ecological resources

(i.e., natural support system), needs and wants, as well as exploring his or her dreams and aspirations across the domains of employment; education; living; health and well-being; social and community life. This approach is about striking a healthy balance between what is being brought to the table that is useful, productive and positive with what is necessary with regard to the kind of support that is needed or desired that will assist the student or the family to move forward.

A balanced strengths and needs-based profile allows for greater individualization, and therefore more targeted, case planning, coordination and intervention while simultaneously raising the potential for more deeply engaging the student and the family in taking ownership and responsibility for present and future positive outcomes. Service plans are directly tied to assessments, so it is very important that the assessment presents a comprehensive picture of who the student is based on strengths, capacity and potential; what he or she envisions for their life and how to best support the person to mitigate barriers to successfully progressing forward to meet the goal(s).

Ideas for developing strengths and needs assessments

Assessment is one of the most important tools for establishing the focus for the collaborative effort that will take place between the student, family and other key members of the student's support network. It is an essential vehicle for surfacing and weighing the areas in life that are important to a person within a given context. Assessment for transition planning sets a context for future orientation within key life domain areas that must be attended to in the present. Service planning and coordination are integral components to ensuring that the programs and supports the student and the family need to successful make the transition from school life to adult life.

Of course, selecting the type of assessment(s) to conduct will vary depending on what the specific purpose the assessment will be meeting. What needs to be understood or learned about? What is the best approach to use, based on the individual's preferences and needs? What is the student and the family interested in exploring or understanding?

Once the reason for conducting the assessment is established, it is easier to select the best tool for getting the job done. Not all assessment tools will work for every situation. It is important to know a variety of tools and approaches so that the assessment can be customized to the person, not the other way around. As with any strengths-based tool, the purpose for using it must be situated in the positive.

Here are a few assessment questions that can be useful. These questions can be answered Yes/No or open-ended:

- Do you hope to continue with school once you are out of high school?
- Do you plan to live where you are now once you get out of high school?
- Do you have friends?
- Do you wish you had more friends?
- Do you want to find a job?
- Do you know what kind of work you want to do when you are out of high school?

Assessment questions that utilize a scale can also be useful to assist students in rating how important the question is to their current or long-term goals. For example:

EMPLOYMENT ASSESSMENT: Mark how much you agree with the following statements.	**Definitely**	**Somewhat**	**Neutral**	**Not Really**	**Not at All**
I want a job	1	2	3	4	5
I know what kind of job I want	1	2	3	4	5
I know what I am good at doing	1	2	3	4	5
EDUCATION					
I know what helps me learn new things	1	2	3	4	5
I want to continue my schooling	1	2	3	4	5
School is important to my career goal	1	2	3	4	5
HEALTH and WELL BEING					
My family has enough food	1	2	3	4	5
I feel safe when I am home	1	2	3	4	5
I get the help I need with my medicine	1	2	3	4	5

Or you could incorporate a checklist in your strengths-based assessment, such as this one:

STRENGTHS-BASED ASSESSMENT: Put a checkmark next to all the words that describe you.					
	ACTIVE		OUTGOING		CHEERFUL
	AMBITIOUS		CALM		GOAL-DIRECTED
	DYNAMIC		ENTHUSIASTIC		PROFESSIONAL
	EAGER		PATIENT		COMMITTED
	MOTIVATED		CAREFUL		GOOD-NATURED
	OBSERVANT		FLEXIBLE		QUICK
	ARTICULATE		PERCEPTIVE		EFFICIENT
	EASY-GOING		CHARISMATIC		ORDERLY
	OPEN-MINDED		FRIENDLY		ASSERTIVE
	ARTISTIC		PRODUCTIVE		ENERGETIC
	AUTONOMOUS		ENTERPRISING		ORGANIZED

Remember, information gathered across the student's life domains will serve as the initial basis for setting goals and developing a transition plan. In addition to the excerpts of assessments located above, be sure to include substantive information, when appropriate, from past experience, current status as well as future focus/aspiration.

Here is a two-part example of components that might be included in a strengths-based service plan.

Part 1: Positive Personal Profile

- **Goal(s)** -What is important to me/us (hopes, dreams, aspiration)
- **Strengths** (skills, talents, experiences, tools that will support the goal)
- **Personal and Social Networks** (people who are willing and able to help)
- **Needs** – Things that are getting in the way of achieving the goal; (supports that are required or requested)

Part 2 - My Goals, Objectives and the Supports that will Help Me to Meet Them

Repeat this section for as many goals and support areas as needed.

- **Goal/Outcome**
- **Objective**
- **Strengths**
- **Support Needs**

	Task	Activities	Who	How Often	Starting	Ending
Social						
Family						
Service						

Progress

- What have we tried?
- What have we learned?
- What are we pleased to learn?
- What concerned us?
- What do we need to learn or try next?

Prioritizing Needs

After completing the strengths assessment, priority areas should be selected in order to begin goal setting. Remember that the assessment process served a particular purpose. Why was a particular process used? What rose to the surface as a result of the assessment process?

Earlier in this module, an assessment process called *A Framework for Planning* was mentioned. This is a process that is facilitated to populate information within eight interrelated sections (Attributes, Talents/Interests, Priorities and Preferences, Values/Purpose, Contributions of Citizenship, Supports Needed, Goals and Resources, and Action Planning), driven by the identified purpose for conducting the assessment. If, for example, the purpose for the assessment was identified as: "Finding direction for my life after high school," then the section called *Priorities and Preferences* would be completed based on this understanding.

> **Purpose**: To find direction for my life – I don't know if I should go to school or get a job, I don't know what I want to do when I get out of high school.
>
> **Student Priority**: Investigate areas of interest (identified earlier in the process) for employment potential/options.
>
> **Student Priority:** Complete the first two workbooks in *Cultivating True Livelihood.*
>
> **Student Preference**: Do this work at school during study hall time with Mrs. B.

In the Resources section at the end of this module is a a link to a downloadable resource, *Working on Purpose: Six Steps to Employment and a Framework for Planning Toolkit*, that Case Managers can use as a resource when working with youth and families around identifying, prioritizing, planning for and addressing needs.

Identifying Priorities

It is not surprising to find that there may be competing priority areas. Needs are based on pressures from two distinct need areas: the urgent and the important, and different people will put different measures of importance in different areas for legitimate, but different reasons.

Urgent needs have to do with critical means for survival, such as food, clothing, shelter, employment, financial, health and/or safety needs. Important needs are pressing issues that are impacting enhancement or improvement to quality of life. Opening a savings account to pay for transportation to and from work, studying for the exam that graduation is dependent upon, attending group therapy sessions, working with a job coach to find a decent paying job, meeting with a benefits planning counselor to establish a plan leading to financial self-sufficiency are examples of important need areas. To put it in simple terms: urgent needs are *now* needs. Important needs can (and often do) wait.

It's hard to concentrate on much of anything if people are hungry, sick or fearful. The urgent will always take energy away from the important. So it is important that priority setting is based first on dealing with the need and risk experienced by a family (the now needs) while simultaneously holding other important priorities (bigger picture goals) in the balance. What is the goal or goals that the family holds for the longer term? For example, a long term goal might be to have braided resources from social insurance programs in conjunction with part-time employment while a short-term goal might be to get enrolled in public programs that off-set or pay for heating costs.

This is the time to begin to integrating the strength and skills sets that emerged through the assessment process. It will be key to positioning and supporting the student and the family in tackling some of the issues successfully.

Remember! Priority identification needs to be made within the context that has been defined for purposes of assessment and/or planning. It is best to understand what is driving the purpose in the first place (i.e. to go to college; to find a job; to make friends; etc.) through conversation and inquiry. Then it may be useful to provide targeted choices within broad categories. For example, about environment: "Do you prefer to be indoors or outdoors most of the time?" could include a check list indicating yes or no to: a) in rain or snow? b) sunny days? c) hot days? etc.

Why are you interested in (purpose)?	What is the worst thing that you can think of happening about (purpose)?
What is most important about (purpose) to you right now?	What kinds of things or people ruin your day or make you really unhappy?
What would make (purpose) perfect for you?	What would be the best days/times for you to (purpose)?
Where do you think that the best place for (purpose) would be?	What is getting in the way of (purpose) right now?
What would a great day in (purpose) look like?	What would help you to be successful in/at (purpose)?
What kind of people would you want to be around?	What do people need to know about you that will make (purpose) easier or more fun?
Do you prefer to be indoors or outdoors most of the time?	What do you hope to get from (purpose)?
What do you need to have or to do to make (purpose) happen?	What is the best thing you can think of about (purpose)?

Service Planning, Coordination and Goal Setting (Youth and Family)

The assessment and prioritizing processes, along with informal conversations and formal discussions, should help case management practitioners surface clear goals that the student and/or the family are committed to achieving. Practitioners are responsible for writing a formal service plan that is designed to respond to the individualized goals and objectives of the family.

Fundamentally**, a service plan is a set of action steps designed to achieve one or more of the goals identified during the strengths assessment and priority identification**. The task for case management practitioners is to organize all of the information gathered through meetings, interviews and assessments in a clear, sensible way so that resources are effectively identified, obtained and utilized to address the student or the families:

- Long term goals – one or two years from now
- Short term goals objectives – immediate to short interval benchmark time frames, i.e. one month; three months
- Concrete actions that will be taken for each identified benchmark for each short-term objective, including where and how the steps will be taken
- The names of person(s) responsible for completing each step
- Dates for the steps to be accomplished
- How progress will be charted and reviewed

Strengths assessment is a planning technique based upon the individual student or family. The service plan is also meant to be person-centered and based on the individual student and their family. The service plan is facilitated as a collaborative process between the family, the school, service providers and others who play a role in the life of the plan. The service plan should be updated as needed and should remain a flexible, “living” document that is referenced and updated frequently during regular case management meetings.

Supporting Youth and Family in Selecting Services and Providers

Traditionally service plan development and service delivery have occurred within one service agency. Service providers offer a menu of services that are designed to be responsive to a common supply and demand formula that is driven by a variety of internal and external influences. With regard to service choice, service users pretty much get what the provider has to offer with little room for much modification or customization.

More recently, the service plan has been expected to be developed in a “conflict-free” manner. Conflict-free means that the family receives and understands all the information needed and the options that are available to make an informed decision about what kind of service support they are seeking and how they would like the service to be delivered.

The service plan serves as a vehicle for negotiation between the family and potential providers based on the family goals, interests, and needs. The interests and the needs of the family should drive the type,

frequency and condition of service provision. Since the service plan is a **formal agreement** from which important decisions about services are made, it is critical that all available options are presented and explained fully to the family. Remember, *services should be aligned to support the goals of the student and family* rather than the other way around. Several resources are available to assist students and families in learning about and understanding what service programs and options are available to them.

Case management practitioners may want to utilize or refer students and/or families to the Online Disability Service Locator at paths.nyspromise.org\locator. This online tool offers individuals a 1-3 minute assessment of the other services and supports they may be eligible for that align with their individual needs. Users can create and print a report of these findings.

Service Plan Monitoring and Engagement

This section of the manual describes what should happen at case management meetings and highlights the tabs in NYESS for which data should be collected and entered. NYS PROMISE case management includes meeting with intervention group (IG) youth and parents by phone or in-person on a quarterly basis, as well as intermittent meetings in order to gauge youth progress and needs. Control group youth and parents are contacted by phone on a semi-annual basis.

Schedule of Case Management Meetings and Required Updates to NYESS Forms

The table below highlights the case management meeting schedule practitioners are expected to utilize when contacting youth and families in the control and intervention groups. For each meeting, case managers will update the youth and family forms in the NYESS data collection system.

More information about these forms and Charting protocols is included in *Module 6: Case Recording*

NYESS Form Title	Intervention Group	Control Group
Youth Tracking Form A (YTFA)	Intake and Annually	Intake and Annually
Youth Tracking Forms B and B2 (YTFB and YTFB2)	Intake and Quarterly	Intake and Semi-Annual
Youth Tracking Form C (YTFC)	Quarterly	Intake and Semi-Annual
Guardian Update	Intake and Quarterly	Intake and Semi-Annual

Maintaining Charts and other Documentation

All charts and documentation collected for NYS PROMISE are to be maintained for the duration of the project (October 1, 2013 to September 30, 2018) and beyond as required by the guidelines of the grant. All Personally Identifiable Information (PII) collected by case managers on students and their families should be treated with confidentiality and respect. Additional guidance is available by viewing the *NYS PROMISE Security Guidelines* and the *NYS PROMISE Policies and Procedures Manual*.

Case Management Meeting Checklists

The case management process is described in depth in the *NYS PROMISE Implementation and Intervention Manual*. We will briefly review the processes covered in case management, practitioners should refer to the manual and the *NYS PROMISE Policies and Procedures Guide* for more details.

Intake and Screening

Program enrollment was open from April 30, 2014 to April 30, 2016.[1] Upon enrollment, youth were randomly assigned to the Control Group (CG) or Intervention Group (IG). Youth in the IG receive additional services, youth in the CG do not receive additional services. Youth and families in the control group (CG) are contacted semi-annually to update contact information, and are periodically (and selectively) invited to participate in focus groups and surveys.

Once a youth enrolled in NYS PROMISE is randomly assigned to the either the control or intervention group, the next step for their assigned case management practitioner is to schedule an initial meeting. Case managers are assigned to youth based on youth's school (i.e. research demonstration site, or RDS) or location (i.e. community case managers in NYC serve youth based on their zip code). For youth in the control group (CG) the initial meeting focused on collecting basic information on the youth and parent. For youth in the intervention group (IG) that meeting focused on collecting basic information on the youth and parent, recording, developing or enhancing their transition plan, and initiating their first referrals for NYS PROMISE services.

Family coaches within Regional Parent Training Centers must participate in the initial planning meeting with the RDS/student/parent in the control group, and minimally annually thereafter to update NYESS. Subsequent parent update meetings may be completed via phone, or in person, and may or may not, be conducted in conjunction with one of the regular scheduled quarterly RDS student meetings.

This initial intake meeting is considered the first case management meeting and all subsequent meetings should include <u>all</u> of the elements listed in the checklists below.[2]

[1] For more information on Outreach and Recruitment please see the *NYS PROMISE Outreach and Recruitment Guide*.

[2] These checklists are excerpted from the *NYS PROMISE Intervention and Implementation Guide*.

Intervention Group Youth Intake

PRE-MEETING PLANNING

Timing: Conducted within two weeks of enrollment

Who is responsible: RDS case manager (primary) and family coach.

Required attendees: Youth, parent, case manager, and family coach

Prepare a file with the following documents (if available):[1]

- ☐ Contact information for youth and parent/guardian.
- ☐ Most recent IEP or 504 Plan; and academic records, including information on: Attendance, grade level, English Language Learner status, free/reduced price lunch status, participation in general vs. special education programming, Regents exam participation, expected diploma/credentials, Participation in self-determination or transition activities.
- ☐ Employment information.
- ☐ Information on participation in work incentives programs.
- ☐ Information regarding services planned and/or current services being received.
- ☐ Seek input from IEP committee member, CSE chair or special education teacher on youth's service needs and possible NYS PROMISE services.

DURING THE MEETING

- ☐ Review NYS PROMISE, articulate program expectations, and outline what participants in the meeting can expect.
- ☐ RDS Case Manager: collect data using the Youth Tracking Form – A (YTF-A, required) and YTF – B/B2 (optional) (or directly using NYESS).[2]
- ☐ Family Coach: collect data using the Guardian Update Form/Tab (or directly using NYESS).
- ☐ Discuss the service planning and referral process for youth and for parents.
- ☐ Review, develop, or enhance the transition component of the youth's individualized education program—working closely with appropriate district-based personnel, such as the Chair of the Committee on Special Education (CSE).
- ☐ Decide what next steps/actions should be made and who will do what action (note that additional meetings may be necessary to assess and plan for actual NYS PROMISE service referrals).
- ☐ Address any specific concerns expressed by youth and parent.

[1] See the "Charting Protocol" section of the Policies and Procedures Manual for additional information on gathering and storing documents

[2] Much of the information to be collected during these meetings may be available in the documents outlined above. Prior to meeting with the youth/parent, we recommend reviewing the available records, determining which areas you do and do not have information on in the records; and then focusing your meeting with parents on gathering the information you do not already have. This will eliminate redundancy and streamline the meeting.

- ☐ Share relevant information on both NYS PROMISE intervention services, as well as on non-NYS PROMISE transition planning services and supports and parent training and information. [1]
- ☐ Share information on incentives for continuing to participate in NYS PROMISE (e.g., the option to get gift certificates for participating in surveys, focus groups or other research activities).
- ☐ Disseminate: Contact Sheet, including information on: case manager, family coach, local providers, CSE Chairperson; Information on upcoming Regional Parent Training Center NYS PROMISE Core Training; Just-in-Time postcards, as appropriate based on student need.
- ☐ Schedule the next quarterly meeting (required attendees: youth, parent (if warranted), case manager and/or family coach).

AFTER THE MEETING:

- ☐ If data was collected via paper-based form during the meeting, enter information from the YTF-A (and YTF – B/B2, if collected) and Guardian Update Form into NYESS immediately after
- ☐ Securely store any paper forms with the youth's chart and shred old paper forms each quarter (only keep the most current version of each paper form).
- ☐ Document any concerns expressed by parents, and follow up with Cornell or OMH contact to resolve any issues, if necessary.
- ☐ Work with the appropriate school/CSE personnel to update the IEP and ensure that this is shared with the youth, parent, teacher, etc.
- ☐ Follow up on any action items or to-do, schedule any necessary assessment, planning or follow-up meetings.
- ☐ **Make service referrals** (if appropriate): Add an Agency in NYESS; Add Service in NYESS; Add Funding to Service in NYESS; Send Referral to Provider in NYESS; Print Referral Cover Sheet; E-mail Provider to alert them that a referral has been sent; and Mail Provider the Referral Packet.
- ☐ **Ongoing:** Regularly check NYESS to ensure that referrals have been accepted and acted upon by providers; support youth/parents in connecting with providers.

Control Group Youth Intake

PRE-MEETING PLANNING

Timing: To be conducted within two weeks of enrollment

Who is responsible: RDS case manager (primary) and family coach.

Required attendees: Youth, parent, case manager and a family coach.

Prepare a file with the following documents, (as available):[2]

- ☐ Contact information for youth and parent
- ☐ Most recent IEP or 504 Plan
- ☐ Academic records, including information on attendance, grade level, English language learner status, free/reduced price lunch status, participation in general vs. special education

[1] These incentives are described in greater detail at the end of this document.

[2] See the "Charting Protocol" section of the *NYS PROMISE Policies and Procedures Manual* for additional information on gathering and storing documents.

programming, Regents exam participation, expected diploma/credentials and participation in self-determination or transition activities
- ☐ Employment information
- ☐ Information on participation in work incentives programs
- ☐ Information regarding services planned and/or current services being received

DURING MEETING

- ☐ Review NYS PROMISE, articulate program expectations as it relates to being assigned to the control group, and outline for participants in the meeting what they can expect.
- ☐ RDS case manager: collect data using the Youth Tracking Form – A (YTF-A, required) and YTF – B/B2 (optional) (or directly using NYESS).[1]
- ☐ Family coach: collect data using the Guardian Update Form/Tab (or directly using NYESS).
- ☐ Address any specific concerns expressed by youth and parent.
- ☐ Share relevant information on non-NYS PROMISE transition planning services and supports and parent training and information.
- ☐ Share information on incentives for continuing to participate in NYS PROMISE (e.g., yearly gift certificates and the option to get additional gift certificates for participating in surveys, focus groups or other research activities).
- ☐ Schedule the next quarterly meeting (youth, parent (as warranted), and Case Manager and/or Family Coach).

AFTER MEETING

- ☐ If data was collected via paper-based form during the meeting, enter information from the YTF-A (and YTF – B/B2, if collected) and Guardian Update Form into NYESS immediately after.
- ☐ Securely store any paper forms with the youth's chart; shred old paper forms each quarter (only keep the most current version of each paper form).
- ☐ Document any concerns expressed by parents/guardians or youth, and follow up with your Cornell or OMH contact to resolve any issues, if necessary.

Ongoing Case Management Plan Implementation Activities

Case management practitioners should regularly check NYESS to ensure that referrals have been accepted and acted upon by providers; support youth/parents in connecting with providers.

Intervention Group Quarterly Meeting:

Timing: Conducted minimally on a quarterly basis following in the initial planning meeting.

Who is responsible: RDS case manager (primary)

[1] Much of the information to be collected during these meetings may be available in the documents outlined above. Prior to meeting with the youth/parent, we recommend reviewing the available records, determining which areas you do and do not have information on in the records; and then focusing your meeting with parents on gathering the information you do not already have. This will eliminate redundancy and streamline the meeting.

Required attendees: youth, parent (if warranted), RDS Case Manager, NYS PROMISE participating providers, service provider personnel, as appropriate.

Update the planning file with the following documents (as available):[1]

- ☐ Most recent IEP or 504 Plan.
- ☐ Academic records, including information on: attendance, grade level, English Language Learner status, free/reduced price lunch status, participation in general vs. special education programming, Regents exam participation, expected diploma/credentials, participation in self-determination or transition activities.
- ☐ Employment information.
- ☐ Information on participation in work incentives programs.
- ☐ Regarding services planned and/or current services being received.
- ☐ Contact information for youth and parent/guardian.
- ☐ Seek input from IEP committee member, CSE chair or special education teacher.

DURING THE MEETING

- ☐ Review NYS PROMISE, articulate program expectations, and outline what participants in the meeting can expect going forward in the program.
- ☐ RDS case manager: collect data using the Youth Tracking Forms B, B2 and C (YTF - B, YTF-B2 and YTF-C; or directly using NYESS).Discuss the service planning and referral process for youth and for parents.
- ☐ Review, develop, or enhance the transition component of the youth's individualized education program—working closely with appropriate district-based personnel, such as the Chair of the Committee on Special Education (CSE).
- ☐ Decide what next steps/actions/referrals should be made and who will do what action.
- ☐ Address any specific concerns expressed by youth and parent.
- ☐ Share relevant information on both NYS PROMISE intervention services, as well as on non-NYS PROMISE transition planning services and supports and parent training and information.

Disseminate:

- ☐ Contact Sheet, including information on: case manager, Regional Parent Training Center, local providers, CSE Chairperson.
- ☐ Information on upcoming Regional Parent Training Center NYS PROMISE Core Training.
- ☐ JIT postcards, as appropriate based on student need.
- ☐ Schedule the next quarterly meeting (Required attendees: youth, parent (if warranted), Case Manager, and Family Coach if appropriate).

AFTER THE MEETING

- ☐ If data was collecting using the paper-based forms during the meeting, enter information from the Youth Forms in NYESS immediately after

[1] See the "Charting Protocol" section of the Policies and Procedures Manual for additional information on gathering and storing documents.

- ☐ Document any concerns expressed by parents, and follow up with Cornell or OMH contact to resolve any issues, if necessary
- ☐ Work with the appropriate school/CSE personnel to update the IEP and ensure that this is shared with the youth, parent, teacher, etc.
- ☐ Confirm next steps with NYS PROMISE participating agencies where services may be referred
- ☐ Securely store any paper forms with the youth's chart; shred old paper forms each quarter (only keep the most current version of each paper form)
- ☐ Follow up on any action items or to-do
- ☐ Make service referrals
- ☐ Add an Agency in NYESS
- ☐ Add Service in NYESS
- ☐ Add Funding to Service in NYESS
- ☐ Send Referral to Provider in NYESS
- ☐ Print Referral Cover Sheet
- ☐ E-mail Provider to alert them that a referral has been sent
- ☐ Mail provider the Referral Packet

Intervention Group Ongoing Interactions

RDS case managers and family coaches should maintain ongoing contact with youth and/or families and regularly complete referral and billing information in NYESS.

RDS CASE MANAGEMENT (FREQUENCY: ONGOING)

- Communicate with youth/parents.
- Communicate with service providers.
- Monitor service progress, youth experience in NYESS by ensuring that service provider has accepted the referral.

If the referral has not been accepted for over four weeks after referral, call service provider to discuss the issue and call parent/guardian to make sure they have necessary information regarding services and providers to whom the referral was made.

PC FAMILY CASE MANAGEMENT (FREQUENCY: ONGOING)

- Communicate with parents.
- Communicate with service providers.
- Update the PTF - RFRLS and Activities sections of NYESS
- Monitor service progress, parent experience in NYESS by ensuring that service provider has accepted the referral.

If the referral has not been accepted for over four weeks after referral, call service provider to discuss the issue and call parent/guardian to make sure they have necessary information regarding services and providers to whom the referral was made.

Confirm Service Completion and Authorize Payment (Frequency: Monthly)[1]

- Check NYESS to get billing forms from providers in NYESS
- Review reports and ensure the services provided and outcomes reported align with the NYS PROMISE service rubrics in the Intervention and Implementation Guide
- Approve or deny final billing activity in NYESS
- Close the service in NYESS
- Inform provider of approval or denial of service

MAKE SERVICE REFERRALS[2] (FREQUENCY: AS APPROPRIATE)

- Add an agency in NYESS
- Add service in NYESS
- Add funding to service in NYESS
- Send referral to provider in NYESS
- Print referral cover sheet
- E-Mail provider to alert them that a referral has been sent
- Mail provider the referral packet

Intervention Group Annual IEP/Transition Planning Meetings

The RDS case managers should attend IEP meetings for IG youth. These IEP meetings may be combined with a regular quarterly meeting (with data collection done during the meeting.) At IEP meetings the case manager should:

- Collect and enter data in NYESS using the Youth Forms (may act as one of the quarterly update meetings).
- Share with planning team the diary dates for upcoming quarterly NYESS updates.
- Disseminate JIT postcards as appropriate, based on student need.
- Disseminate registration materials for upcoming Regional Parent Training Center Core NYS PROMISE training.

Update and disseminate a contact sheet for IEP members, including relevant project contact information (inclusive of contact info for case manager, Regional Parent Training Center, local providers, CSE chairperson, dates for upcoming quarterly case management meetings/follow-ups) as needed/or requested

Control Group Semi-Annual Meeting:

Timing: Conducted semi-annually after the initial planning meeting.[3]

Who is responsible: RDS case manager (primary)

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[1] *Refer to the NYS PROMISE Policies and Procedures Manual for additional details on billing processes*

[2] Refer to the *NYS PROMISE Policies and Procedures Manual* for additional details on referral processes.

[3] May be combined with annual IEP meeting, as appropriate.

Update existing file with the following documents (as available):[1]

- ☐ Most recent IEP or 504 Plan, academic records, including information on attendance, grade level, English Language Learner status, free/reduced price lunch status, participation in general vs. special education programming, Regents exam participation, expected diploma/credentials, participation in self-determination or transition activities.
- ☐ Employment information.
- ☐ Information on participation in work incentives programs.
- ☐ Information regarding services planned and/or current services being received.
- ☐ Contact information for youth and parent/guardian.

Required attendees: Youth, parent (as warranted), RDS case manager

DURING MEETING

- ☐ Review NYS PROMISE, articulate program expectations as it relates to being assigned to the control group, and outline for participants in the meeting what they can expect over remaining time in the program.
- ☐ RDS case manager: collect data using the Youth Tracking Forms B, B2 and C (YTF-B, YTF-B2 and YTF-C; or directly using NYESS).
- ☐ Address any specific concerns expressed by youth and/or parent.
- ☐ Share relevant information on non-NYS PROMISE transition planning services and supports and parent training and information.
- ☐ Schedule the next quarterly meeting (youth, parent (as warranted), and Case Manager).[2]

AFTER MEETING

- ☐ If data was collected via paper-based form during the meeting, enter information from the Youth Forms into NYESS immediately after.
- ☐ Securely store any paper forms with the youth's chart; and shred old paper forms each quarter (only keep the most current version of each paper form).
- ☐ Document any concerns expressed by parents/guardians or youth, and follow up with your Cornell or OMH contact to resolve any issues, if necessary.

Collaboration: Partnership Building

The development and enhancement of interagency collaborations and partnerships is a key goal of the NYS PROMISE program. In an environment where there are many organizations engaging in interrelated work and serving the same clients, effective communication and collaboration can increase program integration, effectiveness and the quality of client experience.

[1] See the "Charting Protocol" section of the *NYS PROMISE Policies and Procedures Manual* for additional information on gathering and storing documents

[2] Meetings will happen at minimum quarterly, you may want to also let parents know contact can/may happen in between these more formal meetings.

"Collaboration" can have a variety of meanings; within NYS PROMISE we think of collaboration along a continuum of best practices:

- **Networking** is a stage of "loose" collaboration through facilitated dialog, common understanding and information sharing.
- **Cooperation** slightly formalizes communication by identifying semi-formal interagency leadership and limiting repetition of services.
- **Coordination** merges resources—through joint budgets and "new" resources—to address common issues, and establishes frequent, clear communication; interagency leadership is formalized via official roles and sub-groups to target specific resources and practice issues.
- **Coalition** has agencies commit to formal, minimum three-year collaborative agreements.
- **Collaboration** is the stage in which a shared vision is realized, with clear benchmarks and interdependent systems addressing common issues/opportunities.[1]

NYS PROMISE aims to foster conditions that support increasingly intensive and productive collaboration that moves along this continuum.

Evaluation and Assessment of Collaboration

Levels of collaboration are assessed on an annual basis in Q3 (spring). Each agency will receive 1-2 invitations for key personnel to fill out the annual Collaborative Network Survey. The survey asks questions about the relationships agencies have with other agencies, schools, and service providers in their region. The intent of the evaluation is not to critique the relations, but to monitor the on-going growth and development of the collaborative network of agencies involved in the NYS PROMISE project over time.

Strategies for Increasing and Improving Collaboration

The NYS PROMISE Collaborative Network survey is an annual survey of interagency **levels of collaboration** among NYS PROMISE partners – Research Demonstration Sites (RDS), Service Providers (SP), and Parent Centers (PC). The survey takes place each spring.

The spring 2016 survey found increased overall levels of collaboration from 2015 to 2016. Partners reported higher collaboration "ratings" from all partner types. There was also a higher network density statewide. This included more formalized relationships and a higher frequency of communication between partner agencies.

To continue to improve the strength of the collaborative network, the NYS PROMISE team reported the following recommendations:

[1] Hogue 1993.

Frequency of Communication

RDS staff indicated strengthening relationships from previous year, particularly between case managers and Regional Parent Training Center staff

Additional TA needs indicated in formalizing the **frequency** and **type** of communications needed between case managers and SP staff

Case Management

- Working with partners to be flexible and responsive to parent schedules.
- Creative planning between RDS and PC staff for initial and subsequent case management sessions (location, time, dealing with cancellations, alternative methods of communication).
- Increased communication between RDS and PC staff (shared calendars, weekly check-ins, office hours, clear role allocation and sharing of tasks/responsibilities).

Service Referral

- Dealing with 'lag time' in getting students referred.
- Different views from site to site about how frequently communications with SPs should occur, and what communications should look like.
- Best practices: regular, weekly communication across RDS/provider agencies; collaborating to strategize services; formulating opportunities for SP staff to be present in the school.

As the project moves forward, we will be looking to increase the frequency of our interactions between NYS PROMISE partners. We will try to identify the types of interactions that are essential, that build trust and respect, and what actions help partners delegate and collaborate on tasks. We will also look at the formality of the network system being developed, and what guidance and best practices can be learned and shared with others.

Service Evaluation

As a part of NYS PROMISE there are a number of ways in which participants will be asked to provide input on their satisfaction with the program and services.

Surveys and Focus Groups

Periodically throughout the project youth and parents will be invited to complete surveys (online or via phone) and/or to attend focus groups. As a part of these activities, they may be asked questions about their experiences with transition in general and with NYS PROMISE specifically.

Group Planning Sessions and Case Management Meetings

After each service, the youth/parent, case manager and service provider are expected to meet to discuss the outcomes of the service and next steps. These meetings should include asking the youth/parent for input on their experience with the service just completed, as well as with the case manager and service provider. Youth and parents should also be asked about their experiences at their quarterly/semi-annual case management meetings. While the information that families share during these conversations will not be formally integrated into Cornell's research findings, it should be immediately useful to case managers and service providers in adapting their services to better meet the needs and expectations of participants.

Service Provider Audit

Service Providers are audited on a semi-annual basis in winter and summer. NYS OMH will perform the audits, which will consist of the regional specialist visiting each service provider, reviewing files selected at random by Cornell University, and comparing files against the Service Rubric quality indicators. Service Providers will be given individual audit feedback and technical assistance.

As reviewers and approvers of services for Intervention Group youth and families, case management practitioners play a vital role in on-going provision of quality services. Case Managers should periodically review the service rubrics to maintain their familiarity with the quality indicators NYS PROMISE utilizes, and make sure quality review standards are consistently applied to the outcomes they expect from their service referrals for youth and families in the Intervention Group.

Module 5: Resources

See the "Charting Protocol" section of the Policies and Procedures Manual for additional information on gathering and storing documents

Working on Purpose: Six Steps to Employment and a Framework for Planning Toolkit
http://nyrehab.org/images/downloads/Resource_Explosion_Event/toolkit_working_on_purpose_six_steps_to_employment..pdf

> This 13-page Toolkit provides concrete tasks and worksheets to help Case Managers implement Person-Centered Planning techniques and strategies in their work with youth and families.

Cultivating True Livelihood Work in the 21st Century.
http://store.diversityshop.com/ctl.html

> Denise Bissonette's comprehensive approach to delivering employment services, based in the principles of Activity Based Placement. At this site you can find links to videos of Denise describing the complete program.

Transition to Independence Process (TIP) Model: Evidence-Supported Practice for Improving the Progress and Outcomes of Youth and Young Adults with EBD
http://www.tipstars.org/Portals/0/documents/Website%20TIP%20Model%20OVERVIEW%20PDF%20092714.pdf

> The TIP model prepares youth with Emotional and Behavioral Disorders for moving into adult roles via an individualized process that engages them in their own future planning and provides developmentally-appropriate, appealing, supports. This 12-page overview provides an overview of the TIP model, a case study, and guidelines for implementing it in your own work.

VIA Character. Values in Action Inventory of Strengths.
https://www.viacharacter.org/www/

> This site offers the VIA Survey, a central tool of Positive Psychology. This survey is a psychometrivally validated test that measures an individual's character strengths – their core capacities for thinking, feeling, and behaving.

Case Management Community of Practice, Sessions #1-3, Adene Karhan and Carol Blessing. Cornell University. www.nyspromise.org/secure Learning Community Resources, Case Management and Service Delivery, Trainings.

Module 6: Case Recording

Introduction

As a part of NYS PROMISE, case management practitioners regularly collect information on youth and families and document that information within their own files/charts and in NYESS. This module draws on information from the *NYS PROMISE Policies and Procedures Manual*, as well as case noting best practices to provide detailed guidance on how to collect, store and record youth and families' information. It closes with information on the data collection and reporting that OMH and Cornell will be engaged in as a part of the program.

Data Collection and Management

The table below highlights the case management meeting schedule that practitioners are expected to utilize when contacting youth and families in the control and intervention groups. For each meeting, case management practitioners will update the youth and family forms in the NYESS data collection system.

NYESS Form Title	**Intervention Group**	**Control Group**
Youth Tracking Form A (YTFA)	Intake and Annually	Intake and Annually
Youth Tracking Forms B and B2 (YTFB and YTFB2)	Intake and Quarterly	Intake and Semi-Annual
Youth Tracking Form C (YTFC)	Quarterly	Intake and Semi-Annual
Guardian Update	Intake and Quarterly	Intake and Semi-Annual

NYS PROMISE operates on the calendar quarter system, with a one-month grace period for data entry following each quarter. All data collection should be completed by the end of the quarter, and all data should be entered in NYESS within one month after the quarter.

Quarter Dates	**Grace Period**
January-March	April
April-June	July
July-September	October
October-December	January

Tracking Data Collection Schedules

There are a variety of ways that Case Managers can track when data collection and updates are due for individual youth and parent/guardians. NYS PROMISE provides two sets of tools to support sites in tracking this information.

- **Scheduling Checklists**: The scheduling checklists included at the end of this section may be included in each participant file to track when updates occur or are next due.
- **Mid-Quarter Report**: The Mid-Quarter report that Cornell develops includes the dates of the last update to each of the NYESS forms listed above, which can be used to identify the next anticipated due date. If you would like support to use the mid-quarterly report in this way, please contact your regional OMH or Cornell contact.

NYESS Forms: RDS Case Managers

The information below is from the *NYS PROMISE Policies and Procedures Manual*; it outlines the NYESS Forms that are required to be completed/updated by the NYS PROMISE Research Demonstration Sites (RDS). For youth and family in the intervention group, it is expected that case management practitioners will meet with them at a minimum on a quarterly basis. For youth and family in the control group, it is expected that case management practitioners will meet with them on a semi-annual basis, at a minimum.

Youth Tracking Form A (YTF-A): Educational Background

This section of NYESS youth tracking should be completed at intake and updated annually for youth in the intervention and control groups. To update this section, current school records and/or meetings with school personnel who are most knowledgeable about the youth, should be used to provide the information.

- Be sure to click the "Save" button to save all the changes in the database.
- A paper copy of YTF-A can be found in Appendix H of the *NYS PROMISE Policies and Procedures Manual*.
- If you have any questions about the information found in YTF-A, please contact **Andy Sink** at **518-474-3616**.

Youth Tracking Form B and B2 (YTF-B and YTF-B2): School Program Participation Tracking

This section of NYESS youth tacking must be completed at intake and updated once every quarter for youth in the intervention group. For youth in the control group, this tracking form should be completed at intake and updated semi-annually.

- Be sure to click the "Save" button to save all the changes in the database.

- Pre-specified quarter timelines including the start and end dates will be made available after recruitment begins in the project.
- YTF-B must be completed before YTF-B2 will be available in NYESS.
- A paper copy of YTF B and B2 can be found in Appendix H of the *NYS PROMISE Policies and Procedures Manual*.
- If you have any questions about the information found in YTF-B or YTF-B2, please contact **Andy Sink** at **518-474-3616**.

Additional information by question:

Which of the following areas are addressed by the measurable post-secondary educational goals in the youth's IEP?

Definitions:

- **Community living**: includes where the student plans to live, and community citizenship.
- **Employment**: Employment at or above minimum wage. This includes supported employment.
- **Post-secondary education and training**: 2 or 4 year college or career technical education
- **Independent living skills**: includes, transportation, social/recreational/interpersonal skills, etc.

Which categories of transition services/activities are indicated in the youth's IEP?

Definitions:

Below are brief descriptions of New York Stated Education Department's (NYSED) measureable post-secondary goals and transition needs found in a youth's IEP. For more complete descriptions, please visit NYSED's website: http://www.p12.nysed.gov/specialed/publications/iepguidance.htmhttp://www.p12.nysed.gov/specialed/publications/iepguidance.htmhttp://www.p12.nysed.gov/specialed/publications/iepguidance.htmhttp://www.p12.nysed.gov/specialed/publications/iepguidance.htm

- **Coordinated Set of Activities**
  - **Instruction** - includes course of study and/or skill area needed to prepare the youth for post-secondary living.
  - **Related services** - includes services needed to reach projected post-secondary outcomes (e.g., integrated work, education and living environments).
  - **Community experiences** - this include community-based exploration of integrated settings (e.g., job or college tours) needed to achieve post-school outcomes.
  - **Development of employment and other post-school adult living objectives** - these include services or activities aimed to develop work-related skills and behaviors including (but not limited to) career exploration, participation in a work experience program or supported employment.

  - **Acquisition of daily and independent living skills** - these include services or activities that will assist the youth in activities of daily living, including skills for self-care.
  - **Functional vocational assessments** - these include alternative assessments of vocational skills in community-based settings.
- **Supportive Services**
  - **Related services** – includes services that assist the youth in benefiting from other special education services or in accessing the general curriculum such as speech and language therapy, occupational therapy, physical therapy, counseling, hearing and vision services, orientation and mobility services and school health services.
  - **Supplementary aids and services** – includes services and supports which allow youth with disabilities to be educated with nondisabled youth to the maximum extent appropriate, in the least restrictive environment. This includes special education teacher support services – e.g., resource room, consultant teacher services, or one-to-one paraprofessional services.
  - **Assistive technology services** – includes any service that assists the youth in the selection, acquisition and use of assistive technology device(s) necessary for youth's participation in school.
  - **Testing accommodations** – allow youth to participate in assessment (i.e., testing) on an equal basis with their nondisabled peers.

How often did the youth participate in general education classes in the last quarter?
Definitions:

- **Never** – Did not participate in general education classes.
- **Rarely** – Less than 25% of his/her time was spent in general education classes.
- **Sometimes** – Between 25 – 50% of his/her time was spent in general education classes.
- **Frequently** – About 75% of his/her time was spent in general education classes.
- **Always** – 100% of his/her time was spent in general education classes.

Youth Tracking Form C (YTF-C): Work Incentive and Ticket to Work Program History

This section of NYESS youth tracking must be completed at the first quarterly meeting for youth in the intervention group. For youth in the control group, this tracking form should be completed semi-annually.

- Be sure to click the "Save" button to save all the changes in the database.
- Pre-specified quarter timelines including the start and end dates will be made available after recruitment begins in the project.
- A paper copy of YTF – C can be found in Appendix H of the *NYS PROMISE Policies and Procedures Manual*.

- If you have any questions about the information found in YTF – C, please contact **Andy Sink** at **518-474-3616**.

Additional information by question:

Did the youth access services, or utilize any of the following work incentives during the previous quarter? (For additional information on work incentives, see the Social Security Administration's 2017 Red Book: http://www.ssa.gov/redbook/index.html)http://www.ssa.gov/redbook/index.html)

Definitions*:*

- N/A - Example, the youth did not work during the past quarter.
- **Work incentive Services**
  - **Work Incentive and Planning Assistance (WIPA) programs** - these are regional programs sponsored by the Social Security Administration providing information on public benefits and work. You can find a local WIPA on the Choose Work website: http://choosework.net/ (click on the "Find help" tab).http://choosework.net/ (click on the "Find help" tab).
  - **Protection and Advocacy for Beneficiaries of Social Security or PABSS** - these are individual state programs sponsored by the Social Security Administration providing advocacy and legal representation to beneficiaries regarding discrimination, barriers or issues they experience along their path to employment. You can find a local PABSS on the Choose Work website at: http://choosework.net/ (click on the "Find help" tab).http://choosework.net/ (click on the "Find help" tab).
  - **Work Incentive Seminar Events or WISE** - these programs are locally organized by WIPA programs to provide information on benefits and work.
- **SSI Work incentives**
  - **Plan for Achieving Self-Support or a PASS Plan** - an income exclusion which allows a SSI beneficiary to set aside income and resources to achieve employment goals.
  - **Property Essential to Self-Support, or PESS** - a work incentive that allows a beneficiary to not count certain resources used for the express purposes of self-support, such as farm equipment, etc.
  - **Student earned-income exclusion** – allows a SSI beneficiary under the age of 22, who is regularly attending school, a special earned income exclusion of over $1,790 per month, to over $7,200 per year [2017]. This figure changes annually.
  - **Impairment-Related Work Expense** - this work incentive provides an earned income disregard for impairment-related work expenses paid for by the individual such as medical devices or special transportation services to/from work. The expense must be paid for by the beneficiary, and must be related to the individual's disability and required for him/her to work.
  - **Blind Work Expense** - this work incentive provides an earned income disregard for expenses associated with working that are paid for by the individual who is blind.

Eligible expenses enable an individual to work and must not be reimbursed; however, the expense does not need to be related to the blindness.

- **Expedited Reinstatement** – is a mechanism which allows individuals who have stopped receiving benefits due to work to restart his/her benefits without requiring repeat application.

- **SSDI Work incentives**
  - **Trial Work Period** - this work incentive allows individuals to earn above Trial Work Period amounts (around $840 per month in 2017) for nine months within a 60 month rolling window without impacting their level of SSDI cash benefit.
  - **Extended Period of Eligibility (EPE)** - this work incentive allows Individuals to receive cash benefits in any month their earnings dip below substantial gainful levels (SGA). EPE begins the month Trial Work Period ends and lasts for 36 months.
  - **Impairment-Related Work Expense** – this work incentive provides an earned income disregard for impairment-related work expenses paid for by the individual such as medical devices or special transportation services to/from work. The expense must be paid for by the beneficiary, and must be related to the individual's disability and required for him/her to work.
  - **Subsidy or Special Considerations** - are work incentives that allow an individual to reduce his/her gross earnings which are considered in substantial gainful activity (SGA) decisions, as SSA only uses earnings that represent the real value of work an individual performs. A subsidy is a support provided by an employer that may result in an individual receiving more pay than the actual value of the service he/she performs. A special condition refers to support an individual may get from a third party to aid them in performing their job (this includes self-employment).

Has the youth enrolled with an Employment Network?
Definitions:

- **Employment networks** – include public or private organizations under contract with the Social Security Administration that provide supports for people with disabilities to work and/or earn more money under the Ticket-to-Work (TTW) program.

Used Cont. financial support offered within section 301 of SSA during prior quarter?
Definitions:

- **Section 301 of Social Security Act in the last quarter** - offers individuals who are deemed no longer disabled due to medical improvement to continue receiving benefits while they are participating in an appropriate vocational rehabilitation program or similar service (e.g., for youth, age 18 to 21, an active individualized education program (IEP) may qualify). This applies to youth whose disability is determined to be medically ceased during their age 18 re-determination process. For youth, age 18 to 21, an active individualized education program (IEP) may qualify.

Jobs Info Tab

This youth tracking section of NYESS is required to be updated at each instance of information on a participant's employment changes. NOTE: this includes any employment experience, paid or unpaid, NYS PROMISE-related or non-NYS PROMISE related.

- Be sure to click the 'Save' button to save all the changes in the database.
- This includes, but is not limited to, changes to wages, hours, and employment status.
- Most often, Jobs Info Tab will be completed by providers; however, it is the responsibility of the RDS to verify the accuracy of information found in this tab.

NYESS Forms: Family Coaches

The information below is from the *NYS PROMISE Policies and Procedures Manual*; it outlines the NYESS Forms that are required to be completed/updated by the NYS PROMISE family coaches. For families in the intervention group, it is expected that family coaches will be in contact on a quarterly basis, at a minimum. For families in the control group, it is expected that family coaches will be in contact on a semi-annual basis.

Family coaches are responsible for the following:

- NYS PROMISE Guardian Update Tab (PRMS Guard Update) and Parent Referral Tracking Sheet (PRMS PTF-RFRLS).
- Family coaches are be required to enter Activities in NYESS related to each interaction, including Information Services, Training and Goal Development.
- If Goal Development Activities take place, family coaches are required to complete the Goal Development fillable PDF and a printed copy will be stored in the Parent/Guardian record at the Regional Parent Training Center.

NYS PROMISE Guardian Update Tab (PRMS Guard Update)

This section of NYESS should be completed at intake and updated quarterly for participants in the intervention group. For participants in the Control Group (CG), this section of NYESS should be completed at intake and updated annually. Please note that parents in the control group should be contacted on a semi-annual basis to maintain contact, but this tracking form information only needs to be collected annually. This form is to be entered at initial parent meeting and updated as appropriate. Additional Parents/Guardians can be added here as needed.

- Be sure to click the 'Save' button to save all the changes in the database.
- A paper copy of NYS PROMISE Guardian Update Tab can be found in Appendix H of the *NYS PROMISE Policies and Procedures Manual*.
- If you have any questions about the information found in PRMS Guard Update, please contact **Andy Sink** at **518-474-3616**.

Additional information by question:

Does anyone in the household besides NYS PROMISE participant receive any of the following public benefits (check all that apply)?
Definitions:

- For information on the Federal public benefits listed in this section, please see Social Security's website: www.ssa.gov.
- For information on the State public benefits listed in this section, please see New York State's myBenefits website: https://www.mybenefits.ny.gov/ https://www.mybenefits.ny.gov/ https://www.mybenefits.ny.gov/ https://www.mybenefits.ny.gov/
- For information on New York State health benefits listed in this section, please see New York State's Health Insurance Programs website: https://www.health.ny.gov/health_care/

Parent Referral Tracking Sheet (PRMS PTF-RFRLS)

This section of NYESS will be updated at each instance of referral, including the outcome and level of satisfaction.

- Be sure to click the 'Save' button to save all the changes in the database.
- Use this tab when making a formal referral, not for capturing information services, which should be entered in the Activities module.
- A paper copy of PRMS PTF-RFRLS can be found in Appendix E of the *NYS PROMISE Policies and Procedures Manual*.

If you have any questions about the information found in PRMS PTF-RFRLS, please contact Andy Sink at 518-474-3616Maintaining Charts and other Documentation

The *NYS PROMISE Policies and Procedures Manual* provides detailed guidance maintaining charts and other documentation on youth. For convenience, the information pertinent to case management practitioners is reprinted below.

Charting Protocol: RDS Case Managers

RDS case managers should maintain files in alignment with the protocol below.

A. Section One: Participant Information
    a. This includes, but is not limited to:
        i. Participant Information Sheet (see Appendix G in the *NYS PROMISE Policies and Procedures Manual*); and
        ii. Authorization(s) for Release of Information

iii. Back up documentation including, but not limited to psychological, social and/or behavioral assessments.

B. Section Two: Plans and Assessments
   a. Copies of IEP/504 Plans
   b. Back-up documentation including, but not limited to psychological, social and/or behavioral assessments
C. Section Three: Referrals
   a. These will be printed from the PDF Referral Cover Sheet (See Appendix E in the *NYS PROMISE Policies and Procedures Manual*)
D. Section Four: NYS PROMISE Intervention Reports (e.g., CUTE).
E. Section Five: Progress Notes
F. Section Six: Miscellaneous
   a. This section includes any additional information, records or documents.

Charting Protocol: Family Coaches

Family coaches should maintain files in alignment with the protocol below.

A. Section One: Participant Information
   a. This includes, but is not limited to:
      i. Participant Information Sheet (see Appendix G of the *NYS PROMISE Policies and Procedures Manual*); and
      ii. Authorization(s) for Release of Information
      iii. Back up documentation including, but not limited to psychological, social and/or behavioral assessments.
B. Section Two: Goal Development Forms
C. Section Three: Referrals
   a. For Initial Intake – BWI Family andFLT, Financial Literacy Training and Benefits, Work Incentives, and Asset Development Planning and Assistance – Family, referrals will be made using the Referral Cover Sheet. Additionally, the referral must be recorded using the Parent Referral Tracking Sheet for quick access to referral details (Appendix E of the *NYS PROMISE Policies and Procedures Manual*).
   b. For all other non-NYS PROMISE service referrals, Parent Centers will track referrals using the PTF-RFRLS Tab in NYESS and also keep track in the record using the Parent Referral Tracking Sheet for quick access to referral details (Appendix E of the *NYS PROMISE Policies and Procedures Manual*).
D. Section Four: NYS PROMISE Intervention Reports (i.e., Financial Literacy Training and Benefits, Work Incentives, and Asset Development Planning and Assistance forms; see Appendix D of the *NYS PROMISE Policies and Procedures Manual*).
E. Section Five: Progress Notes
F. Section Six: Miscellaneous
   a. This section includes any additional information, records or documents.

Privacy and Confidentiality

Identity and Health Information

NYS PROMISE involves the collection and handling of confidential, ***personally identifiable information (PII)*** and ***personal health information (PHI).*** PHI is any information that identifies an individual and relates to the past, present, or future physical or mental health or condition of the individual, or the provision of healthcare for that individual. This includes healthcare payment information. PHI information gathered for PROMISE may require compliance with HIPPA regulations. To learn more about HIPPA, please see description of federal guidance on confidentiality at: https://www.hhs.gov/hippaa

All NYS PROMISE personnel are expected to protect PII/PHI, which includes:

- Participant name(s)
- Date of birth
- Address
- Telephone number
- Facebook or other social media usernames
- Social Security Number (SSN)

This information requires the highest levels of data security and maintenance of security protocols.

Email: Any documents containing PII/PHI must be password protected prior to being emailed (with password shared in a separate communication). PII/PHI should not be included in the body or subject line of an email.

Mail: If secured data must be mailed, you should utilize certified mail or a bonded courier. Printing of documents containing PHI/PII should only occur in a secured area, and staff should stay with the printer until their print job has completed. PHI/PII should be stored in locked file cabinets, digital files should be encrypted, and PHI should not be left out overnight in any unsecured area. If you must travel carrying PHI/PII, utilize a locked carrier. Documents containing PHI/PII should be shredded as soon as they are no longer necessary/required to be stored.

Faxing: No items containing PII should be faxed unless arrangements are made for an individual who has been notified of the fax to wait next to the machine to receive it.

Confidentiality

Complying with these general guidelines will help the NYS PROMISE team ensure that the data collected for the research project is properly maintained.

1. Only individuals who MUST handle the data for a specific reason AND have the appropriate security clearances should have access.

2. Store all materials with PII/PHI out of sight and locked in appropriate locking storage when not in use.
3. Keep work surfaces and open storage areas clear of materials containing PII/PHI. Never leave paper documents or portable media containing PII/PHI unattended.
4. When displaying PII/PHI on your computer, ensure that unauthorized people cannot see the information.
5. Log out of any data entry system (NYESS, password protected Excel document, etc.) and activate a screen saver whenever you leave your computer.
6. Do not email PII/PHI or include PII/PHI in the subject line or body of emails. Do not attach documents that contain PII/PHI.
7. Be sure that unauthorized people cannot overhear PII/PHI being discussed in person or over the phone.
8. If you share a workspace but must have a confidential conversation, transfer your phone call to a private space or ask to call the individual back from a private space.
9. If you must speak to a NYS PROMISE or national PROMISE team member about a participant but the individual you want to speak to is not available, please leave a message asking them to call you back. Do not leave phone messages containing PII/PHI.
10. Report the loss, disclosure, or misuse of PII/PHI to your supervisor immediately. This includes: lost or stolen laptops, USBs, lab or office space left unlocked, lost keys to secure cabinets, etc. Accidents happen, but it is in the projects' best interest to report any lapse in data security immediately.

    (Excerpted in part from McCutcheon, 2014)[1]

Federal Guidance on Confidentiality

There are two federal laws related to confidentiality that case managers need to be familiar with in working with student and family records. The Health Insurance Portability and Accountability Act (HIPAA) protects the privacy of an individual's health care records. The Family Educational Rights and Privacy Act (FERPA) is a federal law that protects the confidentiality of a student's educational records. Within the public high school setting, "educational records" is a broad term that includes immunization records and records held by the school nurse. Most schools are not required to follow HIPAA regulations. However, when an outside party that is not contracted or employed by the school is working with a student, the outside provider's records are not considered "medical records". If the provider performs any electronic transactions (such as billing a health plan) the provider must follow HIPAA regulations.[2] Both HIPAA and FERPA involve parental consent for the release of personally

1 McCutcheon, AnnaMaria. PROMISE Procedure Manual Slides, NYS. Mathematica Policy Institute. June 15, 2014. PowerPoint Presentation, June 17, 2014.

2 U.S. Department of Health and Human Services & U.S. Department of Education (2008). *Joint guidance on the application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to student health records.*

identifying information about students. After a student turns 18, the right to consent transfers to the student.

The following links provide guidance on HIPAA and FERPA regulations:
FERPA Guidelines: https://www2.ed.gov/policy/gen/guid/fpco/ferpa/for-parents.pdf
HIPAA Guidelines: https://www.hhs.gov/hipaa/index.html

Effective Case Notes

Case noting is the most valuable tool in the NYS PROMISE case management practitioner's tool belt. While at times it may seem a horrific inconvenience and a distraction from the important 1:1 work performed over the course of a day, maintaining detailed records contributes to not only organizational effectiveness but also the individuals served.

The case management system for NYS PROMISE is embedded in NYESS. It is a repository for data associated with assessment, planning, service delivery, and progress tracking. In addition, many case management practitioners keep working files on clients for ease of access of information and to retain original copies of forms and releases. In both situations it is vital that practitioners maintain accurate and complete information and that required data is entered and archived in NYESS. A centralized data management information system like NYESS is essential for analyzing data in an efficient manner, and in turn gaining insights into which methodologies or interventions are producing high yield outcomes.

The National Association of Social Workers provides case management and proper documentation standards. According to their requirements,[1] well documented case records should contain, at a minimum, the following:

- Releases of information, signed by the client and/or guardian
- Historical and demographic information
- Assessment data
- Individualized planning documents or activities
- Projected and realized outcomes
- Referrals to other agencies or resources
- Service costing and expenditures (cost of care)
- Reasons for changes in services and/or termination

The NYESS was developed with these indicators in mind. Case management practitioners following procedures outlined in the *NYS PROMISE Intervention and Implementation Guide* and recording required NYS PROMISE information should be in compliance with these standards. Case management practitioners must also recognize and be responsive to the fact that case records can be subpoenaed as court documents.

[1] http://www.socialworkers.org/practice/naswstandards/CaseManagementStandards2013.pdf

Case Records and Case Noting

For the purposes of NYS PROMISE we expect that case records include both NYESS data and working files the case management practitioner employs. It is critical in keeping working files that strict guidelines be held to regarding their storage, use and destruction. Additional guidance on file security and storage can be found in t*he NYS PROMISE Security Guidelines* and the *NYS PROMISE Policies and Procedures Manual.* Case noting is a process case management practitioners engage in to record information regarding a particular case or intervention. Case notes are considered part of the case record and may be included in both the NYESS system as well as working files maintained by the practitioner.

Case notes are an important and critical part of the case record and their purpose is manifold:

1. Provide a summary of assessments—capturing a snap shot of relevant data to the case
2. Provide sequential tracking and reporting of contact and progress of the client. Including new barriers that may arise and modifications to individualized planning
3. Provide an accountability system which tracks internal oversight, monitoring and auditing of a particular case
4. Provide a vehicle for tracking ethical responsibilities
5. Provide a system for tracking information and sharing it with other critical stakeholders—both internal and external (with authorization and release)

Writing Strategies

Case notes should be written in a timely, accurate and complete manner, using acceptable grammar, while at the same time being clear and brief. Delays in making case notes can often result in forgetting critical information, causing a lapse in the case record. When writing case notes the writer should at all costs avoid diagnosing specific situations and using unfamiliar language. Remember, other case management practitioners may review this record, and it is vital that they understand what has been written. Cultural sensitivity is also an important factor to keep in mind when writing case notes—make sure to avoid prejudices and stereotypes.

When making case notations, case management practitioners often fail to include other qualitative information that may be observed or stated during a case management intervention. Statements made by the client and/or guardian may provide important context to case notations, as well as behaviors that are reported. At the same time, the case management practitioner should record their own observations—making sure to substantiate any conclusions or judgments made in the course of their own observations.

Remember, case notation provides a story of how services and supports were identified as needed, provided, evaluated and the degree to which they led to a desired outcome. Case notes provide a critical record of interactions relevant to a given case or incident. Remember to use person-first language and

avoid deficit-based, derogatory and/or emotive language. When case notes are written well, they provide accurate and objective descriptions grounded in fact, experience and evidence.

Reporting

In an effort to support ongoing case management, Cornell and OMH will be developing reports each quarter to provide RDS with information on the status and progress of NYS PROMISE participants. Using these reports, Cornell and OMH will work with sites each quarter to identify areas and strategies for improvement.

Mid Quarterly Reports

RDS are required to conduct many activities on a quarterly basis. Halfway through each quarter, RDS will receive a customized report detailing NYESS data and progress for each of their participants. The goal of this report is to assist sites with gauging their progress and strategizing their workload for the rest of the quarter.

Mid-Quarterly Reports will consist of a password-protected Excel spreadsheet containing NYESS data on each youth who is enrolled within a particular RDS (each RDS will receive a spreadsheet containing information on only their own participants.) These reports will include information on:

- Youth background information (e.g., name, school)
- RDS information (e.g., RDS name, case manager)
- YTF Data (to include A, B, B2 and C)
- Most recent two services
- Information on the date the student records were last updated

These reports should allow sites to identify youth files/information in need of updating and youth not currently engaged in services or other activities. Cornell and OMH will use these reports to identify areas for technical assistance at the RDS, regional and state level.

End-of-Quarter Reports

At the conclusion of each quarter, Cornell and OMH will generate a summary report outlining the NYESS data for each RDS and region. The goal of this report is provide a snapshot of case management, service referral and delivery, and data entry. These reports will also be used to compare RDS performance and activities, to identify broad areas for TA and are intended to meet biannual reporting requirements establish by the funding agency.

End of Quarter reports will consist of a brief summary of data from NYESS, focusing on overall numbers rather than on individual youth-level data (as the mid-quarterly reports do). RDS and regional level reports may be shared across the state, either via electronic documents or OTAC.

These reports will include information on youth enrollment, NYESS data entry completeness and youth program participation (e.g., case management meetings, services referred for and received, etc.).

Program Fidelity Site Visits

Twice a year, staff from Cornell will visit each RDS to collect additional data about NYS PROMISE implementation. The focus of these visits will be 1) meeting with program staff to get information on program implementation, issues and to answer questions, and 2) reviewing youth NYS PROMISE records to learn more about the service planning and delivery process and about case management. The information collected will be used to achieve the following:

- Better understand what implementation of NYS PROMISE looks like at the local level
- Identify challenges or barriers that RDSs and other groups in the state are encountering related to NYS PROMISE
- Develop technical assistance or training materials to support implementation of NYS PROMISE
- Modify program processes, tools, etc. to better support NYS PROMISE-related work
- Identify variations across programs participating in NYS PROMISE
- Ensure youth files are being kept in alignment with the guidelines in the of the *NYS PROMISE Policies and Procedures Manual*

Prior to each of these site visits Cornell staff will provide RDS with information about the information to be accessed.

The information gleaned from youth records will be combined with information from other organizations across each region and/or the state in any reports published publically. No information will be shared publically that would identify a specific organization or particular youth or parents.

One of the goals of gathering this information is to use it to provide direct assistance to each RDS– as such, the findings from site visit reviews will be combined with other fidelity data being collected to inform guidance, technical assistance or other interactions that Cornell or OMH staff may engage in with organizations participating in NYS PROMISE.

Preparing For Site Visits

Program fidelity sites visits are an opportunity for Cornell staff to collect data and for RDS staff to ask questions or request assistance. Prior to these visits, both Cornell and RDS have a number of activities to complete.

Cornell Staff Will:

- Contact RDS staff to schedule a convenient date for the visit (visits occur approximately April/May and September/October)
- Share information with the RDS about the goals and agenda for the visit

- Randomly select a small number of youth at each RDS and review their NYESS data (Cornell staff will then review the files of these students during the visit)

RDS Staff Should:

- Update all student files to ensure they are complete and current
- Update NYESS data as much as possible
- Decide which staff to include in the visit
- Generate questions, issues or areas for TA to discuss during the visit

Telling Your Stories of Success

As a part of NYS PROMISE, one goal is to share information, learning and success across the state, with other PROMISE research sites, with our Federal funders, and to exterior stakeholders. To that end, we've developed a mechanism for documenting and disseminating success stories from around the state. These can be shared in a variety of formats:

- Podcasts
- Videos
- Written word
- Webinars
- Community of Practice
- Learning Community

Experiences encourage and enlighten our learning community, and share with others the struggles, successes, tears and rewards of being involved in NYS PROMISE. Success includes individuals whose stories are complicated, not-so-happy, in-progress, or are waiting on a resolution. For the youth and families involved in NYS PROMISE, a success story may be as simple as taking the first step towards self-determination, attending their first IEP meeting as a family, or having a case manager listen to them as they discuss a difficult period they are going through.

Sites, case managers, family coaches, and service providers can share their story in regional meetings, with program fidelity specialists, with the regional OMH representatives, or by emailing their story to nyspromise@cornell.edu. Individuals may be asked to talk in greater detail about their story for an upcoming video, podcast, or may be invited to participate as a speaker during a learning community event or webinar.

Module 6: Resources

Scheduling Checklists for NYESS Data Collection and Reporting

Intervention Group Youth

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Form A (YTFA) **Annual**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Forms B and B2 (YTFB and YTFB2) **Quarterly**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Form C (YTFC) **Quarterly**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Control Group Youth

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Form A (YTFA) **Annual**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Forms B and B2 (YTFB and YTFB2) **Semi-Annual**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Form	Date Collected	Next Due	Date Collected	Next Due
Youth Tracking Form C (YTFC) **Semi-Annual**		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Intervention Group Guardian

Form	Date Collected	Next Due	Date Collected	Next Due
Guardian Update Tab ***Quarterly***		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Control Group Guardian

Form	Date Collected	Next Due	Date Collected	Next Due
Guardian Update Tab ***Semi-Annual***		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December
		☐ January-March ☐ April-June ☐ July-September ☐ October-December		☐ January-March ☐ April-June ☐ July-September ☐ October-December

Module 7: Counseling

Introduction

Counseling is the heart of proactive case management for family coaches and case managers. In this module, we will review the proactive activities practitioners can incorporate into their daily practice. We will introduce critical youth and family touchpoints in the transition process. We will discuss communication issues and challenges, and explore how to build resilience to challenges. Finally, we will begin an exploration of some of the challenging family situations common to this audience, and how to respond to angry individuals.

Empathy and Trust in Counseling

In order for a counseling relationship to develop successfully, the most essential feature is the development of rapport and trust between the helper and the individual being served. This trust is established within the context of an empathetic relationship in which the case manager communicates an ability to step into the shoes of the individual and understand his/her feelings. Empathic communication involves listening and responding with both verbal and non-verbal communication strategies that demonstrate that the case manager has attended, listened, and accurately perceived the message.

Transference and Countertransference in Case Management[1]

The field of psychology acknowledges that the helper/helpee relationship does not exist within a vacuum, and that each individual brings his/her own thoughts and feelings into every encounter that takes place within the case management relationship. The term **transference** is the client's projection of thoughts, feelings and wishes (both conscious and unconscious) onto the professional. In some cases, these thoughts, feelings, and wishes are driven by past relationships in the client's life (parent, sibling, etc.). Regardless of where the thoughts and feelings originate from, they are assumptions and responses that take root in the client's own interpretations and perceptions, and as such, are not necessarily accurate. At the same time, within each therapeutic helping relationship, the professional is subject to thoughts and feelings that he/she projects onto the client, and this is known as **countertransference.** Case managers should take transference and countertransference into account with every case management interaction in order to remain objective and to understand the underlying dynamics of the relationship that may be affecting progress. Evaluating the potential impact of transference issues on the relationship can help the case manager to make more sound clinical decisions.

[1] Walsh, J. (2003). Supervising the countertransference reactions of case managers. *The Clinical Supervisor, 21*(2), 129-144. 10.1300/J001v21n02_09

The following countertransference issues are commonly found within case management professionals:

- Having a need for clients to be dependent. This helps the case manager feel fulfilled and needed.
- Needing to be liked by the client. This may lead to trying too hard to please or being easily hurt by the client.
- Needing to control the relationship.
- Showing too much curiosity about the personal details of the client's life.
- Behaving too aggressively or confrontationally.
- Being uncomfortable with certain types of emotional reactions, leading to avoidance or suppressing of the client's feelings.
- Over-identifying with clients with similar problems to one's own.
- Idealizing clients based on strong positive feelings. May set them up for unrealistic goals and place undue pressure on the client to please the case manager.

The best way to manage transference and countertransference issues is for case managers to engage in dialogue with a supervisor about the dynamic underpinnings of the therapeutic relationship. This allows the supervisor to view the relationship from a non-biased perspective, and the supervisor can help the case manager to minimize the impact that these dynamics have on the well-being of the client and the professional.

Boundaries in Therapeutic Relationships[1]

Within the context of therapeutic relationships, **boundaries** are behavioral limits that allow for "space" between the client and professional in order to maintain healthy interactions. Boundaries prevent the case manager from exerting any undue power (consciously or unconsciously) over the other individual, who is in a more vulnerable position in the therapeutic relationship. Boundaries include elements such as time spent with a client, attention provided, gifts given, personal information self-disclosed, etc. Without boundaries, the working relationship runs the risk of becoming ambiguous, and transference and countertransference factors can become more damaging.

Boundary crossings are brief movements across boundaries with a return to the professional relationship.[2] This may include extending a visit for a client, providing a small gift, or doing a minor favor. Many boundary crossings fueled by good intentions towards the client. However, once a professional begins stepping over the boundary line, roles and rules become more ambiguous and confused, and this can sometimes lead to a **boundary violation** in which a professional goes outside the boundary of the professional relationship and establishes a social, economic, or personal relationship

[1] Malone, S. B., Reed, M. R., Norbeck, J., Hindsman, R. L., & Knowles 3rd, F. E. (2004). Development of a training module on therapeutic boundaries for mental health clinicians and case managers. *Lippincott's Case Management: Managing the Process of Patient Care, 9*(4), 197-202. 10.1097/00129234-200407000-00007

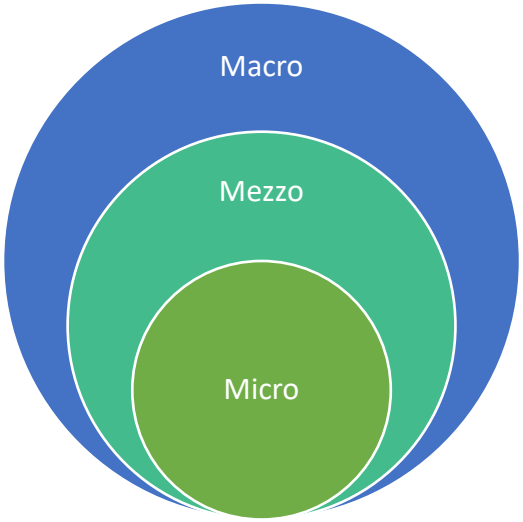
[2] Manfrin-Ledet, L., Porche, D. J., & Eymard, A. S. (2015). Professional boundary violations: A literature review. *Home Healthcare Now, 33*(6), 326-332. 10.1097/NHH.0000000000000249

with a client. Boundary violations pose a significant risk to clients due to their vulnerable position within the relationship. **It is always the responsibility of the professional to maintain healthy boundaries in the relationship due to his/her position of power and influence in the therapeutic relationships.** Boundary violations can lead to serious consequences such as termination and/or legal action.

Many professionals underestimate the potential to become engaged in a boundary violation. However, the movement from boundary crossings to boundary violations often happens gradually over time, and in many cases, the professional had no intent of engaging in a boundary violation in the beginning. However, as the relationship lines become more blurred and transference and countertransference factors come into play, the relationship can move in an unhealthy direction if boundary violations are not dealt with properly. Professionals who interact with clients in their home are at greater risk of becoming involved in boundary difficulties, because these environments do not provide the same supervision and resources that are available in other work settings. As suggested above with issues of transference and countertransference, regular supervision can help provide a safeguard against the potential damage of unhealthy boundaries.

Person in Environment Perspective

The field of social work recognizes that individuals do not exist within a vacuum and that they are influenced by multiple factors within their environment. The picture below provides a visual model of the different aspects of one's environment that impact behavior. This model provides a tool for visually conceptualizing how various aspects of an individual's life can interact with one another.



The **micro level** consists of biological, psychological, developmental, spiritual, emotional, cognitive, recreational, and financial aspects of personality and individual functioning that is considered essential to his/her well-being. It also includes age, gender, income, and ethnic background. The **mezzo level** is comprised of family, friends, co-workers, neighborhood, work environment, church activities, local resources and services, and transportation. The outermost level, or **macro level**, includes larger social forces such as government policy, discrimination, social policy, economic conditions, historical events, and other forces that can impact an individual.

Figure 7.1 Person in Environment

Solution-Focused Approach to Case Management in Mental Health

The field of mental health has begun shifting away from the medical model, which views mental health disorders as debilitating and focused on symptoms, to embrace a more hopeful recovery-oriented model of mental well-being. Recovery is highly individualized, and means different things to different individuals. The following factors have been shown to help promote recovery in individuals with mental health disorders[1]:

1. Hope

In this context, hope is defined as goal-related thinking, in which the individual is able to identify one or more clear routes to a goal and views himself/herself as capable of achieving the goal. Helping the individual move away from despair and move towards hope is important, because often individuals with significant mental health symptoms feel demoralized by a history of recovery followed by periods of relapse. It is helpful to remind individuals that there is more to life than their mental health disorder. Case managers should identify strengths and assist in maintaining a focus on the future and achieving small goals.

2. Coping skills

Case managers can help individuals identify coping mechanisms (breathing techniques, cognitive strategies, etc.) and then reinforce the following skills related to using appropriate coping mechanisms:

1) Recognize when feeling stressed.
2) Identify the stressor.
3) Remember from past experiences what helped with the stressor.
4) Pick a coping strategy and use it.
5) If that doesn't help, use another coping strategy.

Note: In some cases, it is helpful to print coping techniques on small cards that can be laminated and carried in the pocket in a key ring as a reminder when the individual has difficulty recalling coping techniques to try in a given situation.

3. Empowerment

Often individuals with mental health disorders feel marginalized and demoralized within society and relationships. Case managers can assist them in making self-determined decisions and in identifying strengths, resources, competencies and skills.

[1] Greene, G. J., Kondrat, D. C., Lee, M. Y., Clement, J., Siebert, H., Mentzer, R. A., & Pinnell, S. R. (2006). A solution-focused approach to case management and recovery with consumers who have a severe mental disability. *Families in Society, 87*(3), 339-350. doi:10.1606/1044-3894.3538

4. Supportive social networks

Maintaining a supportive social support network is a crucial aspect of mental health recovery. Case managers can help individuals identify friends, family, and professionals who can help to support them in maintaining mental health well-being.

Solution-focused brief therapy (SFBT) is a short-term strength-based approach to working with individuals that strives to separate people from their problems. The main components of SFBT include[1]:

1. Looking for previous solutions that were helpful to resolving similar problems.
2. Acknowledging the problems, but identifying exceptions to the problems that provide insight into solutions (Asking, "What were you doing differently when the problem was less frequent or less intense?")
3. Focusing on present and future rather than the past.
4. Using scaling questions (e.g., "On a scale of 1-10 how well do you feel like things are going in coping with this problem right now?"), coping questions (e.g., "How have you managed to prevent things from becoming worse?), and the Magic Wand Question (described below):

Magic Want Question:

Imagine that I have a magic wand and by waving the magic wand I could make your problems disappear just like that. Describe to me what your world would look like. What would you be doing and how would you be spending your time?

Note: Continue prompting the individual by asking, "What else?" until he/she has described up to 3 behaviors/differences, which will indicate positive changes that will help with setting goals.

Principles of Trauma-Informed Care

In recent years, the field of human services has become more aware of the impact that trauma has on the physical, emotional, and cognitive development of youth. This has led to a movement by service providers to a more trauma-informed approach to care, which recognizes that a large number of individuals in any population are statistically likely to have experienced some sort of trauma, and that in the context of interacting with those individuals, staff are in danger of triggering or re-traumatizing the individual. Trauma-informed care (TIC) is an approach that an organization or program adopts that strives to prevent re-traumatization while promoting healing of individuals.[2] Organizations and individuals acknowledge that many staff members and individuals served have likely experienced some type of trauma in their lives, and that when services delivered feel safe, empowering, and welcoming,

[1] Wells, K. and McCaig, M. (2016), The Magic Wand Question and Recovery-Focused Practice in Child and Adolescent Mental Health Services. *J Child Adolesc Psychiatr Nurs, 29*, 164-170. doi:10.1111/jcap.12159
[2] Koury, S. P., & Green, S. A. (2017). Developing trauma-informed care champions: A six-month learning collaborative training model. *Advances in Social Work, 18*(1), 145-166. 10.18060/21303

individuals are more likely to engage in and benefit from care.[1] When individuals do not behave in the way that is expected, the question that is asked by TIC organizations is not "What is wrong with you?" but "What happened to you?"

The Substance Abuse and Mental Health Services Administration (SAMHSA) describes trauma-informed programs as being those that:[2]

1. Realize the widespread impact of trauma and understand potential paths for recovery.
2. Recognize the signs and symptoms of trauma in clients, families, staff, and others involved in the system.
3. Respond by fully integrating knowledge about trauma into policies, procedures, and practice.

SAMPHSA also proposes that trauma-informed programs should strive to incorporate the following key principles into interventions with clients:

- Safety
- Trustworthiness and transparency
- Peer support
- Collaboration and mutuality
- Empowerment, voice, and choice
- Cultural, historical, and gender issues

Ideally, staff within roles across an organization should receive training in TIC. Education and training should be provided to staff regarding the nature of trauma, the impact of trauma on brain development and functioning, and examples of various ways that systems may unintentionally re-traumatize individuals or trigger traumatic responses in individuals who have been exposed to trauma.[3] It is also beneficial to provide training to staff on how to respond to activated clients. In addition, everything should be reviewed through the lens of TIC -- from the look and feel of waiting rooms and restrooms to agency policies and procedures. The agency should assess the potential impact that every facet of the services that it delivers may have on individuals who have experienced trauma.

One of the foundational beliefs of trauma-informed care is that all individuals need to feel safe in order to pursue higher goals and aspirations. Children who have grown up in poverty and in violent neighborhoods have often been exposed to experiences and circumstances that have led them to believe that the world is not safe and that others are not trustworthy. In 1998, the groundbreaking Adverse Childhood Experiences (ACEs) study measured the occurrence of ten different types of adversity

[1] Yatchmenoff, D. K., Sundborg, S. A., & Davis, M. A. (2017). Implementing trauma-informed care: Recommendations on the process. *Advances in Social Work, 18*(1), 167-185. 10.18060/21311
[2] Substance Abuse and Mental Health Services Administration (2015).Trauma informed approach and trauma-specific interventions. Retrieved from. http://www.samhsa.gov/nctic/trauma-interventions.
[3] Yatchmenoff, D. K., Sundborg, S. A., & Davis, M. A. (2017). Implementing trauma-informed care: Recommendations on the process. *Advances in Social Work, 18*(1), 167-185. 10.18060/21311

children in the United States experience. These included various forms of child abuse, child neglect, and household dysfunction. Out of 17,000 adults studied, 64% reported experiencing at least one ACE, and 13% experienced four or more ACEs.[1] This study led to a paradigm shift in which, for the first time, the field of human services began to look at the lifelong impact of cumulative trauma experienced by individuals.

Understanding the Impact of Trauma on Individuals and Families

Dr. Bruce Perry, a child and adolescent psychiatrist and neuroscientist, defines trauma as "an experience or pattern of experiences, that impairs the proper functioning of a person's stress response system, making it more reactive or sensitive."[2] According to Dr. Perry's research, when young children, whose brains are still developing, are exposed to prolonged periods of stress, the neural pathways in their brain can change, causing them to remain in a heightened level of stress even after the threat has been removed. Many individuals who have experienced chronic trauma exist in a permanent state of hypervigilance, which means that their natural fight-or-flight response is over-activated and they remain on alert, scanning the environment for danger at all times. In some cases, this can cause an individual to be over-responsive to threat, becoming verbally and/or physically aggressive to others.. Others learn to numb themselves to the experience of pain through dissociation, or the disconnection of the mind from the body. When the brain is in the fight-or-flight state, it is very difficult for individuals to focus and absorb new information.

When an individual (especially a child) experiences a traumatic event that they are unable to verbally or emotionally process, their body symbolically stores the memory as physicological reactions to stimuli, situations, or feelings of arousal that are connected to the traumatic event (trauma responses).[3] These trauma responses can resurface unpredictably in response to stimuli within the environment. Even after an individual is removed from a traumatic environment, he/she may have distressing memories attached to events that resurface and are triggered by sights, sounds, smells, and tastes that they encounter (e.g., seeing someone who looks like an individual who abused them, hearing loud noises, seeing someone raise their hand, etc.).[4] The individual who is experiencing the traumatic memory may be completely unaware of the connection between the original traumatic event and the trauma trigger, yet their body may begin the experience the same level of intense and distressful feelings that were experienced at the time of the original trauma. This lack of awareness can leave the individual unable to

[1] Oral, R., Ramirez, M., Coohey, C., Nakada, S., Walz, A., Kuntz, A., . . . Peek-Asa, C. (2016). Adverse childhood experiences and trauma informed care: The future of health care. *Pediatric Research, 79*(1), 227-233. 10.1038/pr.2015.197

[2] Supin, J. (2016). The long shadow: Bruce Perry on the lingering effects of childhood trauma. *The Sun*, 4-13.

[3] Reeves, E. (2015). A synthesis of the literature on trauma-informed care. *Issues in Mental Health Nursing, 36*(9), 698-709. 10.3109/01612840.2015.1025319

[4] Martin, S. L., Ashley, O. S., White, L., Axelson, S., Clark, M., & Burrus, B. (2017). Incorporating trauma-informed care into school-based programs. *Journal of School Health, 87*(12), 958-967. 10.1111/josh.12568

explain what appears to be very bizarre or "out of control" behavior that seems out of context for the environment.

The National Child Traumatic Stress Network summarized the following assumptions about the impact of trauma on children and families:[1]

1. Traumatic experiences are inherently complex.
2. Trauma occurs within a broad context that includes a child's personal characteristics, life experiences, and current circumstances.
3. Traumatic events often generate secondary adversities, life changes, and distressing reminders in child's daily life.
4. Children can exhibit a wide range of reactions to trauma and loss.
5. Danger and safety are concerns in the life of a child who has experienced trauma.
6. Traumatic experiences affect the family and broader caregiving system.
7. Protective and promotive factors can reduce the adverse impact of trauma.
8. Trauma and post-trauma adversities can significantly impact development.
9. Developmental neurobiology underlies children's reaction to traumatic experiences.
10. Culture is closely woven with traumatic experiences, response and recovery.
11. Challenges to the social contract, including legal and ethical issues, affect trauma response and recovery.
12. Working with trauma-exposed children can evoke distress in providers.

Dr. Perry asserts that one of the most powerful predictors of how children will recover from trauma is the level of support received from the adults around them. If they are surrounded by nurturing and supportive adults who help them to regulate their emotions, children are often able to recover from the crisis and develop their own internal methods for regulating emotions. However, if they do not have stable and nurturing adults in their lives to comfort them, they may experiencing lifelong difficulties regulating emotions. Dr. Perry states that "Resilient children are made, not born." They develop emotional regulation skills through interactions with those around them. One of the most profound insights that came out of the Childhood ACEs studies was that there is a correlation between the number of adverse childhood conditions experienced and overall lifelong functioning, and individuals who experience multiple adverse childhood experiences are more likely to engage in risky behaviors (substance abuse, unintended pregnancy, etc.) and develop a "trauma organized" lifestyle than those with fewer adverse childhood experiences.[2] This is particularly true of children that have a limited support system. Research shows that youth who have been raised in inner city environments with

1 National Child Traumatic Stress Network Core Curriculum on Childhood Trauma Task Force (2012). The 12 core concepts: Concepts for understanding traumatic stress responses in children and families. (Los Angeles, CA, and Durham, NC. Retrieved from http://www. nctsn.org/resources/audiences/parents-caregivers/what-is-cts/12-core-concepts).

[2] Oral, R., Ramirez, M., Coohey, C., Nakada, S., Walz, A., Kuntz, A., . . . Peek-Asa, C. (2016). Adverse childhood experiences and trauma informed care: The future of health care. *Pediatric Research, 79*(1), 227-233. 10.1038/pr.2015.197

higher rates of disrupted parental attachments are more likely to turn to peers as their primary source of interpersonal support (as opposed to a parent or another adult), placing them at a higher risk for becoming involved in gang activity and other negative peer influences.[1]

Research has shown that mild to moderate exposure to predictable, controllable stress, when surrounded by supportive adults who can model appropriate emotional regulation strategies, can build resilience in children. However, the presence of prolonged or chronic stress in a child's life leads to an over-activation of the body's stress response, which can ultimately result in abnormalities in the structure and functioning of the developing brain, leading to subsequent cognitive, emotional, behavioral, and physical health problems.[2]

Another remarkable discovery in the field of trauma-informed care research is that trauma can be passed down from one generation to the next. The theory of historical trauma proposes that members of historically traumatized populations (e.g., African Americans and Native Americans) are disproportionately vulnerable to experiencing prolonged grief and low self-esteem, and may be at risk for developing PTSD-like symptoms even when they have not been directly traumatized. Supporters of the theory of historical trauma share some of the following assumptions:

- Mass trauma is intentionally inflicted on the surviving populations.
- The trauma endured is not a singular event, but is a continuous and prolonged exposure.
- Traumatic events are experienced throughout the entire population, creating a shared traumatic experience.
- The continuous and prolonged exposure alters the developmental trajectory of the population, and this disadvantage results in universal disparities that persist through generations.

This theory of historical trauma has been used to help explain the link between populations that have been historically oppressed and current risk for experiencing trauma symptoms. For example, the theory asserts that a disproportionate number of African Americans live below the poverty line, that poverty significantly increases one's risk for being interpersonally traumatized, which leads to a greater risk for developing PTSD symptoms.[3]

Trauma and Individuals with Intellectual and Developmental Disabilities

Trauma is typically defined as an individual's experience of an event or condition that is perceived to be a threat to one's safety, and the nature of the experience is so overwhelming that the individual is

[1] Bulanda, J., & Byro Johnson, T. (2016). A trauma-informed model for empowerment programs targeting vulnerable youth. *Child and Adolescent Social Work Journal, 33*(4), 303-312. 10.1007/s10560-015-0427-z
[2] Martin, S. L., Ashley, O. S., White, L., Axelson, S., Clark, M., & Burrus, B. (2017). Incorporating Trauma-Informed care into School-Based programs. *Journal of School Health, 87*(12), 958-967. 10.1111/josh.12568
[3] Danzer, G., Rieger, S. M., Schubmehl, S., & Cort, D. (2016). White psychologists and African Americans' historical trauma: Implications for practice. *Journal of Aggression, Maltreatment & Trauma, 25*(4), 351-370. 10.1080/10926771.2016.1153550

unable to process the event and integrate it into his/her framework of understanding.[1] Among the general population, many individuals experience adverse life events and recover without developing any long-term traumatic responses. However, individuals with intellectual and developmental disabilities (I/DD) have been shown to be more vulnerable to experiencing traumatic events and to developing traumatic responses. Circumstances that are not considered traumatic within the general population can be experienced as highly traumatic for individuals with I/DD (for example, being teased by a peer).[2] These seemingly minor events sometimes resurface pre-existing vulnerabilities, triggering responses that appear disproportional to the current situation. In addition, individuals with I/DD are often less equipped with the emotional regulation and coping skills necessary to respond to the event, and may have difficulty communicating thoughts and feelings to caretakers, resulting in emotional responses and behavior that can be confusing and frustrating to the adults caring for them. Due to this lack of understanding, the individual's behavior may result in disciplinary measures or interventions that can lead to further traumatization.

It is essential that case managers and professionals working with individuals with I/DD consider the possibility that a confusing or challenging behavior in an individual with whom you are working may be rooted in trauma. Remember that all behavior is communication, and when an individual becomes defiant, avoidant, aggressive or "difficult," there is usually a reason or trigger for this behavior. The first step should always be to provide comfort and reassurance to the individual through soothing words and actions, reminding him/her that he/she is safe. More careful assessment of the situation may help to unlock avenues for communicating more directly with the individual about the emotions that are being experienced.

Proactive Case Management and Critical Touchpoints

Proactive case management is an approach that focuses on preparing for and anticipating needs of youth and families. It involves the strategic preparation of targeted interventions over time to increase the working relationship between the case manager and families served. Throughout the case management process, there are key events and situations that trigger strong positive and negative emotions. Being aware of potential emotional touchpoints, and proactively reaching out to the families during these times can provide a much richer and more meaningful experience for families. Touchpoints can include the following:

1. Transitions that move the individual from one phase of life to another and require the individual to adapt or change in some way. Some of the transitions youth and families enrolled in NYS PROMISE might experience are:
    - Moving from middle school to high school

[1] Keesler, J. M. (2014). A call for the integration of Trauma-Informed care among intellectual and developmental disability organizations. *Journal of Policy and Practice in Intellectual Disabilities, 11*(1), 34-42. 10.1111/jppi.12071
[2] Bradley, E., Sinclair, L., & Greenbaum, R. (2012). Trauma and adolescents with intellectual disabilities: Interprofessional clinical and service perspectives. *Journal of Child and Adolescent Trauma, 5*(1), 33-46. 10.1080/19361521.2012.646412

- Turning 18
- Graduating from high school
- Dropping out of school
- Obtaining a new job
- Having a baby
- Getting married
- Decision to leave NYS PROMISE
- End of NYS PROMISE initiative in 2018
- Choice to continue to access NYS PROMISE related services through ACCES-VR
- Moving to a non-NYS PROMISE school, region or state

2. Specific events or crisis within the life of the youth or the family that create opportunities to provide support and strengthen relationships with the family. These events can include:
   - Death or illness of a family member
   - Suicide attempt
   - Admission of youth to hospital or psychiatric facility
   - Behavior of youth causing disruption at home or school
   - Loss of housing
   - Loss of job of caretaker
   - Movement of youth to a higher level of care outside the home (residential, juvenile justice facility)
   - Pregnancy of youth
   - Loss of services from an agency previously involved with the family
   - Change in SSI status of youth or other family members

3. Time-sensitive issues that are important to be aware of in order to help prepare the family and provide necessary information and support. This can include:
   - Educational planning (IEP meetings, scheduled evaluations and assessments)
   - Wage reporting to SSA or other means-tested benefit programs
   - SSI-related decisions (CDR, Age 18 Redetermination, etc.).
   - Employment-related issues (Annual performance reviews, etc.)

Communication in Counseling

Challenging Behavior in Youth

Current research estimates that between 50-96% of youth growing up in urban communities have witnessed or directly experienced some sort of violence, and this exposure to violence places them at an increased risk for a number of negative emotional and behavioral outcomes.[1] Risk factors include anxiety, depression, posttraumatic stress disorder, suicidal ideation, aggression, violence, and higher dropout rates. Youth who were interviewed in high-risk urban environments where violence is part of daily life reported feelings of fear and a general sense of being in danger. Many expressed a sense of hopelessness about their future, and have come to view violence as a normal part of everyday life. African American males are among the highest risk, and although they represent only 15% of the total youth population, they represent over 50% of the juvenile offender population.[2]

Connections between Social Skills and Challenging Behaviors

According to Ross Greene, author of *The Explosive Child* and *Lost at School*, kids with social, emotional and behavioral challenges lack important thinking skills.[3] If you can figure out what skills are lagging, you can better understand why the youth is behaving in a way that creates challenges. The challenging behavior is most likely to occur when the demands being placed on the youth exceed his/her adaptive abilities.

Youth exhibiting challenging behavior are found lagging in some of the following skills:

- Handling transitions and shifting focus from one task to another
- Doing things in a logical sequence or order
- Considering likely outcomes or consequences of actions
- Considering range of solutions to a problem
- Expressing concerns, needs or thoughts in words
- Managing emotional response to frustration
- Handing unpredictability or uncertainty
- Attending to or accurately interpreting social cues from others
- Inaccurate cognitive distortions or biases
- Reflecting on how own behavior is impacting others
- Empathizing with others or seeing another's point of view

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[1] Seal, D., Nguyen, A., & Beyer, K. (2014). Youth exposure to violence in an urban setting. *Urban Studies Research.* oi:http://dx.doi.org/10.1155/2014/36804

[2]Richardson, J. B., Johnson, W. E., & St. Vil, C. (2014). I want him locked up: Social capital, African American parenting strategies and the juvenile court. *Journal of Contemporary Ethnography, 43*(4), 488-522

[3] Greene, R. W. (2008). *Lost at school: Why our kids with behavioral challenges are falling through the cracks and how we can help them.* New York: Scribner.

These lagging skills can be targeted by providers teaching work readiness skills or included in a child's IEP. Identifying and targeting lagging skills can provide a less stigmatizing framework for examining behavior than referring to the behavior disciplinary problem or labeling the child as a "delinquent". Case management practitioners can assist parents in establishing communication with school staff that can help parents develop strategies at home to improve lagging skills in their child.

In his book *It's So Much Work to Be Your Friend: Helping the Child with Learning Disabilities Find Success* (2006), Rick Lavoie explains that because kids with poorly developed social skills suffer from peer rejection and lack of popularity, they are at a higher risk for developing delinquent behaviors. Children with learning disabilities are also more likely to have difficulty with problem-solving and respond to conflict with aggression. Lavoie asserts that all situations are inherently social, and that social skill deficits impact kids more significantly than any other lagging skill, because social interactions can never be completely avoided. Any situation that involves more than one person results in some sort of social interaction.

As an intervention to address lagging social skills in youth, Rick Lavoie developed the *Social Skills Autopsy* (which is described at www.ldonline.org/article/14910). The social skills autopsy is a tangible way of helping youth to explore a social experience that did not go well and identify how he/she can handle a similar situation differently in the future. The first step is to have the youth explain what happened and speculate about what went wrong. Then the adult helps the youth generate alternative responses to the situation. Recently a staff member in the capital district used this technique to help a youth in NYS PROMISE generate alternative solutions to yelling and swearing at her supervisor when she was asked to stay two hours after her shift at the fast food restaurant ended.

Building Resilience to Overcome Challenges

In recent years, researchers have begun to look at the differences between those that experience adversity and go on to experience negative outcomes and those who seem to be protected from those negative outcomes or who "rise above" their circumstances. Resilience research is a strength-based approach that looks at lowering risk in vulnerable populations. Resilience includes behavioral, emotional, social, and cognitive-educational domains.

Resilience-related terms:

Resilience is when individuals or groups are able to adapt positively despite the presence of risk and adversity.

Risk factors include things that increase the likelihood of negative outcomes in the face or risk and

Protective factors are things that help protect against negative outcomes in the face of risk. Protective factors can include both individual factors (such as having an outgoing personality) and environmental factors (such as having access to appropriate educational supports) that help buffer the individual against negative outcomes related to the risk factors to which they have been exposed.

Risk factors can be explored at the individual level or at the family level. At the family level, resilience refers to the way that a family is able to interact and relate to one another in the presence of stress or adversity. The resilience of the family can have a significant impact on the resilience of youth within the family.

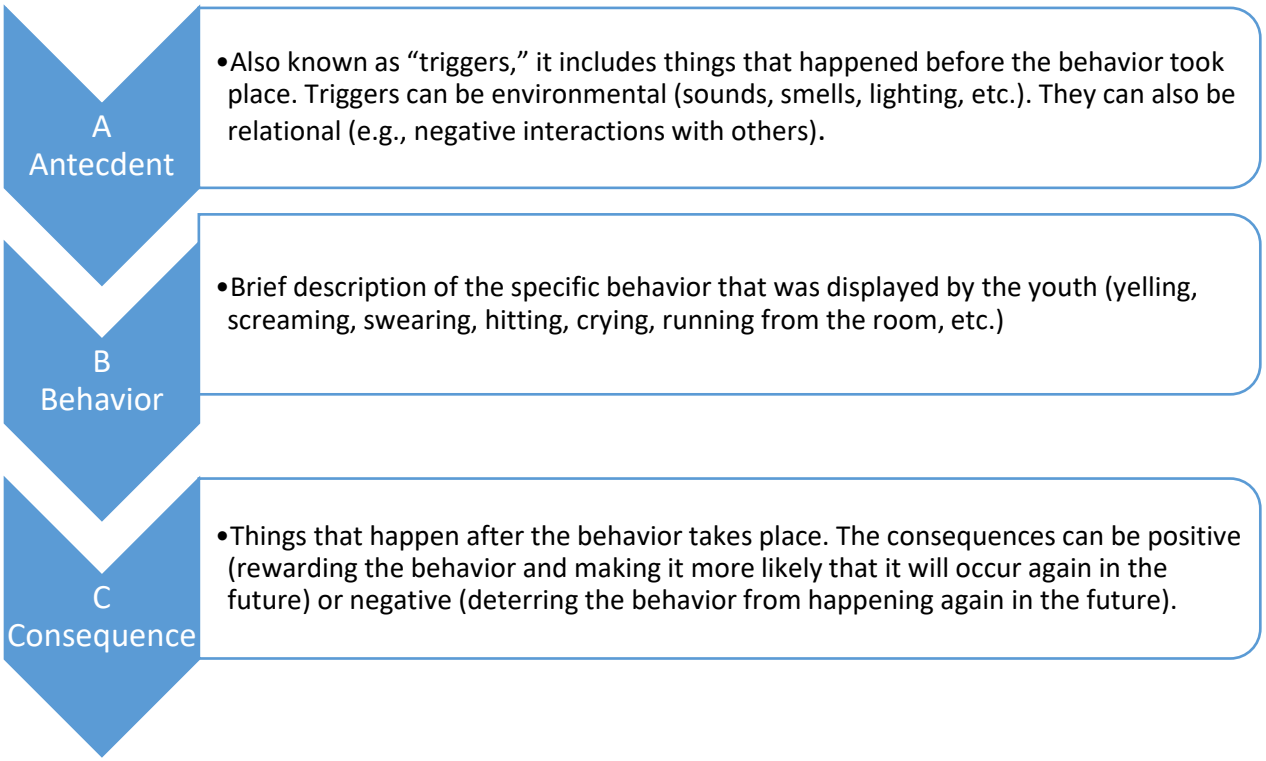
Case management practitioners with an awareness of risk and protective factors for the population with which they work can identify possible prevention and intervention strategies for overcoming the risks.[1] For example, programs teaching problem-solving skills to help youth exposed to violence generate a wider range of responses to conflict have shown some promising results in increasing resilience.[2] Highlighting and celebrating positive achievements of youth and connecting youth to job opportunities and mentors have also been proven to be effective interventions to increase resilience. Research has shown that youth who focus on the present are more likely to have negative outcomes related to self-sufficiency and employment, and interventions that teach more future-oriented thinking combined with job readiness skills have demonstrated positive outcomes.[3] Motivational interviewing provides a helpful framework for guiding discussions that help adolescents to move beyond the present towards more future-oriented thinking.

Behavior is a Form of Communication

One way to view challenging behavior is to recognize it as a form of communication. Approximately 70% of communication takes place non-verbally, and challenging behaviors can be one way that youth who have difficulty communicating verbally express wants or needs. Once we understand that behavior is a form of communication, we can step back and observe the situation more objectively in order to better understand what is being communicated. Within the field of behavior management, the ABC model is one way of breaking down behavioral outbursts and interactions in order to view the situation more clearly.

[1] Whitson, M. L., Bernard, S., & Kaufman, J. S. (2013). The effects of cumulative risk and protection on problem behaviors for youth in an urban school-based system of care. *Community Mental Health Journal, 49*, 476-486.
[2] Sanchez, Y. M. & Lambert, S. F. (2013). Adverse life events, coping and internalizing and externalizing behaviors in urban African American youth. *Journal of Child and Family Studies, 22*, 38-47.
[3] Johnson, S. L., & Cheng, T. L. (2015). Promoting "healthy futures" to reduce risk factors in urban youth: A randomized controlled trial. *American Journal of Community Psychology, 56*, 36-45.

The ABCs of Behavior



When we understand the bigger picture, we can work with the youth and families to identify proactive strategies for reducing triggers and improving coping skills to deal with triggers. If a child has an IEP and the youth has a behavior that is impacting them at school, a Functional Behavior Assessment can be completed through the school, which will look at the triggers and consequences of the behavior. If necessary, a Behavior Intervention Plan (BIP) will be completed by the school to help the youth learn to replace the unwanted behavior with more appropriate behavior.

Some challenging behaviors that occur may be directly related to the child's developmental disability or mental health diagnosis. Parents may not have been provided with information about behaviors and symptoms associated with the youth's diagnosis, so it can be helpful to connect them with an organization or health care provider that can provide information about the specific diagnosis or disability. There may also be local parent support groups in which the parent can become involved. For example, The Autism Society holds events and conferences for families.

De-Escalation Techniques for Agitated Individuals

De-escalation is a technique that consists of a variety of techniques that are used in response to violent and/or disruptive behavior. The goal of de-escalation is to communicate calmly with the client in order to better understand his/her thoughts and feelings, help him/her manage intense emotions, and assist in problem-solving.

Agitation is a behavioral state that can arise from different underlying emotions. For many individuals, fear or anxiety can trigger agitation. Agitation exists along a continuum, which begins with anxiety and escalates to aggression and/or violence. The further an individual progresses along the continuum, the more difficult it is to intervene successfully. In earlier stages of agitation, verbal de-escalation techniques have proven to be highly effective in preventing individuals from escalating along the continuum.[1]

Signs of agitation can include (Richmond et al., 2012):

- Repetitive and non-goal directed motor activity (foot tapping, pacing, hand wringing, hair pulling, banging head with hand, pulling on clothing)
- Repetitive vocalizations ("I have to get out of here. I have to get out!")
- Irritability and heightened responsiveness to stimuli

The main objectives in responding to an agitated client should be:

1. Ensure the safety of the individual, staff, and others.
2. Help the individual manage emotions and distress and maintain or regain control of behavior.
3. Avoid threatening, intimidating, or coercive responses that can escalate agitation.

Strategies for De-Escalation

Individuals who are effective in de-escalation often present as open, honest, supportive, self-aware, non-judgemental, and confident without appearing arrogant.[2]

Strategies for successful de-escalation:

1. Maintain personal control
    - Present the appearance of remaining calm even when you are experiencing anxiety.
    - Focus attention on assessing the situation and the individual's needs rather than your own feelings.
    - Remind yourself that the client is most likely feeling threatened or afraid and lacks the skills to manage emotions effectively.
    - Avoid disagreeing, becoming argumentative or trying to wrestle the individual for control.
    - Keep in mind that individuals who are agitated can be provocative and may challenge the authority and competence of others in order to detract from their own feelings of inadequacy.

2. Scan the environment

[1] Richmond, J.S., Berlin, J. S., Fishkind, A. B., Holloman, G. H., Zeller, S. L., Wilson, M. P., Rifai, A. R., Ng, A. T. (2012). Verbal de-escalation of the agitated patient: Consensus statement of the American Association for the Emergency Psychiatry Project BETA De-escalation Workbook*, Western Journal of Emergency Medicine, 13*(1), 17-25.
[2] Price, O., & Baker, J. (2012). Key components of de-escalation techniques: A thematic synthesis. *International Journal of Mental Health Nursing,* 21, 310-319.

- If possible, remove any furniture or other objects that could cause injury to the individual or others if the agitation escalates to aggression.
- Remove any audience that may have gathered, create as much space from others and privacy as possible.

3. Be mindful of body language and personal space
   - Remember that much of our communication is non-verbal, and the individual may become more agitated if he/she detects negative emotion or judgement in others.
   - Allow two arms' length between you and the individual to allow him/her space and to ensure that you can dodge a punch or kick.
   - Stand at an angle rather than facing directly in order to appear non-confrontational.
   - Avoid closed body language. Folding your arms or turning away may communicate defensiveness or lack of interest.
   - Make sure that your body language matches what you are saying to the individual.

4. Engage in verbal contact with the individual
   - Only one person should verbally interact with the individual.
   - Assure the individual that you want to keep everyone safe.
   - Use short sentences and simple vocabulary. When individuals are agitated, they have more difficulty processing language.
   - Allow time for the individual to process and respond to what you said.
   - Be persistent in calmly repeating your message multiple times until the individual is able to hear it.

5. Engage in active listening
   - Whether or not you can grant the request, always ask what the person wants or needs. (E.g., I'd like to hear more about what you want. Even if I can't provide it, it will help me to figure out how we can work on it together.")
   - Repeat back what you think the individual said to make sure that you understand.
   - Miller's Law states: "To understand what another person is saying, you must assume that it is true and try to imagine what it could be true of."
   - If you can't agree with the individual's view or request, find something that you can agree about and validate the feelings the individual is experiencing.
   - Ask, "What usually helps you when you feel like this?"

6. Set clear boundaries
   - Clearly inform the individual of acceptable behavior or alternative coping methods to verbal or physical aggression.
   - Provide positive validation when alternative strategies are used.

7. Assist with problem-solving
   - Communicate optimism about resolving the problem.

- Suggest a next step that will help to resolve the situation.
- Offer support and assistance with resolving the problem.
- Create a plan for next steps and identify who is responsible for each step.

Responding to Challenging Case Management Situations

When working with families who are facing multiple stressors, case managers often walk into surprising and difficult situations. Due to the unique nature of families, it is impossible to predict every situation that might be encountered, and case management practitioners are forced to respond quickly. Madsen refers to the need for practitioners to develop "practice based improvisation" in ambiguous situations, which means that they need to rely on simple but effective strategies of thinking through complex situations.[1]

Figure 7.1. Collaborative Helping Map

[1] Madsen, W. C. (2009). Collaborative helping: A practice framework for family-centered services. *Family Process, 48,* 103-116.

The Collaborative Helping Map is a tool that can be used to approach these complex situations:

- Step 1: Organizing Vision
  Create a mutually shared concrete vision of how the individual wants life to be different (What would like look like if the problem behavior was suddenly gone?)
- Step 2: Obstacles
  List any obstacles that get in the way (What stops the youth from engaging in more positive behavior?)
- Step 3: Supports
  List any people, resources, or agencies that could help the youth to be successful in changing behavior.
- Step 4: Plan
  Create a plan that uses supports and resources to overcome obstacles. Be as concrete and specific as possible.

Figure 7.2. Collaborative Helping Map as envisioned by Madsen, 2011[1]

[1] Madsen, William C. (2011). Collaborative helping maps: A tool to guide thinking and action in family-centered services. *Family Process, 50* (4), December 2011, 529-543. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/j.1545-5300.2011.01369.x/full

Conflict Resolution Skills

At times case management practitioners encounter family members or youth that are angry. While it can be intimidating and challenging to interact with individuals who are angry, it can also provide a unique opportunity to support the individual through the process of resolving conflict in a healthy manner. It is important not to match the negative emotion and body language that is being expressed by the individual. Taking an internal inventory of your own emotional response, body language, and tone of voice is crucial in helping to maintain an atmosphere of neutrality.

Suggested responses to angry individuals include:[1]

1. Be appreciative.
   Example: "It's helpful to know how you are feeling about this."
2. Ask for more information.
   Example: "Can you tell me when this happened?"
3. Find something with which you agree.
   Example: "I can see how you would feel that way."
4. Begin to focus on a solution.
   Example: "Can you think of anything that would help you to feel better about this situation?"

1 Summers, N. (2012). Fundamentals of case management practices: Skills for the human services. Belmont, CA: Brooks/Cole Cenage. 4th ed. Retrieved from http://static1.1.sqspcdn.com/static/f/995733/19717279/1344045891317/Dia+3.+Summers.+Disarming+anger.pdf?token=1634GyyLFnE8MSzMkk5kckm0vWA%3D

Module 7: Resources

Social Autopsy Worksheet

What happened? (Who, what, where, when?)	
What was the social error? Who was hurt by the social error?	
What (if anything) can be done to correct the error now?	
What could be done differently next time? What skills can be worked on now to help things go differently next time?	

Module 8: Crisis Management

Introduction

This module provides tools to assist case management practitioners in proactively planning for, handling, and resolving crises that may arise over the course of a case. The module begins with strategies for attempting to predict and prevent crisis. However, not all crises can be averted, and the module also provides a planning process to ensure safety of youth and families being served. The module includes tools that have proven effective in managing crises, as well as a list of examples of life experiences that may precipitate a crisis in youth and their families. The strategies discussed in this module offer case management practitioners important tools and approaches that can be employed in attempting to manage and potentially avoid crises.

The Nature of Crisis

It is important to note that while a crisis can arise out of an event or series of events in an individual's life, the crisis is not the actual event. Instead, crisis is the individual's perception of and response to the event itself.[1] A crisis begins with a stressful or hazardous event, but the event also leads to considerable psychological distress within the individual, and the individual is unable to resolve the event using his/her usual coping methods or resources. If an individual continues to experience crisis and disequilibrium without relief, the crisis has the potential to cause severe cognitive, behavioral, and affective malfunctioning.

The following characteristics characterize a crisis:

- A precipitating event is perceived as being meaningful and threatening.
- Traditional coping methods used in the past are not able to modify or lessen the impact.
- Individual experiences increased fear, tension, and/or confusion and exhibits a high level of discomfort.
- Individual proceeds to a state of disequilibrium (confusing emotions, somatic complaints, and/or erratic behavior).

In order to understand how an individual was impacted by an event, one must elicit the meaning that the individual made out of the event, and recognize that different people can experience the same event and have different responses to the event.[2] Each individual's experience of the crisis event will be impacted by characteristics of the individual (age, developmental stage, functioning prior to crisis, temperament) and the strength and weaknesses of the individual's support system following the event.

[1] Roberts, A. R. (2005). Bridging the past and present to the future of crisis intervention and crisis management. In A. R. Roberts (Eds.) *Crisis intervention handbook* (3rd ed.), (pp. 3-34). New York: Oxford University Press.
[2] Webb, N. B. (1999). Assessment of the child in crisis. In A. B. Webb (Ed.), *Play therapy with children in crisis: Individual, group and family treatment* (2nd ed.)(pp. 3-28). New York: The Guilford Press.

Additional factors that impact the nature of a crisis and the degree to which it impacts an individual are:

- Anticipated vs. sudden crisis
- Single event versus recurring events
- Solitary versus shared crisis experience
- Proximity to the crisis
- Loss factors experienced from the crisis/Physical injury or pain
- Presence of violence (witnessed or experienced directly)
- Degree of life threat (to self/family/others).
- Past experience with crisis
- Coping style/resilience
- Pre-crisis adjustment

Although crisis by its very nature brings with it a significant amount of psychological distress, crisis situations can also be viewed as an opportunity to reduce emotional pain and vulnerability and enhance coping and problem-solving abilities.[1] Crises can often serve as bridges to learning for the youth and their family.

Catastrophic events like losing a home in a disaster, being evicted, or losing a loved one can be devastating. Individuals may also be impacted by a series of events that, while not catastrophic, lead to a cumulative sense of crisis. Regardless, all crises, large or small, are opportunities for development and growth. The role of the case management practitioner is to support the youth and/or family through current crises and to assist in anticipating, preparing, and developing a plan to handle future crises.

Critical to effective crisis management is recognizing that crisis management is not risk management. Risk management simply involves assessing potential threats and finding the best ways to avoid those pitfalls. Crisis management involves **dealing proactively with threats** prior to the threat escalating to the level of crisis, **responding to the crisis while** it is occurring, and **reflecting on the crisis** after it has occurred. In light of these three dimensions to crisis management, an effective case management practitioner will equip themselves with tools and strategies to maneuver all three dimensions of crisis management.

Family Crisis and Resilience

Parents of children with disabilities often experience a high level of stress associated with the responsibility of caring for a child with a complex needs as well as juggling other family stressors. At times, the buildup of chronic stressors can lead to crisis. These accumulated stressors can include health problems, child emotional problems, child behavior problems, school stress, family problems, financial stressors, as well as other factors. A recent study conducted with parents of children with autism

[1] Roberts, A. R. (2005). Bridging the past and present to the future of crisis intervention and crisis management. In A. R. Roberts (Eds.) *Crisis intervention handbook* (3rd ed.), (pp. 3-34). New York: Oxford University Press.

spectrum disorder (ASD), found that crisis occurs when there is an imbalance between the cumulative impact of multiple demands coupled with limited internal capabilities to deal with the stress and limited availability of external resources.[1]

Within the life course of a family, there are some stressors that are considered normative demands, or expected events within the family life cycle (e.g., marriage as an adult). While these demands involve some level of stress, they aren't usually viewed as posing a significant risk to families. However, under certain conditions, even normative life events can trigger a crisis in a family.[2] Within families of children with disabilities, when an event does not occur according to the time table that is determined to be the "norm" within societal/cultural standards, families may have a difficult time managing the event. For example, while parents of children without disabilities may view graduation as a positive and exciting life event, parents of children with disabilities sometimes experience grief as they recognize that their child will not be going on to college with his/her peers.

During and immediately after a crisis, family structures often experience a state of chaos, or disequilibrium. Family adaption occurs when families restore a balance between their capabilities and the demands placed on the family system. [3] Every time a family faces a stressor or crisis, they implicitly evaluate how difficult it is or will be in the future. If they have experienced success in overcoming stress and crisis in the past, they will be more likely to assess their chances of overcoming the current situation more favorably. In this way, families create a shared meaning (or understanding within the context of the family) that shapes their ability to be resilient in future hardships. Research has shown that families that have developed a shared meaning that emphasizes what they have learned or how they have grown in the face of challenges experience more favorable outcomes than those who have less positive shared meaning within the family. The (unwritten) script within the resilient family becomes, "This may be hard, but we have gone through hard times in the past and we can do this together."

The following model illustrates the Family Adjustment and Adaptation Response Model (FAAR), which was developed in 1988 by Patterson to show how the buildup of stressors in the life of a family can be mitigated by the internal and external resources and by the meaning applied to the situation.[4] When there is a balance between demands and capabilities and the family is able to hold on to a positive meaning of the challenges that they face, successful adaptation and well-being is achieved, and the family is able to maintain a healthy level of functioning.

[1] Weiss, J. A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism, 18*(8), 985-995. 10.1177/1362361313508024
[2] Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*(2), 349-360. 10.1111/j.1741-3737.2002.00349.x
[3] Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*(2), 349-360. 10.1111/j.1741-3737.2002.00349.x
[4] Weiss, J. A., Wingsiong, A., & Lunsky, Y. (2014). Defining crisis in families of individuals with autism spectrum disorders. *Autism, 18*(8), 985-995. 10.1177/1362361313508024

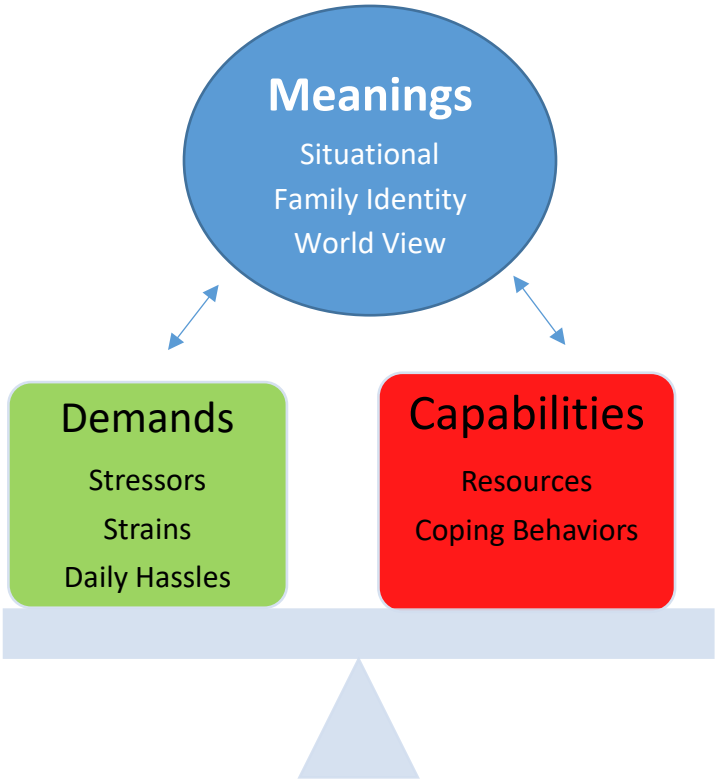


Figure 8.1. Family Adjustment and Adaptation Response Model (FAAR)

Best practice guidelines for helping families to navigate crisis involve establishing rapport with the family, making an attempt to understand the precipitating events that led to the crisis, and inquiring about the types of coping mechanisms that have already been attempted and have failed. It is also important to identify the meaning that the family has made of the crisis. After all of these characteristics are explored, a plan of action can be developed to help increase the functioning of the family system.

The following coping strategies/processes have also been shown to be protective factors in families who have children with disabilities, and supporting families to develop these strategies/processes can be beneficial in assisting families in the face of crisis:[1]

- Balancing illness (or disability) of family member(s) with other family needs
- Maintaining clear family boundaries
- Developing communication competence
- Attributing positive meanings to the situation
- Maintaining family flexibility
- Maintaining a commitment to the family as a unit
- Engaging in active coping efforts

[1] Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*(2), 349-360. 10.1111/j.1741-3737.2002.00349.x

- Maintaining social integration
- Developing collaborative relationships with professionals

Proactive Crisis Planning

Stressful events that are unexpected and unpredictable are more likely to create crisis in a family. Therefore, it can be very helpful to assist individuals to anticipate events and changes in the future and enhance skills so that they are better equipped to avoid or respond to crisis situations. The first component of crisis management is proactive planning. The following steps can help case management practitioners manage this phase effectively:

1. **Look to the past.** A future crisis can often be predicted based on knowledge of past crises. Similar to the ABCs of managing challenging behaviors we discussed in Module 7, understanding the antecedents that precipitated the behavior is important. While practitioners often plan for the worst-case scenario, in most cases this may be misguided, and will not address the real threats that have been evidenced from the past. History can repeat itself, understanding history of crises within the youth and family is critical.
2. **Crisis is a process.** Effective crisis planning is a process that recognizes that people change over time, as do their *behavioral benchmarks*. As individuals become more effective at managing crises independently, the case management practitioner needs to adjust the services and supports they provide—including expectations of the student and family.
3. **Communication is key.** Crisis typically does not just happen to one individual—it has ripple effects that can encompass an array of stakeholders including the family, employer, etc. Knowing who the key stakeholders are in an individual's life, and developing a communication plan that engages them is essential.
4. **Get plans in place early.** Attempt to have crisis plans in place well before the potential crisis occurs, and make sure all key stakeholders are informed and invested in the plan.
5. **Find a devil's advocate.** When it comes to crisis management, a person designated to explore the worst-case scenario and point out flaws in the safety plan can be a valued commodity. This individual can help the case management practitioner, youth, and family explore potential areas of crisis and can be valuable in assessing the efficacy of your plans.
6. **Remember crisis can occur at any time.** Most crises don't occur during workday hours when case management practitioners maintain office hours. The crisis plan must to be readily available and able to be implemented 24/7 by any one of the key stakeholders.

Challenging Behaviors and Mental Health Crisis

Case managers working with individuals with IDD and/or MH conditions should be aware that there may be an increased likelihood of crisis occurring. Research estimates that 5-10% of individuals with IDD display what are considered severe behavior problems.[1] Sometimes a crisis occurs because the individual with the disability exhibits a change in behavior that exceeds the coping skills or resources of the family to manage appropriately. In other situations, crisis may result when there is a change in the family system that leaves the family unable to manage previously-occurring behavior due to lack of resources or coping skills.

Commonly reported challenging behaviors exhibited in individuals with IDD include:

- Self-injurious behavior
- Aggression
- Destruction of property
- Sexual misconduct
- Running away
- Trantrums
- Non-compliance

While the list above includes a list of behaviors that are considered to be most challenging, it is important to be aware that any behavior can become problematic if it occurs excessively, at high levels, and/or impacts functioning significantly.

A mental health crisis occurs when a behavioral, emotional, or psychiatric situation puts an individual at risk for hurting himself/herself or others. Warning signs that there may be an impending mental health crisis in a youth include:[2]

- Inability to cope with daily tasks (dressing, eating, sleeping, etc.
- Rapid mood swings (increased energy, pacing, withdrawn)
- Increased agitation (making verbal threats, violent behavior, destruction of property)
- Abusive behavior to self or others (hurts others, self-injury, promiscuity)
- Psychosis/loss of touch with reality (confusion, paranoia, thinks they are someone they are not)
- Isolation from school, work, family, friends
- Unexplained somatic (bodily) problems (feeling of being outside of body, headaches, changes in facial expressions)

[1] Reed, D. D., Reed, F. D. D., Luiselli, J. K., & James, L. (2013). *Handbook of crisis intervention and developmental disabilities* (2013;1; ed.). New York, NY: Springer Verlag.
[2] NAMI Minnesota. (2016). *Mental health crisis planning for children: Learn to recognize, manage, prevent and plan for your child's mental health crisis.* Retrieved from http://www.namihelps.org/NAMI-MHCrisisPlanforChildrenFeb2016.pdf.

Examples of situations and/or stressors that can trigger a mental health crisis in youth are[1]:

Home	School	Other
•Changes in family structure •Loss of any kind •Transitions between parent homes •Strained relationships with step-siblings or ste-parents •Fights/conflict with siblings or family members •Family poverty •Trauma or exposure to violence	•Worrying about tests and grades •Overwhelmed by homework or projects •Bullying at school •Pressure from peers •Misunderstood by teachers that don't understand behavior •Perceived or real discrimination •Breakup in relationship	•Stops taking meds or missed doseas •Starts new medication or new dosage •Use of drugs or alcohol •Pending court dates •Crowds or large groups of people •Community violence •Major world events of traumatic nature •Arrest or justice involvement

Safety Planning for Youth and Family

An element of proactive planning is ensuring the safety and wellbeing of the person being supported. Developing a *safety* plan is not the same as developing a *crisis management* plan. Safety plans exist when, based on past experiences, there is a potential risk to the safety and wellbeing of the individual being supported, or others around them. Who is responsible for the development the safety plan? More than likely, school-aged youth or individuals served by other formal service systems will have a safety plan in place if it has been identified as necessary. It is critical for the case management practitioner to determine whether there is a potential safety threat and to ask their student and/or family member if there is a current safety plan in place that can be shared with the case management practitioner. If a safety plan is not currently in place, it may be the case management practitioner's responsibility to decide if a plan is needed and to identify the most appropriate party to develop that plan. Regardless of who develops the safety plan, it is essential that the student and/or family members are involved and invested in the development of the plan to ensure its effectiveness and that it will be executed.

A safety plan has several important features:

1. Identification of the potential crisis—including an assessment of likely events that might pose a threat to the safety and/or wellbeing of the individuals or others.
2. Potential outcomes of the crisis—what might happen if this crisis is realized?

[1] NAMI Minnesota. (2016). *Mental health crisis planning for children: Learn to recognize, manage, prevent and plan for your child's mental health crisis.* Retrieved from http://www.namihelps.org/NAMI-MHCrisisPlanforChildrenFeb2016.pdf.

3. Identification of supports—who are the people most likely prepared and ready to help in this crisis and provide support. This includes details regarding the "who," "what," "where" and "when."
4. Emergency contact information—who needs to be communicated with in the case that the crisis occurs.
5. Strategies to avoid and/or resolve the crisis—what has proven effective in the past in averting the crisis or bringing the crisis to resolution.
6. Steps to evaluate the effectiveness of the plan—what and how will the plan be evaluated to determine its effectiveness upon resolution of the crisis.

You will find a sample of an individual safety plan in the Resource section at the end of this module.

Crisis Planning

Planning for and managing a crisis often starts with development of a behavior support plan as discussed earlier in *Module 7* in the section *Managing Challenging Behaviors*. A behavioral support plan has several critical components:

1. Basic identifying information pertaining to the individual
2. The purpose for the plan
3. A description of relevant history
4. Diagnostic information relevant to the behavior, including medication and treatment if applicable
5. A description of target behaviors, including observable elements
6. A functional assessment of the ABCs as detailed in Module 7
7. Specific behavioral goals
8. Proactive strategies to be employed
9. Staff responsible with timeframes
10. Signatures and informed consent

Responding to Crisis

An important first step in responding to a crisis is understanding the nature of the crisis. To determine the level or degree of the crisis, it is important to have some knowledge and understanding of the potential causal force[1] of the crisis. The following checklist may prove useful in aiding the case management practitioner in determining what initiated the crisis event.

Degree of Crisis	Yes/No	Consideration
Is the individual an adolescent?		The initial principle in assessing the issues facing an adolescent crisis is to remember one is dealing with an adolescent first and crisis second—developmental stage is an important variable. What are the big issues for a teen of this age?[2]
Is this a multi-faceted crisis?		The world of adolescents is an interconnected and interrelated entanglement of forces resulting from mental aptitude, aspirations, body image, social development, etc. Usually no one thing will solve a complex crisis, so a careful assessment of a number of dynamics might provide insight to the larger picture of what is going on.
Is the crisis peer- or relationally triggered?		Consideration of social involvement in peer relationships is a significant part of dealing with adolescents. The nature of social connectedness and peer groups must be clearly understood both as symptoms and causal forces.
Is this attainment related?		Understanding where an adolescent is in their development in regard to the future trajectory of their life is important. Sometimes lack of direction for the future can be a causal force in crisis as much as knowing where you want to go and exerting too much pressure on oneself to get there. Lack of dreams for the future, feelings of falling short of needed future benchmarks, as well as dreams collapsing can all be sources for crisis.
Are there physical, emotional or cognitive conditions that may be causal forces of the crisis?		Individuals with disabilities experience causal forces stemming from physical, emotional and cognitive challenges on several fronts. This can take the form of developmental delays or lack of capacity, self-imposed stigma associated with the disability, stigma or harassment from others, as well as disability adjustment.
Are there legal issues or limitations in ability to accept limits?		Assessing the nature of controls and limits in the adolescent's environment are essential. Teenagers need a balance of freedom and limits, and striking this balance can often be a causal force in crisis.
Is the individual struggling with spiritual issues?		Religious ideation of adolescents needs to be assessed in relationship to adolescent spiritual issues. Often faith as practiced by adolescents isn't as much about what they believe but rather how they process their beliefs.

[1] Causal forces are the influences that led to an outcome i.e. what circumstances led to this particular crisis.
[2] For more information on adolescent behavior, please refer to the Case Management Community of Practice training series.

The practitioner should maintain a potential referral network of organizations in case of an emergency or crisis area outside the realm of case management. This should include, but not be limited to, medical emergency, mental health, food and shelter, basic needs and necessities, and other areas. Case management practitioners should not hesitate to make referrals to outside agencies and organizations to ensure the highest quality of care for the student and/or family members they are supporting.

If a situation is endangering the safety of the youth being served or anyone surrounding the youth, call 911 immediately and ask for assistance. If the youth experiencing the crisis has a mental health and/or IDD diagnosis, share this information with the person on the phone, because this increases the chances that they will send an officer trained to work with individuals with IDD/MH.

Resolving Crisis

There is not one universal solution to resolving crisis that may arise. However, several general strategies have proven effective in supporting resolution. This includes, but is not limited to:

- Referral
- Active listening and engagement
- Embracing the uniqueness, qualities and attributes of the individual
- Respecting the world view of the individual
- Investment of other key stakeholders in the individual's life
- Supportive decision making
- Creating a safe place for resolution and interaction

Behaviors That May Complicate Crisis

In *Module 7* we provided a game plan for managing challenging behaviors. Beyond that, it is essential that case management practitioners are well equipped to respond to a range of behaviors. Having community referral sources identified in advance to aid in remediating the issues surrounding these precipitating behaviors is helpful. Below are some different categories of challenging behaviors and potential response strategies.

- **Criminal Behavior** is behavior that infringes on the rights of others and that lawd has been created to prevent. The legal system exists to handle the consequences for criminal acts, and it is not the role of the case management practitioner to aid or harbor individuals engaging in this behavior. Case managers are ethically bound to notify the police when the law is broken. More information dealing with issues surrounding incarceration is included in *Module 10*.
- **Substance and Alcohol Abuse** can often be seen as a remedy for dealing with other underlying issues. While adults over the age of 21 are allowed to drink, individuals who abuse alcohol should be informed of the dangers associated with alcohol use and threat to the safety and well-being of themselves and others. Individuals who choose to use illegal substances are breaking the law. Another form of substance abuse is the modification of frequency, volume, or dosage of prescribed drugs. This may not be illegal, but carries significant risks that should be explored

with the individual. Motivational interviewing is an evidence-based approach that has proven to be particularly effective in working with individuals who are dealing with addiction issues. See Module 5:1 for an overview of motivational interviewing techniques.

- **Threatening, Violent or Homicidal Behavior** is not to be tolerated, and imminent and immediate threats should be dealt with cautiously—ensuring the safety and well-being of those being threatened. Reducing the threat requires withdrawing, leaving, or removing the trigger that may be causing the behavioral response. Speak in regular, calm tones to de-escalate the situation. Engage in active listening and reiterate what the individual is saying to ensure understanding. In situations where there is a known history of this type of behavior, the practitioner is well-advised to meet in public places with identified and open exits. See below for more information on personal safety plans for case management practitioners.
- **Suicidal Thoughts and Behaviors** may occur with individuals who are reeling from a recent crisis and/or struggle with mental health support needs. Thoughts of suicide may arise from feelings of desperation, despair, discouragement, and sometimes from hallucinations. All threats and behaviors of this nature should be taken seriously and referral services should be sought immediately. Safety of the individual is the number one priority during these times. Case management practitioners should be aware of 24-hour crisis services in their area and ensure that if the individual being supported has a prior history of behavior in this area that others in the individual's life have this contact information.

Mobile Crisis Services for Youth

Mobile crisis units (MCUs) are composed of multi-disciplinary staff, often including nurses, social workers, and psychiatrists, who can deliver immediate 1:1 intervention to youth in crisis within the home, school, or community. MCUs provide diagnosis and assessment services, prehospital screening, and case management services. They can also provide transportation for the youth if further medical or mental health assessment is needed. The goal of MCUs is to utilize the least restrictive effective response, and they have been shown to decrease the utilization of emergency room and inpatient mental health admissions and arrests of youth.[1] There are mobile crisis units throughout New York State that can be accessed easily by parents, caretakers and professionals.

[1] Vanderploeg, J. J., Lu, J. J., Marshall, T. M., & Stevens, K. (2016). Mobile crisis services for children and families: Advancing a community-based model in Conneticut. *Children and Youth Services Review,* 103-109.

Responding to Individuals Who Are Considering Suicide

Although case managers within NYS PROMISE are not counselors and are not trained to provide mental health counseling to individuals, they may unexpectedly come into contact with a youth or family member who is contemplating suicide, so it is important to have some strategies for responding to such a situation.[1]

Risk Factors Associated with Suicide

- Females are more likely to consider and attempt suicide, but males are more than five times more likely to complete a suicide, because males often use more lethal means.
- Those with a history of suicide attempts and/or a recent psychiatric hospitalization are at a higher risk.
- Individuals with impulsivity, mood disorders, and behavioral disorders are at a higher risk.
- In families in which there is a history of suicide, individuals have a greater risk.
- Individuals that identify as lesbian, gay, bisexual, or transsexual are at higher risk.
- Alcohol and substance abuse is associated with a higher risk of suicide.
- Individuals with a history of physical or sexual abuse are at greater risk.

Events that May Trigger Suicide Attempt

There are certain events and circumstances in an individual's life that have been known to trigger suicidal thinking in some individuals. These events can include:

- Recent psychosocial stressors (family conflict, a breakup from a romantic relationship, bullying, academic difficulties, disciplinary action/legal problems)
- Depression
- Mania (when depression lifts, individuals sometimes have more energy to attempt a suicide)
- Anxiety
- Psychosis
- Impulsivity (some individuals who have attempted suicide impulsively report afterwards that they were glad that the suicide was not completed)
- Aggression
- Substance abuse
- Access to lethal means (firearms, knives, medications)

[1] Chun, Th. H., Katz, E. R., & Duffy, J. D. (2013). Pediatric health emergencies and special health care needs. *Pediatric Clinics of North America*, 60(5), 1185-1201.

Talking to Individuals About Suicidal Ideations

Although it can feel uncomfortable, it is essential to ask the individual directly if he/she is considering suicide. Asking about suicidal thoughts has not been shown to increase suicidal behavior; it can often have the opposite effect, providing an opening for an honest conversation that may provide a sense of safety and relief. Talk with the individual about reasons for considering suicide and try to help identify any reasons for living (this is a type of motivational interviewing and exploration of ambivalence). Your goal is to develop a plan to ensure safety for now; you are committing to help the individual through this moment of crisis and then connect the individual with a trained mental health professional.

Your Goal=Contracting for "Safety for Now"

Criteria for Immediate Referral to a Mental Health Hospital or Crisis Response Team

- Continued desire to die
- Severe hopelessness
- Ongoing agitation
- Inability to engage in safety planning
- Inadequate support system
- High lethality attempt or attempt with a clear expectation of death

Case managers are usually not trained to assess clinically the likelihood of an individual following through on a suicide attempt. Therefore, it is recommended that you either call 911 or ensure that the individual is immediately assessed by a mental health professional. Primary care doctors should also be informed when an individual is displaying suicidal behaviors so that they can follow up to make sure that the individual receives proper long-term treatment.

Suicide threats should always be taken seriously, even if you believe that the statements are being made in an attempt to manipulate. Never underestimate the kinds of circumstances or events that can trigger suicidal thoughts or the likelihood of a particular person becoming suicidal.[1]

"Any person has the potential to become suicidal when confronted with a situation that produces emotional pain and is believed to be inescapable, interminable, and intolerable."

A guide for community health providers on responding to suicide by Montgomery County Emergency Service, Inc.: http://www.mces.org/PDFs/suicideproviders.pdf

Suicide Safety Contract Template: https://suicidepreventionlifeline.org/wp-content/uploads/2016/08/Brown_StanleySafetyPlanTemplate.pdf

[1] Chiles, J., & Strosahl, K. (1995). The suicidal patient: Principles of assessment, treatment, and case management. Washington, DC: American Psychiatric Press.

Evaluating the Crisis Management Intervention

The crisis management process concludes with an evaluation or assessment of how the plan that was executed worked and whether or not the desired results were achieved. In the case of a proactive management plan, non-occurrence of the behavior may provide evidence to the plan's success. However, it is important that the plan continued to be monitored and updated, and that further assessment be done to evaluate whether other crisis have emerged secondary to the primary crisis planned for. In situations where a behavior plan was enacted following a demonstrated behavior, those involved in the execution of the plan, including the individual themselves, should reflect and evaluate the efficacy of the plan in achieving the intended outcomes. This reflection step provides an opportunity to employ a continuous quality improvement (CQI) approach to modify or enhance the existing plan with lessons learned by the case management practitioner, youth and their family through the experience of managing the crisis.

Mandated Reporting

Mandated reported are individuals within New York State that are required to report suspected child abuse and maltreatment when encountered in their professional role. A detailed list of professions that require mandated reporting are included on the New York State Office of Children and Family Services (OCFS) website at www.ocfs.ny.gov/main/publications/Pub1159.pdf. If child abuse is suspected, mandated reporters are required to call the New York Statewide Central Register of Child Abuse and Maltreatment (SCR) at (800)635-1522.

If you are unsure about whether an incident or observation falls within the mandated reporting guidelines, you can call the SCR hotline and ask to present the details of the situation to determine whether or not a report needs to be filed. If the report is accepted, you will be directed to the OCFS website where you will print and complete a form that will be sent to the SCR. If the report is not accepted, you should ask for the name of the SCR specialist that you spoke with and make a note in the student's file indicating that you presented the information to the SCR.

HIPPA and Privacy

The Health Insurance Portability and Accountability Act (HIPAA) protects the privacy and security of health information and provides individuals with certain rights to their health information. There are several parts to the HIPAA regulations.

1. The HIPAA Privacy Rule provides some specific protection for protected health information (PHI) that is held by providers. PHI includes common identifiers such as name, address, birth date, and Social Security number.
2. The HIPAA Security Rule specifies safeguards that must be put in place by providers in order to protect the security of the PHI that they create, receive, maintain, or transmit.

3. The HIPAA Breach Notification Rule requires those who are covered by HIPAA regulations to notify affected individuals when confidentiality of PHI is either intentionally or unintentionally breached.

Within the case management role, PROMISE staff will regularly come into contact with protected health information. Some examples of the safeguards that have been put in place to protect PHI include:

- Password protection and encryption of any electronic transmissions containing PHI (This includes e-mails containing the student's full names and/or birthdates).
- Utilizing a signed consent to release information when information about the child is shared with anyone other than the parent.
- Individual passwords for all NYESS accounts.
- Securing all youth and family records in locked filing cabinets.
  Staff commitment to avoid acknowledging the connection of any youth or family to PROMISE without his/her permission.

Planning Safe and Effective Home Visits

There may be occasions when the case management practitioner may need to conduct a home visit. Understanding the reason and nature for the home visit is essential in carefully preparing for the event and ensuring personal safety and wellbeing of both the practitioner and the individual or family being visited. Reasons for home visits under the NYS PROMISE typically fall in to three primary areas:

1. The youth and/or the family have not been able to be engaged using other traditional forms of communication (phone, e-mail, and/or letter);
2. The youth and/or family has requested a home visit as an accommodation; and/or
3. The type of intervention to be provided is best conducted in a home setting.

Prior to an initial home visit it is important to always attempt to schedule the appointment by telephone or written communication so that the client will know to expect you and be prepared. Having prior communication with the client ahead of time also provides you an opportunity to get vital background information or an update on their current situation, which may have changed. It is recognized though that often it is challenging at best to make initial contact with youth and/or families and a cold call home visit may be required. In both situation, but especially the latter, it is critical that organizations have well-articulated policies and practices that are implemented, followed and evaluated to ensure efficacy. These policies typically incorporate four important elements:

1. Whenever possible, home visits should be accompanied by colleagues or employees from the same or other agencies who are also working on the same case. In the case of NYS PROMISE, this might include both the RDS-based case manager and PC-based family coach. If you are a practitioner about to conduct a home visit that is potentially unsafe, either based on past behavior of the client or location of the home, you should arrange for a colleague to accompany you—agreeing on the date and time of the event.

2. Procedures to prepare for the actual home visit are essential. This includes articulating the purpose of the meeting and the specific scope of the intervention and what is hoped to be accomplished. Scripting a home visit at this level of detail ensures maximum impact from the effort as well as efficiencies once on-site in achieving the desired objectives.
3. Procedures to prepare the family for a cold call site visit are also important. While youth and families may not respond to queries that are emailed or left on voice mail, that does not necessarily mean that they are not being received. Providing the youth and/or family with an outline of the purpose for the meeting, what is hoped to be accomplished, and copies of any forms that may be completed can set the youth and/or family's mind at ease regarding the meeting. If the purpose is simply to collect and update information, providing these forms in advance along with a self-addressed stamped envelope may prove useful in getting them to respond and be perceived by the youth and/or family as a better option than a home visit. Further, providing a phone number that the youth and/or family can call or other back-up intervention to a home visit may become a more pleasing option.
4. Protocols associated with monitoring of home visits when they occur are also critical. Organizations should have a solid communication plan that monitors the work of case management practitioners in the field. These types of protocols specify procedures that should be followed and can include but not be limited to: code words or notification system should trouble arise; alerting office or back up staff to the occurrence of a site visit (date, time and location); scheduling a ride-along companion; execution of a communication plan when the visit occurs (call in when arrive and depart); making sure someone at the home base office is available and observing the intervention from a distance in case of emergency or need for follow-up; and, debriefing of the home visit experience to add to lessons learned.

Beyond the organizational practices and regardless of the purpose of the home visit, it is critical that case management practitioners have taken adequate measures to ensure the safety and well-being of all involved. A list of potential strategies and approaches are outlined below by stakeholder

For the Case Management Practitioner

- Follow policies and procedures required by your organization.
- Assess the past history of the case and interview others involved with this youth and/or family to evaluate safety risk. If it is a high risk situation, discuss the case with others to develop your strategy and do not conduct the home visit alone.
- Always carry a charged cellular telephone or back up charger for mobile devices.
- Make sure at to alert others as to location, date and time of home visit.
- Do not enter an elevator with people who are suspicious-looking or cause a level of discomfort in any way. If feeling nervous, pretend to use your mobile device and do not get on the elevator. If uncomfortable in the elevator, because someone new comes on, get off at that floor or immediately press the button of the next floor to get off.

- When approaching the home, step back from door after ringing the doorbell or knocking as often a family pet may be involved and could lunge when the door opens. Make sure to keep a brief case or bag in front of you to use as a defense if needed.
- If allergic to pets or dust, make sure to have medicine available in the case of an unexpected reaction.
- Once in the home based setting, identify where the exits are in the home and in building hallways.
- Use respectful titles when addressing youth and/or family members.
- If feeling unsafe during an interview immediately end the intervention and leave—run if necessary. Proactively have a story ready to alleviate the awkwardness of coming up with a story on the fly.
- Remain aware during the home-based intervention and constantly survey the surroundings.
- Remember to maintain an air of professionalism and to remain cool during the intervention—even if the situation gets out of control or potentially dangerous. Do not become too comfortable.
- If the environment does not feel safe, suggest a more public venue for the meeting—offering to buy a cup of coffee at the local café. Assess surroundings to identify potential meeting places prior to the actual meeting.
- Remember, not all homes are clean. Dress comfortably but with maximum coverage to minimize skin exposure to sitting surfaces.
- Make sure to wear comfortable shoes while working in the field.
- Make sure to carry hand sanitizer and wash hands regularly.

For the Youth and/or Family

- While making primary contact may have proven unsuccessful in the past, take measures to notify the youth and/or family of the date, time, and purpose for a home visit. Taking a copy of the communication to the home visit provides a critical reference point to share with the client demonstrating evidence that there were attempts made to ensure it wasn't a cold call. If the client is upset, work with them to simply reschedule the meeting at a different location, date and/or time and apologize for the inconvenience—making sure to convey how important they are and how invaluable it would be to be able to meet with them.
- Make sure cultural and ethnic considerations are at the forefront of the visit. Never schedule home visits during religious holidays and always make sure to understand the cultural diversity that the family may represent. Also be sensitive to not offend the youth and/or family if certain traditions are offered (such as tea, refreshment, taking off shoes, etc)
- Some members of families may have chemical sensitivities. Do not wear perfume or colognes and try to use scent free soaps, detergents and toiletries.
- If the case management practitioner is sick or has been exposed to a contagious disease, re-book the appointment to ensure that youth and/or family are not compromised.

- Do not be overfamiliar with the youth and/or family and ask permission prior to entering, sitting, petting the family pet, etc.
- Upon arrival, immediately explain the purpose of the meeting and what is hoped to be accomplished. Ask the youth and/or family if there is something specific they would like to see accomplished and/or how further assistance can be provided.

Taking Care of the Case Management Practitioner

Working with youth with disabilities who receive SSI and their families can be very stressful. Poverty, illness, unemployment, family crisis, and legal issues can all add additional stressors to an already fraught relationship for case management practitioners. It is very important to ensure that practitioners take the time and effort to attend to their own physical, mental, and emotional well-being. Professional development may provide additional opportunities to develop skills that may be useful in helping you to manage the most common stressors. Helping professionals are vulnerable to developing burnout and/or vicarious trauma symptoms if they don't engage in protective measures.

Burnout and Vicarious Trauma in the Helping Professions

Burnout is a process that occurs over time when work demands outstrip personal resources. Burnout symptoms typically build up gradually over time, and are usually the result of a very high or stressful workload. Burnout can be divided into three different dimensions:[1]

1. Emotional exhaustion- Feeling depleted, over-extended, fatigued
2. Depersonalization- Cynical attitudes towards one's work or individuals served in work
3. Reduced personal accomplishments- Negative self-evaluation of one's work with individuals or overall level of competence

Burnout has been linked with increased depression, anxiety, sleep problems, impaired memory functions, neck and back pain, and alcohol consumption. Individuals who report higher levels of burnout also report an increase in flu-like symptoms and gastrointestinal problems. As burnout symptoms build, feelings of hopelessness often occur within the helping professional, and they often feel like the work they are doing makes no difference.

The key to overcoming or preventing burnout is to garner greater resources. Burnout occurs when demands outweigh resources, but resilience occurs when personal resources can be elevated to meet the level of those demands.[2]

[1] Morse, G., Salyers, M. P., Rollins, A. L., Monroe-DeVita, M., & Pfahler, C. (2012). Burnout in mental health services: A review of the problem and its remediation. *Administration and Policy in Mental Health and Mental Health Services Research, 39*(5), 341-352. 10.1007/s10488-011-0352-1

[2] Back, A. L., MD, Steinhauser, K. E., PhD, Kamal, Arif H., MD, MHS, & Jackson, Vicki A., MD, MPH. (2016). Building resilience for palliative care clinicians: An approach to burnout prevention based on individual skills and workplace factors. *Journal of Pain and Symptom Management, 52*(2), 284-291. 10.1016/j.jpainsymman.2016.02.002

Below is a list of common pitfalls that helping professionals fall into that can contribute to burnout symptoms along with corresponding resilience skills that can be used to prevent those pitfalls:

Common Pitfalls	Resilience Skills
• Trying to "power through" rather than taking a break. • Thinking that doing more is always better. • Internalizing problems (e.g., "I'm overwhelmed- What's wrong with me?" • Rumination/catastrophizing (e.g., "Everything is going wrong.") • Accepting perfectionist's assessment on what work is enough.	• Track activation level during the day and match work demands to energy level when possible. • Setting realistic and healthy external boundaries. • Self-regulating emotions. Avoiding personalization. • Recognizing cognitive distortions (e.g., It's not true that everything is going wrong. Here are some things that are going well…") • Developing realistic expectations of one's own performance.

Vicarious trauma can occur in situations in which helping professionals either observe or listen to details of traumatic experiences that have been endured by others (especially when individuals recount stories of abuse and/or violence that was forced upon them). Professionals who work with individuals who have been traumatized sometimes experience symptoms similar to PTSD, such as difficulty sleeping, intrusive images, difficulty concentrating, etc. Vicarious trauma can lead to alterations in the helping professional's cognitive schemas, beliefs, and expectations of self and others. For example, the helping professional who has worked with a number of traumatized individuals may come to view the world as a more dangerous place and may become more suspicious of the intentions of others.

The following strategies can be helpful in mitigating the impact of vicarious trauma:[1]

- Regular supervision and/or team meetings.
- Connection to personal community (family/friends). These relationships involve a reciprocity that is very different from the one-way relationship that exists between the helping professional and client. Receiving nurturing and care from others can help restore depleted emotional reserves.
- Engaging in mindfulness strategies. Being intentionally more aware of the present and one's internal and external surroundings.
- Becoming more cognitively flexible to embrace complex and ambiguous situations more easily. This skill can be built by consciously reminding yourself through self-talk and imagery that there are other ways of viewing life.

[1] Harrison, R. L., & Westwood, M. J. (2009). Preventing vicarious traumatization of mental health therapists: Identifying protective practices. *Psychotherapy: Theory, Research, Practice, Training, 46*(2), 203-219. 10.1037/a0016081

- Learning to simultaneously hold multiple perspectives (self and others) so that you don't become emotionally fused to the individuals that you are helping. Reminding yourself that they have a story, and that their story is not your story. You can listen to it and empathize without taking the story on as your own.

Time Management

Time management for case management practitioners is crucial, and an area where they can struggle on a day-to-day basis. Being able to organize time and tasks effectively will help create order, manage responsibilities, and cope with the stress that arises from time to time when dealing with youth and families in difficult situations.

- Make a daily plan of tasks.
- Prioritize the list. Identify those tasks that have to be done today (As) from those which should be done, but could be done tomorrow (Bs) and those which are not that important (Cs).
- Attend to your "A" tasks first.
- Keep lists simple and realistic.
- Carry your list with you – consult it often.
- Let your list be your guide, not a ball and chain. You will find that you often have to adapt and revise.
- Let the clients know when you are available to schedule appointments, and show up at the allotted time or call to reschedule or let them know that you will be late. Showing dependability is crucial in establishing credibility with families.
- Make a "grass-catcher" list. This is an ongoing list of things to be done, but do not have a specific deadline. When you are making your daily "to do" list, consult this "grass-catcher " list.
- Always ask "what is the best use of my time right now?"
- Do not always do other people's "A" tasks at the expense of your own.

(List excerpted from Utah Case Management Field Guide, p. 40-41)[1]

Organization styles vary from person to person. Planners, task lists, appointment calendars and to-do lists are available as downloadable templates from the internet or through retailers to assist in honing organizational skills.

[1] Utah Department of Human Services. (2004). A *field guide on case management for children with serious emotional disturbances and their families.* Retrieved from http://dsamh.utah.gov/pdf/case_management/cm_field_guide_children.pdf

Stress Management

When it comes to stress management, it is helpful to work as a team. Create a supportive work network with staff and supervisors. Within this network, share stresses and frustrations with others to help reduce the tension and find humor in difficult situations.

Use relaxation techniques – breathing exercises, meditation, stretches. Take a few minutes every few hours to check in on how you are feeling and apply these techniques when needed. Take small breaks, and make sure to work in rest and relaxation time off when needed. Schedule, and use, vacation time. Don't forget to use sick time when needed.

Sometimes a good laugh is the best way to defuse a tense situation or a seemingly impossible task. Identify a peer who can commiserate while maintaining confidentiality.

Reach out. A supportive partner or a close friend can be a welcome shoulder to lean on when the going gets tough at work. While the confidential nature of case management prohibits too much sharing, being able to rely on a solid network of supportive friends, family, and community can help refill your tanks and make it through stressful times at work.

Exercise! Take a few minutes to go for a walk, say hello to passersby, visit a peaceful or green space. A few pleasurable moments like these can be calming activities that help refresh the mind and heart and show things from a new perspective. It also may help to be conscious of body positioning and breathing – stress can muscles tense and breathing shallow, contributing to overall feelings of anxiety and fatigue.

Most importantly, recognize the signs of burnout.[1] It's easier deal with if recognized in the early stages.

- Enthusiasm – "…a tendency to be overly available and to over-identify with clients
- Stagnation – "…expectations shrink to normal proportions and personal discontent begins to surface"
- Frustration – "Difficulties seem to multiply and the helper becomes bored, less tolerant, less sympathetic, and she or he copes by avoiding and withdrawing from relationships"
- Apathy – "Characterized by depression and listlessness"

The consequences of burnout, if ignored, can be serious.[2] Individuals may experience stress, fatigue, insomnia, negative spillover into relationships and home life, depression, anxiety, alcohol or substance abuse, heart disease, high cholesterol, Type 2 diabetes, stroke, obesity, and vulnerability to illnesses. It is important to try to manage stressors experienced in the course of work and assess feelings and need for changes.

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[1] List of burnout indicators excerpted from Edelwich, J., & Brodsky, A., (1980). *Burn-out: Stages of disillusionment in the helping professions.* Human Sciences Press.
[2] Mayo Clinic. (2015). *Job Burnout*. Mayo Clinic Patient Care and Health Info Website: http://www.mayoclinic.org/healthy-lifestyle/adult-health/in-depth/burnout/art-20046642?pg=2

Module 8: Resources

Conducting Safe Home Visits

There are many practical field guides and tools for maximizing the effectiveness of home visits. Some of these resources can be found online:

Tips and Resources for Making Safe and Effective Home Visits:
http://kc.vanderbilt.edu/kennedy_files/HomeVisitsTipsandResourcesJune2011.pdf

The "Home Ranger" Rides Again: Making Home Visits Safer and More Effective:
http://hpp.sagepub.com/content/9/4/323.full.pdf

Home Visitor's Handbook:
www.ehs nrc.org/PDFfiles/EHS-Home-VisitorHdbk.pdf

Safety Tips for Home Visitors
http://www.achd.net/hvn/pubs/pdf/HVNSafety.pdf

Home Visit Safety Guide
https://www.heartlandaea.org/media/cms/Home_Visit_Safety_Guide_40D7CE03F5AC9.pdf

Safety Plans

The following link shows an example of a school safety plan template for a student:
https://studentservices.madison.k12.wi.us/files/stusvc/Individual_Student_Safety_Plan_Form_0.pdf

Follow this link to view a guide for community health providers on responding to suicide that was published by Montgomery County Emergency Serivice, Inc.:
http://www.mces.org/PDFs/suicideproviders.pdf

Suicide Safety Contract Template:

https://suicidepreventionlifeline.org/wp-content/uploads/2016/08/Brown_StanleySafetyPlanTemplate.pdf

Module 9: Engaging Families

Introduction

It is critically important for successful outcomes that case management practitioners in NYS PROMISE actively engage the youth and their family as partners in the counseling and case management process. In this module, we will explore how case managers can incorporate family-centered principles in their planning. We will review what families need out of the case management process, and the vital support and collaboration case managers can provide. We will explore cultural competency, what this means for case management practitioners, and how they can build professional development in this area into their career paths. Finally, we will provide an overview of unique issues in engagement with immigrant youth and families

Families as Partners

Historically the human services profession has taken a directive approach with case management. In a directive relationship, the case management practitioner makes most of the decisions and is seen as the "expert." The individual or family being served by the program is seen as the receiver of the information and is placed in a more passive role. In recent years, research on motivational interviewing and solution-focused case management has shown that when the individuals or families receiving services are viewed as partners, they are much more engaged in the process and more long-term and meaningful changes take place.

Family-Centered Principles

The human service profession has come to realize that in providing services to youth, we can't view the youth apart from the family. A family-centered approach is one that values the strengths of the family and establishes a partnership between the helping professional and the family. The family is viewed as the most knowledgeable about the youth. They have seen the youth develop over time, and hold a wealth of information about the youth's strengths and needs. Therefore, they should be integrally involved in all decision-making.

Core principles of family-centered case management:[1]

- Focusing on family strengths
- Respecting family diversity and values
- Encouraging family decision-making and empowerment
- Communicating with families in an open and collaborative fashion
- Recognizing the value of informal support systems

[1] Bailey, D. B., Raspa, M., & Fox, L. C. (2012). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education, 31*(4), 216-223.

What the Family Can Bring to the Partnership

When working with families as partners it is important to highlight the unique resources and wisdom that they bring to the relationship. Family members are able to provide information and stories about the youth's strengths and challenges over time and in a variety of contexts. In order to maintain family stability, parents have often utilized a variety of approaches to deal with any functional implications of the youth's disability. These past attempts to address problems and concerns can provide a wealth of information to providers about potential future interventions. Family members can also give insight into the natural resources that already exist within the youth's life.

What Families Need in Partnering

1. To feel heard and understood

Many family members of high-risk youth have had past negative experiences with professionals, and won't always trust that you have their best interest in mind. When encountering a family for the first time, try to demonstrate with both verbal and non-verbal communication that you are interested in their story. Open-ended questions are helpful in facilitating conversations with the family.

Examples for encouraging dialogue:

- "Tell me more about your child."
- "I would love to hear more about your own experiences in the work force."
- "What are your greatest dreams for your child?"
- "What have been the biggest challenges you have faced as a single mother?"

2. Assistance in accessing information and resources

There are a variety of reasons that families lack adequate information and resources. Some families have difficulty reading, or don't have access to the Internet and other reading material. They may be isolated and unaware of local community agencies. Some have had negative experiences with school and other institutions and lack the trust to form direct relationships. At times, parents don't know what they don't know; they are unfamiliar with the special education process or aspects of parenting a child with a disability and don't realize that there is information available that can help them.

Potential sources of information and resources:

- School staff working with the youth
- Medical and mental health providers
- Community groups focusing on specific disabilities
- Local Parent Network
- Local library
- On-line resources

Strategies for family collaboration and partnership

1. Help the parent become more confident in understanding and participating in the special education process.
    - Find out if the parent has any questions or concerns about the special education process.
    - Review the IEP or 504 plan with the parent and make sure that they understand the child's classification and supports that the child is receiving.
    - Refer the parents to the regional Parent Training Center if more information and training is needed on the special education process.
    - Find out what method of communication the parent is most comfortable with (phone, e-mail, text, etc.) and make this information available to school staff.
    - Offer to attend school meetings and sit next to the parent at the meeting.
2. Engage the parent in discussions about the child's future.
    - Inquire about the hopes and dreams of the parent and the youth.
    - Help the parent access information and participate in discussions about the child's living, earning and learning goals for the future.
    - Make sure the parent knows what kind of diploma track their child is on so that there is time to revise the plan in order to better prepare for the future if necessary.
3. Recognize and validate the parent for his/her strengths.
    - Research shows that parents become more engaged when they feel valued and are consulted about the needs of their child. Sometimes the involvement of the school and other agencies is perceived by parents as an attempt to judge or critique their parenting, and it can be perceived as a threat.[1]
4. Spend less time talking and more time listening.
    - Try spending about 20% of your meeting or phone call talking and 80% listening. This can be accomplished through the use of open ended questions that encourage the parent or youth to talk openly.
5. Meet the parents where they are at (emotionally and physically).
6. Be as flexible as possible in the delivery of services.
    - Offer home visits and meetings via telephone.
    - Offer late afternoon/evening visits.
    - Provide reminder calls to parents the day of the scheduled appointment.

Benefits of Home Visits

- Gives you a perspective on the daily life and struggles of the family.
- Families may feel more comfortable interacting with staff in the familiarity of their own home.

[1] Sime, D. & Sheridan, M. (2014). 'You want the best for your kids': Improving educational outcomes for children living in poverty through parental engagement. *Educational Research, 56*(3), 327-342.

- Allows you to meet siblings and other family members and see how family members interact with one another.
- Breaks down barriers, makes professionals seem more approachable and "real."

Keep in mind, as discussed in the previous modules, the importance of employee safety planning strategies when conducting off site meetings.

Cultural Competency

Case management practitioners are working in an increasingly diverse world. Successful practitioners are expected to be culturally competent, in fact, this may have been a required qualification in the hiring description for the position. Cultural competency is a set of skills that helps case management practitioners adapt their approach to a wide variety of cultural environments. Culture itself can embrace race, ethnicity, religion, gender and many other personal characteristics. Individuals may be members of many different cultures simultaneously. Situational context impacts which cultural affiliations are 'active' and influencing the perspective of the youth and their family. For example, a youth a school may identify more strongly with a different set of cultures (i.e. student with a disability, athlete, high-school senior, Latino-American) than those that rise to prominence at home or in their community (i.e. oldest sister, grandchild of immigrants, Puerto Rican, Catholic). Case management practitioners may find that they engage differently with youth and families based on the context of where they are meeting, who is present at the meeting, and what point in the transition to adulthood is currently under discussion.

There are four components of professional cultural competence.

Awareness	Attitude
Knowledge	Skills

Effective cultural competence does not mean that practitioners are experts in their client's cultures. It does, however, mean that the case manager is able to be aware that others may have different reactions to the world than oneself. The practitioner is conscious of their reactions to others differences.

Case management practitioners who are proficient in cultural competency are also cautious about their attitudes. They take training that helps to develop their own awareness and recognition of cultural bias. They examine critically their personal reactions, beliefs, and values about culture.

Culturally competent case management practitioners seek to increase their knowledge about the cultures they encounter. In all situations, they are respectful and curious, willing and open to learning

more and yet patient, understanding that it may be challenging to understand a culture without time, immersion and personal experience.

Practicing and growing skills in cultural competence is a life-long professional development activity. The following strategies can help to improve cultural competency:

- Focus on building a trusting case management relationship. Once trust has been established, individuals are more comfortable discussing sensitive issues related to culture and diversity.
- Communicate honestly and respectfully.
- Help bridge communications and language barriers, offer appropriate translation services in advance where appropriate.
- Remain sensitive to youth and family preferences, culture, and religion.
- Ask open-ended questions that help you to learn more about the individual or family. Ask youth and families the values they embrace, how their family functions, and what their priorities are.
- Avoid making assumptions based on previous knowledge and experiences. Cultures may vary internally, and what a practitioner has previously learned may not always be transferrable to other situations.

Case Managers as Cultural Brokers

Case management practitioners incorporate their own perspectives with the family's cultural views and engages in cultural translation between the two different orientations.

Case management practitioners can serve as a bridge, linking the family to school and other service providers.

Case management practitioners can establish a long-term relationship with the family and their relational network in order to facilitate a familiar environment for the family.

Active listening and understanding can help practitioners avoid making assumptions about a family's values which could lead to friction and disagreements during the development of the youth's transition plan, service referrals and case management meetings.

Motivational interviewing is a counseling technique which helps clients explore and resolve ambivalence about making changes, may be helpful for practitioners when encountering family friction or uncertainty about appropriate self-determination goals for youth.

These techniques are covered in greater depth in *Module 5: Case Planning and Service Coordination*.

Family Dynamics

Each family has a unique way of interacting and making important decisions. Some of these dynamics may be impacted by the family's culture, and some may be unique to that particular family system. It is helpful to understand how decisions are made and how power is shared within the family so that you can support self-determination. Sometimes this information can be gathered from observations. For example, a mother may frequently tell you that she needs to talk with her husband first before making a decision. Another good way to clarify family dynamics is to ask some direct questions. For example, ask "How are decisions made within your family?" or "Who do we need to include in the decision-making process as we prepare for the future?" In some cases, family members who are involved in decision-making live in other countries and there is a need to allow time for family members to contact one another before the final decision is made.

What is the primary language of the family? If a language is not spoken fluently by the case manager, would the family/youth like the assistance of a translator during case management?

Staff Backgrounds

At times, staff members may have to examine their own beliefs and cultural biases to make sure that they are not imposing their own beliefs upon the youth or families with whom they work. For example, a staff member may have been raised in a family or larger culture that values independence and autonomy, but if the youth belongs to a family that believes in shared decision-making, then the staff member needs to work on building lines of communication with all family members who are involved in the youth's life. While sharing a common cultural background often facilitates initial engagement and connection with families, it is not necessary for a case manager to belong to a family's culture in order to build a strong therapeutic relationship. Inviting the family to share more about their cultural backgrounds and beliefs during early interactions can greatly improve the working relationship between the case manager and family.

Immigration and Cultural Diversity Topics

Between January and June of 2011, the United States, deported more than 46,000 parents of children who are citizens, and more than 5,000 of these children were placed in foster care.[1]

Immigration and Cultural Diversity in Families

While the youth enrolled in NYS PROMISE are documented U.S. citizens, there may be family members who are not citizens, and this can complicate the process of connecting families with community

[1] Rogerson, S. (2012). Unintended and unavoidable: The failure to protect rule and its consequences for undocumented parents and their children. *Family Court Review, 50*(4), 580-593.

resources. It is helpful to have some knowledge about the different types of citizenship status and the impact that this status may have on obtaining benefits and resources for the family.

Immigration-Related Terms[1] [2] [3] [4]

Undocumented immigrant- Term constructed by the Department of Homeland Security as an official category to identify immigrants who have entered the country illegally.

Child of an immigrant family- Child who has at least one foreign-born parent.

Mixed-status immigrant family- Family composed of a mixture of undocumented immigrants, documented immigrants, and U.S. citizens.

First generation immigrant child- Child born outside of the country in which they are living.

Second generation immigrant child- Child born in the country to a foreign-born parent.

Refugee- Someone who has been forced to flee his/her own country because of persecution, war, or violence and has or seeks legal residence in another country.

Immigrant Visa- Allows individuals to live and work in the U.S.

Green Card- Permanent resident card or Form I-551; Gives individual official immigration status in the U.S.; Issued through the U.S. Citizenship and Immigration Services (USCIS); once issued, valid for 10 years.

Naturalized Citizen- An individual who was not born in the U.S., but who obtained citizenship later.

Family Eligibility for Public Benefits[5]

Temporary Assistance for Needy Families (TANF)

- Funds are to be used to provide beneficiaries with cash and/or benefits and services, such as subsidized childcare and transit subsidies.
- Undocumented individuals are not eligible for these benefits, but can receive benefits for their children that are documented in the U.S.

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[1] Lad, K., & Braganza, D. (2013). Increasing knowledge related to the experiences of undocumented immigrants in public schools. *Educational Leadership and Administration: Teaching and Program Development, 24*, 1-16.
[2] Enriquez, L. E. (2015). Multigenerational punishment: Shared experiences of undocumented immigration status within mixed-status families. *Journal of Marriage and Family, 77*, 939-953.
[3] Cowden, J. D., & Kreisler, K. (2016). Development in children of immigrant families. *Pediatric Clinic of North America*, 775-793.
[4] USA.gov (2016). Citizenship and green cards: Learn about issues with citizenship and residency documentation. https://www.usa.gov/citizenship-and-green-cards
[5] American Academy of Pediatrics. *Immigrant child health toolkit*. Available at: https://www.aap.org/en-us/Documents/cocp_toolkit_full.pdf

- Documented permanent residents over age 18 are eligible after 5 years of legal residents in the U.S.
- Refugees and those with asylum are eligible for these benefits without any waiting period.

Supplemental Nutrition Assistance Program (SNAP)

- Undocumented parents are not eligible, but may apply on behalf of their documented U.S. children, and the benefit will be calculated based on the parent's income. The parent and any other undocumented family members will be excluded from the household size.
- Documented permanent residents over age 18 are eligible after 5 years of legal residents in the U.S.
- Refugees and those with asylum are eligible for these benefits without any waiting period.

Public Housing/Subsidized Housing

- Citizens and qualified immigrants are eligible regardless of immigration status of other family members without any waiting period.
- For mixed-status families living in the same household, the benefit is prorated and reduced in proportion to the number of non-qualified immigrants living in the house.

Health and Medical Care

- Undocumented immigrants are not eligible for Medicaid, CHIP, or other health insurance subsidies provided through the Affordable Care Act (ACA).
- The Emergency Medical Treatment and Active Labor Act (EMTALA) requires hospitals to treat anyone needing emergency healthcare regardless of citizenship, legal status, or ability to pay. They are required to stabilize the individual but not to provide preventative or outpatient care.

Immigrant Youth in Schools[1]

Regardless of their immigration status, children who move to the U.S. from other countries have the right to a free public K-12 education. Schools are prohibited from requiring proof of citizenship or legal residence in order to enroll a child in school or provide services. In addition, the McKinney-Vento Act requires school districts to allow homeless children to enroll in public schools when they are unable to provide proof of residence or guardianship status.

Impact of Citizenship Status of Family Members on Engagement

Today in the United States it is estimated that there are approximately 16.6 million people who live in mixed-status families in which the family is composed of a mixture of undocumented immigrants,

[1] American Academy of Pediatrics. *Immigrant child health toolkit*. Available at: https://www.aap.org/en-us/Documents/cocp_toolkit_full.pdf

documented immigrants, and U.S. citizens.[1] These families face a constant threat of separation and loss of family members to deportation. Over the past decade, the United States has become much more aggressive in the deportation of undocumented individuals. When a parent is deported, a child may be left with a single parent in the country or placed with another relative or caregiver. Between January and June of 2011, the United States deported more than 46,000 parents of children who are citizens, and more than 5,000 of these children were placed in foster care.[2]

Parents who are not documented immigrants often face significant parenting challenges.[3] They are unable to obtain a Social Security number and legally access employment, so they are often working under the table in jobs where they earn 14-24% less than their peers who are documented. In order to provide for their family, many need to work long hours that prevent them from spending time with their children. In addition, they are unable to obtain a driver's license, which can significantly hinder school involvement and their ability to access resources within the community. A large number of undocumented immigrants drive without a license, but this puts them at risk for heavy fines and/or deportation.

Due to the constant daily fear of deportation, many mixed-status families attempt to avoid law enforcement and judicial officials in order to avoid drawing attention to their undocumented status.[4] Their children often learn to mimic some of this behavior, and become hyper-vigilant within their environment. Research on children of mixed-status families reveals that they worry about standing out in school, and are more hesitant to contribute in class and draw attention to themselves. They may also be wary about making new friends and sharing personal information about themselves for fear of revealing information about the undocumented status of family members. In addition, they can feel somewhat detached from school because they don't know how long they are going to be in the United States and are more focused on getting a job and saving money than on engaging in school. Since their parents have fears about the school discovering the existence of undocumented family members, they are less likely to be in communication with the school and reinforce academic engagement with their child.

[1] Enriquez, L. E. (2015). Multigenerational punishment: Shared experiences of undocumented immigration status within mixed-status families. *Journal of Marriage and Family, 77*, 939-953.
[2] Rogerson, S. (2012). Unintended and unavoidable: The failure to protect rule and its consequences for undocumented parents and their children. *Family Court Review, 50*(4), 580-593.
[3] Enriquez, L. E. (2015). Multigenerational punishment: Shared experiences of undocumented immigration status within mixed-status families. *Journal of Marriage and Family, 77*, 939-953.
[4] Cavanagh, C., & Cauffman, E. (2015). The land of the free: Undocumented families in the juvenile justice system. *Law and Human Behavior,* 152-161.

Barriers Faced By Students from Mixed-Status Families[1]

- Language barriers (may have more difficulty with reading and understanding nuances of the English language)
- Missing records (birth certificates, report cards, emergency information)
- Increased mobility in family
- Difficulty trusting and forming relationships
- Detachment-not knowing if and when family members will be deported, focus on making money and moving back to home country
- Lack of family advocate, parents not engaged in school
- Economic stress, parents paid "under the table" at minimal salaries
- Multiple family members living in close quarters
- Lack of access to healthcare and other resources due to lack of information and parents' hesitancy to share information with others outside the family

Adaptation Process of Youth in Families that Have Immigrated

As a result of socialization and educational opportunities within school, children of immigrant families often adjust to the U.S. culture much more quickly than adults. In many families, these children serve as cultural brokers for their parents and other family members by translating and interpreting the new language and cultural expectations.[2] This can lead to a role reversal in which youth sometimes feel responsible for taking care of their parents. In some cultures, this role reversal is culturally relevant and accepted by all family members. However, in other cases this can lead to conflict between generations when youth, through the acculturation process, begin to accept the values of individuation and independence that are promoted within the U.S. and thereby challenge the family's adherence to the values of their home country. Case managers should be conscious of the dynamic occurring between themselves, their young clients, and families when managing multiple languages to ensure that the case manager and family are not asking or expecting the youth to act as an interpreter. Sensitive situations may require the inclusion of an external interpreter in order to make sure that the case manager, parents and youth are communicating clearly and accurately. Interpreters who share language as well as culture of the youth and families may also be able to offer Case managers additional insight into cultural factors impacting their conversations.

[1] Lad, K., & Braganza, D. (2013). Increasing knowledge related to the experiences of undocumented immigrants in public schools. *Educational Leadership and Administration: Teaching and Program Development, 24,* 1-16.
[2] Oznobishin, O. & Kurman, J. (2016). Family obligations and individuation among immigrant youth: Do generational status and age at immigration matter?" *Journal of Adolescence, 51,* 103-113.

Module 9: Resources

Preparing a Program to Treat Diverse Clients
https://www.ncbi.nlm.nih.gov/books/NBK64076/

From "Treatment Improvement Protocol (TIP) Series, No. 46, Chapter 4", by the Center for Substance Abuse Treatment, 2006. Provides recommendations on how to improve the cultural competence of treatment programs.

How Do I Become Culturally Competent?
http://www.apa.org/gradpsych/2010/09/culturally-competent.aspx

Guidance from the American Psychological Association for psychologists and counselors in training.

Cultural Competence Checklist: Personal Reflection
http://www.asha.org/uploadedFiles/Cultural-Competence-Checklist-Personal-Reflection.pdf

Part of a series of Cultural Competence Checklists from the American Speech-Language-Hearing Association. This checklist is designed to heighten practitioners' awareness of how they view clients and patients from culturally and linguistically diverse populations

Cultural Competence Checklist: Policies and Procedures
http://www.asha.org/uploadedFiles/Cultural-Competence-Checklist-Policies-Procedures.pdf

A tool to heighten awareness of your agency's programs, policies, and procedures and the impact of cultural and linguistic factors.

Cultural Competence Checklist: Service Delivery
http://www.asha.org/uploadedFiles/Cultural-Competence-Checklist-Service-Delivery.pdf

A tool to heighten awareness of how a practitioner serves clients from culturally and linguistically diverse populations.

Pathway to US Citizenship
https://www.uscis.gov/sites/default/files/USCIS/Office%20of%20Citizenship/Citizenship%20Resource%20Center%20Site/Publications/PDFs/M-685.pdf

Provides an overview of the process by which an immigrant becomes a citizen

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Module 10: Protection and Advocacy

Introduction

This module offers an overview of Protection and Advocacy (P&A) services, with a description of programs that may be helpful for NYS PROMISE students and families.

Protection and Advocacy (P&A)

P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities (based on a system of priorities for services). These agencies devote considerable resources to ensuring full access to inclusive educational programs, financial entitlements, healthcare, accessible housing and productive employment opportunities. The National Disability Rights Network (NDRN) is a voluntary national organization comprised of all the P&A and Client Assistance Programs (CAP) agencies and information contained in this subsection was derived from their website.

Over the years, the focus of P&A work was broadened to one that secures the rights of persons with all types disabilities wherever they reside. P&A statutes were expanded to give the P&A additional authority so that the P&A now devote considerable resources to ensuring full access to inclusive educational programs, financial entitlements, healthcare, accessible housing, transportation, and productive employment opportunities, as well as continuing to seek prevention of abuse and neglect.

P&A Programs

There are eight separate P&A programs – all described briefly below, in order chronologically based on when they were created.

PADD (Protection and Advocacy for Individuals with Developmental Disabilities). PADD is the first P&A program, created by the Developmental Disabilities Assistance and Bill of Rights (DD Act) of 1975. P&A agencies are required by the Act to pursue legal, administrative and other appropriate remedies to protect and advocates for the rights of individuals with developmental disabilities under all applicable federal and state laws. The DD Act provided for the governor of each state to designate an agency to be the P&A and to assure that the P&A was, and would remain, independent of any service provider. Most entities designated as P&A are private non-profit organizations created specifically for the purpose of conducting the P&A programs. However, some P&A are part of state government, a few are hybrid quasi-public agencies, and a few P&A reside within civil legal services programs. Subsequent P&A statutes, with a single exception (CAP), provide for the new P&A programs to be housed within the same agency designated by the governors under PADD.

CAP (Client Assistance Program). CAP was established by the 1984 Amendments to the Rehabilitation (Rehab) Act. Services provided by CAPs include assistance in pursuing administrative, legal and other

appropriate remedies to persons receiving or seeking services from state rehabilitation agencies under the Rehab Act. A CAP agency may provide assistance and advocacy with respect to services that are directly related to employment for the client or client applicant. CAP is the only program that does not require the funds to go to the entity designated as the P&A under PADD.

PAIMI (Protection and Advocacy for Individuals with Mental Illness). The PAIMI Program was established in 1986. These P&A are mandated to protect and advocate for the rights of people with mental illness and investigate reports of abuse and neglect in facilities that care for or treat individuals with mental illness. The Act was subsequently amended to allow P&A also to serve individuals with mental illness who reside in the community.

PAIR (Protection and Advocacy for Individual Rights). The PAIR program was established by Congress under an amendment to the Rehabilitation Act in 1993. PAIR programs provide for services to persons with disabilities who are not eligible for services under the three previously established P&A programs (PADD, PAIMI, and CAP). With PAIR, the P&A were thus authorized to serve persons with all types of disabilities. Although PAIR is funded at a lower level than PADD and PAIMI, it represents an important component of a comprehensive system to advocate for the rights of all persons with disabilities.

PAAT (Protection & Advocacy for Assistive Technology). The PAAT program was created in 1994 when Congress expanded the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) to include funding for P&A to assist individuals with disabilities in the acquisition, utilization, or maintenance of assistive technology devices or assistive technology services through case management, legal representation and self-advocacy training.

PABSS (Protection & Advocacy for Beneficiaries of Social Security). The PABSS program was established in 1999 when the Ticket to Work and Work Incentive Improvement Act (TWWIIA) was enacted into law. Under this Act, grants to the P&A programs provide advocacy and other services to assist beneficiaries of Social Security secure or regain gainful employment.

PATBI (Protection & Advocacy for Individuals with Traumatic Brain Injury). The PATBI program was created in 2002 to provide protection and advocacy services to individuals with traumatic brain injury. Although P&A often served such individuals under PAIR, CAP, or PABSS, this grant provides more resources specifically to address the unique needs of this population.

PAVA (Protection & Advocacy for Voting Accessibility). The PAVA program was established in 2003 as part of the Help America Vote Act of 2002 (HAVA). Under this program, P&A have a mandate to help ensure that individuals with disabilities participate in the electoral process through voter education, training of poll officials, registration drives, and polling place accessibility surveys. P&A agencies may not use PAVA program funds for litigation. There is no such restriction in any of the other P&A programs.

Module 10: Resources

Contacting Your P&A

Disability Rights New York (DRNY) is the Protection & Advocacy System and Client Assistance Program (P&A/CAP) for persons with disabilities in New York. As the P&A/CAP for New York, DRNY advocates for the civil and legal rights for New Yorkers with disabilities. New York residents with disabilities can contact DRNY for assistance with problems directly related to their disabilities. DRNY investigates complaints and provides direct assistance to callers with disability-related issues under the terms of its federal grants and its annual goals and priorities. DRNY is supported by the U.S. Department of Human Services, Administration on Intellectual and Developmental Disabilities; Center for Mental Health Services, Substance Abuse & Mental Health Services Administration; U.S. Department of Education, Rehabilitation Services Administration; and, the Social Security Administration. P&A and CAP services and supports are readily available in every area of New York State. To learn more or access services and supports, contact:

725 Broadway, Suite 450
Albany, New York 12207

25 Chapel Street, Suite 1005
Brooklyn, New York 11201

44 Exchange Blvd, Suite 110
Rochester, New York 14614

(518) 432-7861
(518) 512-3448 (TTY)
(800) 993-8982 (Toll Free)
(518) 427-6561 (Fax)
mail@DRNY.org

Module 11: Triaging Benefits and Entitlements to Support Career Development and Work

Introduction

Youth with disabilities who receive Supplemental Security Income (SSI) and their families typically maneuver a maze of public benefits and entitlements. At times navigating this unfamiliar territory can be challenging for these youth and their families and often decisions are made to minimize behaviors that might jeopardize these programs. Further complicating matters, case managers, educators and even community rehabilitation practitioners often have limited knowledge and understanding of how these benefit and entitlement programs work. This means they also are unsure how to support youth and families that receive them, and how to influence perceptions of these programs as short-term assets to support integrated work in the community versus life-long supports that may lead to long-term poverty and reliance on these programs.

The number of youth in special education receiving SSI is growing exponentially. Case management practitioners must understand not only how to triage benefits and entitlements to support career development and work, but also how to integrate these efforts within the special education process and the student's individual education program. Congress has intentionally designed features in the SSI program to provide incentives for youth to stay in school, complete their education, and participate in VR, while at the same time minimizing the impact of earnings while they are in school on their SSI benefits. Further compounding the complexity of the case management practitioner is the dynamics of the SSI recipient's family. Often families have more than one family member with a disability, have low educational achievement themselves, and lack the necessary information to increase their own financial self-sufficiency. This added complexity requires that case management practitioners have access to and can refer for additional supports that the family may need.

The goal for case management practitioners should be to help families and youth understand benefits and entitlements as short-term assets meant to support competitive or supported integrated employment in the community versus life-long supports that may lead to long-term poverty and reliance on these programs. At the same time, case management practitioners also need to recognize that for some youth with significant disabilities, work may not be of interest, and these benefits and entitlements provide critical financial and health safety nets for individuals that need to be ensured over time.

Case management practitioners need to be able to:

1. Understand and explain the two benefit programs administered by the Social Security Administration and disability eligibility; Title II and Title XVI (SSI).
2. Understand and explain the SSI program and how it supports career development and work outcomes.

3. Understand and explain SSI work incentives and how they can be used to maximize youth and family education, employment and economic outcomes.
4. Employ strategies to support decisions to work.
5. Access the right services and supports for beneficiaries and their families at the right time.
6. Engage credentialed benefits and work incentives practitioners to support benefits planning.
7. Integrate benefits and work incentives planning goals into individualized service planning documents.

Overview of the Social Security Administration and Disability Eligibility

The Social Security Administration (SSA) is a very large, independent federal agency based in Baltimore, MD. SSA is headed by a Commissioner who reports directly to the President of the United States, the agency has ten Regional Offices located across the country. The Regional Offices oversee the work of the 1230 statewide Field Offices that provide direct services to beneficiaries. With a total of almost 60,000 employees nationwide and an annual budget in the billions, SSA is one of the largest federal bureaucracies and is responsible for maintaining lifeline programs for its beneficiaries.

SSA administers two major disability programs for its beneficiaries:

- Title II, including Social Security Disability Insurance (SSDI), Childhood Disability Benefits (CDB) and Disabled Widows Benefits (DWB); and
- Title XVI; the Supplemental Security Income program (SSI).

The two programs are vastly different and are directed at very different beneficiaries. For the sake of this Field Guide, we will focus exclusively on the SSI program.

Both SSI and the SSDI programs use the same definition of disability during the initial application process. That definition contains three major eligibility requirements for both the SSI and Title II programs. *Individuals must have a medically determined impairment(s)* and must be *unable to earn above the applicable substantial gainful activity (SGA) level* for a period of *at least 12 consecutive months.* For youth under the age of 18, there is a separate disability standard that does not include the substantial gainful activity[1] prong of the definition, but rather a focus on how marked and severe the disability is. For youth found eligible by SSA for disability benefits, they will need to have their eligibility re-determined for benefits under the adult disability standard at age 18. This is discussed later in this chapter.

[1] Substantial Gainful Activity is a term used by the SSA to define a specific earning threshold. In 2017, SGA is defined as $1,950 or more a month for individuals who are blind, and $1,170 or more a month for other individuals with disabilities. This amount is annually indexed and current and historic calendar year thresholds are available online at https://www.ssa.gov/oact/cola/sga.html

Continuing Disability Review (CDR)

The issue of continuing disability eligibility is a critical one. Over the course of a beneficiary's case, SSA will continue to evaluate the degree to which the individual continues to have a disability – this is the **Continuing Disability Review (CDR)**. If at any point SSA makes a decision that the individual no longer meets the SSA disability standard, benefits will be terminated. Children receiving SSI should receive a CDR every 3 years, and then undergo a Redetermination at the age of 18 to establish whether they meet the adult definition of disability, which is very different than the childhood criteria. Additional information regarding the types of Continuing Disability Reviews case management practitioners will encounter are available online at paths.nyspromise.org.

Age 18 Redetermination

Every SSI beneficiary under the age of 18 MUST undergo an Age 18 Redetermination to continue to receive SSI benefits upon turning age 18. This review is NOT a new application OR a Continuing Disability Review (CDR). It is a determination that focuses on whether the child with a disability now meets the adult disability standard and, therefore, remains eligible for SSI payments. Should SSA make a favorable determination, SSI benefits will continue. If the determination is negative, benefits may be payable pending appeal or through the application of Section 301. If not, benefits will be terminated. In the event that an overpayment occurred as the result of a "good faith" appeal of an Age 18 Redetermination denial of disability, SSA will generally waive these overpayments upon request.

It is important for parents and youth to be aware of and prepare for the Age 18 Redetermination. The adult disability review process involves determining whether the individual is able to engage in any substantial gainful activity (SGA).

Due to differences in the adult standards for assessing disability, a young adult can be determined ineligible for SSI benefits even though there has been no change in medical condition or ability to function since being found eligible for childhood SSI benefits. A significant number of youth who turn 18 are found to be ineligible for SSI benefits as an adult, which is surprising to many young adults and their families.

Statistics from 2014 data from SSA reveal that approximately 55% of child recipients are initially found ineligible for adult SSI benefits during the Age 18 redetermination process. This 2014 report from SSA can be found here: http://www.socialsecurity.gov/oact/ssir/SSI14/index.html.

For more information about the Age 18 redetermination process, visit the VCU Work Incentives Planning and Assistance National Training and Data Center website at https://vcu-ntdc.org/resources/viewContent.cfm?contentID=22

Safety Nets to Protect Youth in Danger of Losing SSI Eligibility

As youth receiving SSI approach their 18th birthday, it is essential that parents and other adults in their life help them to prepare for financial self-sufficiency, especially given the significant rate of youth that are denied adult SSI benefits during the Age 18 redetermination process. The following work incentives help youth to set aside money so that they are able to save for adult living expenses:

Section 301 Protection

Section 301 is an important facet of the SSI program for youth that allows continued payment of an SSI benefit to individuals who have been medically ceased, due to their participation in an approved educational or vocational rehabilitation program, employment services, or other support services. This is particularly relevant for youth who are not determined eligible for adult disability benefits following their Age 18 Redetermination—potentially eliminating barriers associated with losing their benefits while attempting to complete an approved program that will lead to better careers and increased self-sufficiency. Additional information on the Age 18 Redetermination Review is available at paths.nypromise.org.

Plan For Achieving Self Support (PASS)

PASS allows an individual to set aside their own income/or resources in a special account, not counted for SSI purposes, to support their objectives and activities associated with assisting them in achieving a specific work goal.

Student-Earned Income Exclusion (SEIE)

SEIE helps students under the age of 22 who regularly attend school, receive SSI, and work to exclude up to $1,790 per month and up to a maximum of $7,200 per year in 2017. These figures change annually.

Appealing SSA Decisions and Supporting Students and Families

Any denial of an application for benefits for medical or financial reasons will be accompanied by a statement of appeal rights. Individuals have the right to appeal any "initial determination" made by SSA. Initial determinations also include the denial of benefits, reduction of benefits, termination of benefits, and overpayments. There are four levels of the appeals process. Individuals have 60 days from the time they receive an Age 18 Redetermination notice of termination from SSA to file appeals. **However, in order to continue receiving benefits during the appeal process, the appeal must be made within 10 days**.

SSA will assume that individuals received the notice five days after the date shown on the notice, unless individuals can show that they received it later. Whenever SSA sends a notice, they will indicate which step of the appeals process can be taken. Some case management practitioners may feel they have the expertise to support beneficiaries through the appeals process. However, Protection and Advocacy for Beneficiaries of Social Security (PABSS) programs can provide important advocacy support and often

have personnel dedicated to supporting the appeals process. A directory of PABSS programs is available online at https://www.choosework.ssa.gov/findhelp. In addition, copies of all forms referenced below can be found online at https://www.ssa.gov/forms, some of which can be completed online.

The four steps of the process must generally be taken in order. The levels of appeal are described below.

Reconsiderations

A Request for Reconsideration is a complete review of the disability claim by someone who did not participate in the original decision. All the evidence originally submitted will be reviewed. Any additional evidence submitted will also be considered. Reconsideration can be requested by completing form SSA-561-U2. This form can be obtained online at https://www.ssa.gov/forms/ssa-561.pdf

Request for Hearing

Individuals who disagree with the reconsideration decision may ask for a hearing before an Administrative Law Judge (ALJ). The ALJ has had no part in either the original or reconsidered decision. A hearing is requested by completing a form HA-501. This form is also available online at https://www.ssa.gov/forms/ha-501.html. Individuals may review their entire SSA file prior to the hearing. The ALJ's Hearing Assistant will be present and will record the hearings. In a disability case the individual, their representative, or the ALJ may request further medical exams/tests be ordered if more medical information is necessary. The individual and their representative will have the opportunity to attend the hearings and explain their case in person. The individual may question witnesses, provide new information such as medical records, submit a written statement about their case, and review the information the ALJ will use to make the decision. They will receive written notice of the hearing decision.

Request for Review by the Appeals Council

If individuals disagree with the hearing decision, they may request a review by the Appeals Council. A request for an Appeals Council Review can be made by completing form HA-520. This form is also available online at https://www.ssa.gov/forms/ha-520.html. The Appeals Council considers all requests for review, but may deny appeal requests if it believes the decision by the Administrative Law Judge was correct. If the Appeals Council decides to review the case, it will either decide the case or return it to an Administrative Law Judge (ALJ) for further review. Generally, the Appeals Council Review is a paper process and an action must be taken within 90 days. Individuals are sent written notice of the Appeals Council decision.

Federal Court Review

If individuals disagree with the Appeals Council decision or if the Appeals Council decides not to review their case, or misses the 90-day deadline, a lawsuit may be filed in a Federal District Court. The complaints must be filed in a U.S. District Court within 60 days of the date that the notice of the Appeals

Council decision is received. The Federal Court will review the evidence and previously made decisions and will not conduct a new trial. At this point in the appeals process, the claimant must either proceed "pro se" or be represented by an attorney.

It is also important to note that SSA is experimenting with the traditional appeals process in an effort to make the process shorter. As a result, the “usual” appeal process may not be the one used in your area. Be sure to check with your Office of Disability Adjudication and Review or Field Office to observe local protocol.

Roles during Appeals

It is critical for practitioners and beneficiaries to understand and recognize the roles they can play during an individual’s appeals process. Practitioners may not be in a position to represent a beneficiary who is negotiating the appeals process. The practitioner can play a supportive role that could include, but not be limited to providing:

- General Information on the appeals process
- Information and referral to individuals/agencies that have the skill and ability to help with appeal
- Copies of forms needed to appeal
- Support in making choices and understanding the appeals process

Remember, having a network of competent and capable legal representatives who can assist beneficiaries during the appeals process is important. Beyond PABSS programs which are referred to above, case management practitioners may want to develop connections and relationships with local law clinics and legal service clinics as well.

Overview of Supplemental Security Income and Incentives to Promote Career Development and Work

Supplemental Security Income

Supplemental Security Income (SSI) is a means-tested program—meaning, it is based on the amount of “other” income you receive and is only intended to bring a beneficiary up to a certain minimum level of income. This minimum level of income is known as a Federal Benefit Rate (FBR).

Some states, like New York, also supplement the FBR. In New York in 2017, individuals who live alone and have no unearned or earned income will receive $822 per month in SSI cash benefits. SSI beneficiaries living with others in 2017, and having no unearned or earned income, will receive $758 per month in SSI cash benefits. Individuals living in someone else’s household (like a child SSI recipient) in 2017, with no other income, will receive $513 per month in SSI cash benefits. This federal determination is made as a result of the person living in the household of another and also receiving some amount of

free or subsidized room and board. In New York, an SSI beneficiary who receives at least $1 of SSI is automatically eligible for Medicaid.

How Going to Work Impacts SSI Benefits

When an SSI beneficiary goes to work, the Social Security Administration (SSA) will decrease the SSI cash benefit a little bit at a time as earnings go up. SSA uses gross earnings (before taxes) to decide how much to subtract from the SSI check. To understand how the SSA calculation works, it is important to understand that SSA considers earned and unearned income differently and allows certain income exclusions against both. Here is how the amount is figured:

- If an SSI beneficiary works, the first $20 of unearned income (Social Security Disability Insurance benefits, Unemployment Insurance benefits, income deemed available from a parent or spouse, etc.) is excluded. The remaining balance is considered the net countable unearned income.
- If there is no unearned income, then the $20 exclusion is taken from earning income (such as wages or self-employment).
- Next, SSA will disregard the next $65 of earned income as a further income exclusion.
- Of the remaining earned income, SSA will then disregard one-half. What is left is considered the individual's net countable earned income.
- If the individual had unearned income from the first step remaining after the $20 exclusion, that amount is then added to the net countable earned income from the preceding step. This equals the total net countable income.
- The net countable income is then subtracted from the SSI cash benefit rate depending on the individual's living arrangement.
- The amount left over is the amount of the person's adjusted monthly SSI cash payment.

Other Incentives to Support Work

The SSI program has other work incentives available that act as income disregards—very similar to the unearned ($20) and earned income ($65) disregards discussed earlier. These work incentives can be deducted from gross monthly earnings as part of SSA's calculation in determining the amount of your adjusted SSI cash benefit. A brief description of each follows.

- Impairment Related Work Expenses (IRWE) are work expenses related to a disability that are needed to work and are paid for by the individual.
- Blind Work Expenses (BWE) are any ordinary and necessary expenses attributable to the earning of income for an individual who is blind and are paid for by that individual.

These are all SSI work incentives and can positively affect the amount of an individual's SSI cash benefit. The impact of each is determined by the placement of the disregard in the SSA calculation.

Below is an SSI Budget worksheet that can be used to assist you in calculating the impact of earning sno SSI.

Step 1: Calculating Total Countable Unearned Income	
1. Unearned Income*	
2. "Any-Income" Deduction	-$20
3. Total Countable Unearned Income (Subtract line 2 from line 1)	=
Step 2: Calculating Total Countable Earned Income	
1. Gross Earned Income	
2. Student Earned Income Exclusions (up to $1,780mos/$7,180yr)	-
3. Remainder (subtract line 5 from line 4)	=
4. "Any-Income" deduction if not used before**	-$20
5. Remainder (Subtract line 7 from line 6.)	=
6. Earned-Income Deduction	-$65
7. Remainder (Subtract line 9 from line 8.)	=
8. Impairment-Related Work Expense, if not blind (IRWE)	-
9. Adjusted Gross Earned Income (Subtract line 11 from line 10.)	=
10. 50% of Adjusted Gross Earned Income as a Work Incentive Deduction (Divide line 10 in half)	-
11. Remainder (subtract line 13 from line 12)	=
12. Blind work expense (BWE)	-
13. Total Countable Earned Income (Subtract line 15 from line 14.)	=

Step 3 Calculating Total Countable Income	
1. Total Countable Unearned Income (Amount from line 3)	
2. Total Countable Earned Income (Amount from line 16)	+
3. Total Countable Income (Add line 17 and line 18.)	=
4. PASS Deduction	-
5. Total Countable Income (Subtract line 20 from line 19)	=
Step 4 Calculating Adjusted SSI Payment	
1. Base SSI Rate (fill in appropriate amount)	
2. Total Countable Income (Amount from line 21)	-
3. Adjusted SSI Payment (Subtract line 23 from line 22.)	=
Step 5 Calculating Total Useable Monthly Income	
1. Adjusted SSI Payment (Amount from line 24)	
2. Gross Earned Income Received (Amount from line 4)	+
3. Gross Unearned Income Received (Amount from line 1)	+
4. IRWE, BWE, or PASS Expenses (Combine lines 11, 15, & 20.)	-
5. Total Financial Outcome (Add lines 25, 26, and 27. Subtract line 28.)	=

*Insert sum of all combined unearned income on line 1

**You only get to use the $20 any-income deduction once. If you do not use all of the deduction to reduce your unearned income, you can use the balance to reduce your earned income.

Employment Decision Making and Supporting Choice[1]

Understanding the impact of earnings on disability benefits and public entitlements is critical to supporting beneficiaries and advancing positive employment outcomes for individuals with disabilities as they develop pathways out of poverty. While information may support individuals in making informed choices about work, making a choice does not always translate into taking action.

Wikipedia defines decision making as:

> *"An outcome of mental processes leading to the selection of a course of action among several alternatives. Every decision making process produces a final choice. The output can be an action or an opinion of choice."*

Immediately, one can see how an individual can make a decision but still not take action. The Work Incentive Plan, or WIP, therefore becomes a critical piece of the "action" plan. A WIP is a listing of action steps that must be taken in order to advance the individual toward work. Each action step is assigned to a responsible person; this individual should most often be the individual returning to work but can also be the practitioner or other support person. Finally, a due date should be assigned to each action step so the progress can be made, documented, and measured.

Decision making is a complex process. An individual's decision to try work, return to work or advance in work isn't as simple as just deciding "to work or not to work." Decisions must be made regarding the individual's *quality criterion* (level of work, career type, support needed, etc.), approaches to securing and/or advancing in a job, choice of service provider, and other variables around conditions of work. All these choices facing the individual make the development of a Work Incentive Plan a multi-dimensional process—with supports from case management practitioners needed to move from each level of decision.

Four Types of Decisions

Beneficiaries are going to be faced with four main types of decisions. Case management practitioners need to be ready to support them on all fronts. They include:

Decisions whether are simply binary choices "to work or not to work." These types of decisions are made by weighing pros and cons. Practitioners are well-positioned to support beneficiaries in making these types of decisions and should press for decisions and the reasoning behind a decision. Practitioners may discover that the individuals have a void in the information that has been provided that they may need to fill to help support individuals in making informed choices.

[1] Material in this section has been excerpted and adapted from:
Yang-Tan Institute (2017). *Benefits and work incentives planning, professional standards, code of conduct, and effective communication.* Curriculum prepared by Yang-Tan Staff for *EDI ONLINE* training modules.

Decisions which are decisions that involve a choice of one or more alternatives from among a set of possibilities and, sometimes, can be based on the "decision whether." For example, "to work part-time or full-time." The choice is often based on how well each alternative measures up to a set of predefined criteria. Presenting scenarios to beneficiaries in reports and during advisement are the practitioner's best tools for supporting beneficiaries in making these types of decisions. Practitioners can help individuals lay out options so that they can consider the option from various angles. Showing the beneficiary the financial outcome of each scenario presented will help to give a clear idea of the amounts of money involved in each possibility.

Contingent decisions are decisions that have been made but are put on hold until some other condition is met. "I have decided to go to work but someone has got to find me a job first". It is critical for the practitioner to understand contingencies that a beneficiary may have before moving to action. This will help the practitioner in identifying subsequent supports, referrals and assistance that an individual may need to have in place to aid in moving to action.

Decisions how involve the "doing" step. "How will I get a job?" "Who will help me find a job?" This type of decision-making requires active support on the part of the practitioner, not passive observance. Making connections to subsequent support providers is critical and will provide necessary linkages to ensure continuity of supports resulting in positive work outcomes. The best way to help individuals is to know your community resources!

Creating a Positive Decision Environment

Each type of decision described above will be made within a *decision environment,* which is defined as the collection of information, alternatives, resources, values and preferences available at the time of the decision. Of course the ideal decision environment would include all possible information, all of it accurate and every possible alternative. Creating an ideal and positive environment is the practitioner's number one priority, and several steps can be taken to help ensure it is developed:

- Gather as much **accurate and comprehensive information** on the individual and their benefits portfolio as possible.
- Verify information collected to ensure **accuracy and reliability** of the alternatives and scenarios generated.
- Understand the specific **goal(s)** the individual is interested in.
- Identify the **reservations and reluctance** the individual may have pertaining to the choice(s) they need to make—this will possibly inform the practitioner regarding contingencies that will need to be in place.
- Establish the **criteria, characteristics** or **requirements** that each alternative must possess to a greater or lesser extent—remember that alternatives will be rated on how well they deal with each criterion.
- Understand the individual and their **values**—this will help the practitioner gauge how desirable a particular outcome or alternative might be.

- Identify the individual's **preferences** providing some insight into the philosophy and moral hierarchy of the individual making the decision.
- Most importantly, create an environment that **supports work** as a positive outcome and sets expectations regarding its value and worth.

Decision Making Strategies

The case management practitioner is inevitably going to be faced with a beneficiary basing a decision on one of four strategies. Understanding each of these strategies and their role in supporting good decision-making is critical. The practitioner must also understand how the conditions created may contribute to selection of the strategy used.

Optimizing is the strategy of *choice*, as it involves selecting the best possible solution to the choice at hand. However, supporting beneficiaries using this strategy requires up-front work on the part of the practitioner to help the individual understand all factors that contributed and were included in the scenarios created for the individual. Making certain an individual understands how the scenarios and alternatives created are based on their original stated goal, preferences, values, and available resources will go a considerable way to assuring them that the options presented are of the highest quality.

Satisfying, while not an ideal strategy, can suffice in some cases. It is settling for the first satisfactory alternative rather than the best alternative. Often beneficiaries who are not presented with a comprehensive array of options will select the first one that appears to meet their minimum expectations. To avoid this pitfall, the practitioner must take the time necessary to create the highest quality outcomes aligned with the individual's values and preferences while balancing other variables discussed earlier.

Maximizing seems to be a decision-making strategy often selected by beneficiaries — not so much because they want it, but because it is how the information is presented to them. Choices are made based on the highest maximum pay-off available to the individual. "You mean if I keep my hours below ten hours a week and don't earn more than $10 an hour I can keep my SSI, Medicaid and not compromise my housing subsidy?" While it is not always the practitioner's intention, often a comprehensive benefits and work incentives analysis report and advice provided may fall short of creating pathways out of poverty and instead focus on how an individual can maximize their entitlements. Practitioners can avoid this pitfall by not marginalizing employment outcomes and emphasizing safety nets that exist to alleviate reluctance and hesitancy individuals may have that keep them from engaging in full employment.

Minimizing is another strategy frequently used. In this scenario, the individual concentrates on the salvage value of the decision and attempts to minimize possible negative impact. This type of orientation may be good when the consequences of a failed decision are particularly harmful. However, in most cases, the practitioner should take the time necessary to make certain the individual understands the available safety nets for minimizing risk and/or harm.

Supporting Work Outcomes

Regardless of the strategy employed by the individual making a choice to work, the practitioner's role is critical. The practitioner can create an environment and provide information that will support a beneficiary's choice to work. The most exquisite and comprehensive advice report will be useless if that report ignores the beneficiary's reluctance and reservations, values, preferences and stated goals.

While a decision to work may not always be in every beneficiary's best interest, the practitioner should approach each individual with an eye toward work and consider which approaches would be most conducive to supporting a choice to work. The role of the practitioner in the decision making process is not just to provide information. Often, practitioners think that presenting the information is enough and fail to press the beneficiary for a decision. Without the beneficiary's final decision, a practitioner cannot begin to prescribe needed services and resources to support further movement toward work.

Another critical task for the practitioner is understanding why a beneficiary made a certain decision. If a beneficiary chooses not to opt for any of the scenarios created, it is important for the practitioner to process with the individual how they came to that choice. It is equally important when a person makes a positive choice to work to understand what led them to that decision. This will give the practitioner better insights into the decision making processes of individuals they are serving as well as showing what the practitioner can learn about the services provided that might produce more positive outcomes.

Below are some questions to ask beneficiaries to guide this type of learning:

- Was the information provided helpful in assisting you in making a decision?
- Did you feel you had all the information you needed to make an informed choice?
- If not, what additional information would be helpful?
- Is your decision final? If not, is there any additional supports I can provide you?
- What factors contributed to your decision?
- Is there something I can do to assist you in putting your choice into action?

Supporting the beneficiary in moving from "knowing" to "doing" is the critical action step. Even in cases where a beneficiary makes a decision to not work, there should be "next steps" involved. Perhaps, now wasn't the right time. Perhaps, there were extenuating circumstances that led to that particular decision that may change in the future. Regardless of the reason, a practitioner should come away from every consultation with a beneficiary having an idea of what they need to do next to support the beneficiary's movement toward work.

The Right Supports at the Right Time

There is no standardized time-sequenced plan to follow when supporting youth toward a career trajectory and improved employment and economic outcomes. While Continuing Disability Reviews (CDR), the Annual SSI Review, and the Age 18 Redetermination Review can be calculated and projected consistently, the rate at which an individual progresses toward greater economic independence and

employment varies considerably. Therefore, assessing where a beneficiary is in their decision making processes, as well as prescribing services and supports most critical to support decision making at the level they are at is critical. This typically includes five primary stages:

1. Pre-contemplation
2. Contemplation
3. Preparation
4. Action
5. Maintenance

The table below provides a description of each stage as well as a description of what the typical beneficiary perspective is at each stage, with corresponding action steps for case management practitioners that they consider. Keep in mind, some action steps at the later stages of decision making will require the expertise of a trained and credentialed benefits and work incentives practitioner which will be described in the next section.

Pre-contemplation (Engagement and Curiosity)	
Beneficiary Perspective	***Practitioner Support***
▪ Curious about work ▪ Seeking info about benefits ▪ No firm commitment to work, but curious about options ▪ Concern about losing benefits and long-term impact of work	▪ Acknowledge concerns ▪ Provide general and basic info on how benefits are impacted by earnings ▪ Create scenarios to show options – future potential ▪ I&R on various types of employment services
Contemplation (Intention and Exploration)	
Beneficiary Perspective	***Practitioner Support***
▪ Considering employment and work incentives as a possible course of action ▪ Seeking info about what is available ▪ May inquire to gain a deeper understanding of impact of earnings on benefits	▪ Staging of information based on need from general inquiry up to in-depth ▪ Benefits and Work Incentives referral ▪ Define preliminary action steps ▪ Illustrate earnings/benefit offset

Preparation (Planning and Decision-making)	
Beneficiary Perspective	***Practitioner Support***
▪ Making plans about work and increased earnings ▪ Taking action steps to get a job ▪ Continued concern about impact of earnings ▪ Seeking information about how to use work incentives	▪ Provide earnings reporting advice ▪ Develop strategies for using work incentives with timelines and action steps ▪ Identify the supports a beneficiary needs and at what times ▪ Explore management strategies
Action (Modification and Execution)	
Beneficiary Perspective	***Practitioner Support***
▪ Working, earning and reporting income ▪ Increasing social/cultural interactions from work ▪ Using and managing work incentives ▪ Questions regarding employer benefits and advancement opportunities	▪ Plan for and provide work incentive mgmt. and monitoring support as needed ▪ Proactively engage beneficiary at certain touchpoints ▪ Review and update action steps ▪ Explore asset accountability strategies
Maintenance (Continuation and Perseverance)	
Beneficiary Perspective	***Practitioner Support***
▪ Attaining employment goals, and possibly thinking about next steps ▪ Anticipating self-sufficiency outcomes ▪ Increased need for info on how to self-manage ▪ Exploration of assets, investment and other financial issues	▪ Provide benefits and work incentives management training ▪ Support development of external supports ▪ Continue to develop plan toward self-sufficiency and financial independence ▪ Provide info on safety nets

Accessing Qualified and Credentialed Benefits and Work Incentives Practitioners

For youth in the NYS PROMISE intervention, Benefits and Work Incentives Planning and Assistance services can be accessed through approved vendors within each of the three regions. The Resources section below provides contact information for each of these approved vendors by region.

In addition, SSA has sponsored a national network of Work Incentives Planning and Assistance (WIPA) to assist beneficiaries in gaining access to information and supports to prepare for and consider work. A national searchable online directory is available at: https://www.choosework.net/findhelp

A list of SSA WIPA services for NYS PROMISE regions is included in the Resources section of this module.

Integrating Benefits and Work Incentives Planning into Individualized Service Plans

As indicated throughout this Field Guide, youth are often involved with several support systems and agencies. Some agencies may be directly involved in programs of training or work placement, while others may be providing critically needed cash or health benefits. In any case, the practitioner must be fully aware of any other service plan that has work as a goal and be cognizant of any work incentives or income and resource rules of ALL of the programs the individual is involved with in order to effectively guide your beneficiary to work. Also consider that these other programs and service providers may have staff that are focused on getting the beneficiary to work and not paying attention to the impact on the beneficiary's total benefits package.

The individual systems youth interface with will dictate which individualized service planning processes the case management practitioner may want to consider. Case management practitioners employed through a local school may integrate their youth's goals, objectives and services within the natural context of their Individualized Education Program (IEP). However, it may also be appropriate to work across other state systems such as vocational rehabilitation (VR), mental health, intellectual/developmental disabilities, and workforce development to ensure that all are working toward common ends of employment and increased economic well-being. Each of these systems develop and maintain their own individualized service planning document which identifies the services and supports needed and how they will be provided and within what timeframe.

The purpose of integrating benefits and work incentives planning goals into individualized service plans is to support action — moving from just knowing about work incentives to actually using them.

The table below outlines the various degrees of fidelity to which these critical services and supports can be integrated into individualized planning documents.

Best Practices	Good Plan	Better Plan	BEST Plan
Individualize work incentive planning supports.	**X**	**X**	**X**
Include comprehensive benefits and work incentives planning and assistance.	**X**	**X**	**X**
Involve the beneficiary and third party influencers in the development of work incentive utilization steps/activities.		**X**	**X**
Include specific strategies to manage benefits and work incentives.		**X**	**X**
Identify specific action items with projected dates and person(s) responsible.		**X**	**X**
Include critical safety nets.		**X**	**X**
Narratively describe the beneficiary's current situation in relation to their desired and anticipated outcomes resulting from the plan.			**X**
Include detailed action strategies including what needs to be done, who will do it, timeframes, how success will be measured, and frequency.			**X**
Include proactive benefits planning touchpoints.			**X**

If no individualized service planning documents exist, the case management practitioner can develop their own action planning document using the template provided below:

Goal:			
Action Step/Activity	**Person Responsible**	**Start/End Date**	**How Will Success Be Measured**

Module 11: Resources

Additional information on the Age 18 Redetermination Review is available online at http:paths.nyspromise.org

WIPAs are authorized to serve all SSA beneficiaries with disabilities, including transition-to-work aged youth. A national searchable online directory is available at: https://www.choosework.net/findhelp

WIPAs for NYS PROMISE regions include:

Abilities Inc.	Albertson, NY
Research Foundation for Mental Hygiene	Brooklyn, NY
Goodwill of Greater NY and Northern NJ, Inc. (I)	Brooklyn, NY
Goodwill of Greater NY and Northern NJ, Inc. (II)	Brooklyn, NY
Neighborhood Legal Services	Buffalo, NY
Goodwill of Greater NY and Northern NJ, Inc. (III)	Long Island City, NY
Research Foundation for Mental Hygiene	New York, NY
Independent Living, Inc.	Newburgh, NY
City University of NY Research Foundation (CUNY)	NY
Resource Center for Independent Living	Utica, NY

For youth in the NYS PROMISE intervention, Benefits and Work Incentives Planning and Assistance services can be accessed through approved vendors within each of the three regions. The Resources section below provides contact information for each of these approved vendors by region.

Wildwood Programs Rensselaer ARC	518-640-3434 518-272-3800	1190 Troy-Schenectady Rd. Latham, NY 12110 79 102nd St. Troy, NY 12180
Heritage Centers WNY Independent Living Center Neighborhood Legal Services	716-856-4202 x287 716-836-0822 x 104 716-847-0650	101 Oak St., Buffalo, NY 14204 3108 Main St., Buffalo, NY 14214 237 Main St., Suite 400, Buffalo, NY 14203
Bronx Independent Living Services Goodwill Industries	718-515-2800 917-251-6056	4419 Third Ave., Suite 2C, Bronx, NY 10457 4-21 27th Ave., Astoria, NY 11102

Module 12: Justice-Involved Youth

Introduction

Many case management practitioners will find themselves called to assist youth and families during or after their involvement with the legal system. This module will provide an overview of the juvenile justice system, define frequently used terms, and illustrate the issues faced by students with special education needs within the justice system.

In the United States there are more than 134,000 youth residing in juvenile justice facilities, and the National Center on Education, Disability and Juvenile Justice (EDJJ) reports that more than 1 in 3 youth entering juvenile justice facilities is a recipient of special education services.[1] It is estimated that 40% of these youth meet the criteria for emotional or psychiatric disorders.[2] Research has shown that youth involved in the juvenile justice system have a number of common risk factors. These risk factors include individual level risks (mental health, substance abuse, disabilities, etc.); family level risks (family disruptions, inconsistent parenting, etc.); and community risks (e.g., high levels of unemployment, community violence, residential instability, etc.).[3]

During the 1990s, juvenile crime rates increased, followed by a series of school shootings and other violent acts. In response to the rising level of crime and violence, schools began devoting more attention and resources to ensuring school safety (metal detectors, surveillance cameras, school resource officers, etc.). The resulting changes in school policies and procedures led to what has become known as the *school-to-prison pipeline*, which is a path from the educational system to the juvenile justice system.[4] In order to demonstrate that they are taking a strong stance against crime and violence, many school implemented zero tolerance policies which led to a dramatic increase in the suspension and expulsion of students. In 2006, the APA created a task force to examine the effects of zero tolerance policies and found that despite the fact that they were created to enhance school safety, these policies have ultimately led to an increase in problem behaviors and school dropouts (McCarter, 2016). Research has shown that when students are removed from schools for disciplinary reasons, they become increasingly isolated from the school community, which increases their susceptibility to high-risk behavior and crime (McCarter, 2016).

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[1] Cavendish, W. C. (2014). Academic attainment during commitment and post release education-related outcomes of juvenile-justice-involved youth with and without disabilities. *Journal of Emotional and Behavioral Disorders*, 22(1), 41-52.
[2] Ochoa, T. (2016). Improving transition support for juvenile offenders with disabilities through a collaborative approach. *Intervention in School and Clinic*, 52(1), 14-50.
[3] Mallett, C. A. (2012). Youth with learning disabilities: Seen things juvenile courts should know. *Juvenile and Family Court Journal*, 63(3), 55-71.
[4] McCarter, S. (2016). The school-to-prison pipeline: A primer for social workers. *Social Work, 62*(1), 53-61.

Categories of Youth Offenders

When a youth is arrested, there are several categories in which the youth can be classified within the juvenile justice system.[1] This determines whether the case will be processed through the Family Court or the criminal court system.

Category	Description
PINS (Person in Need of Supervision)	• Youth under the age of 18 who does not attend school or who demonstrates behavior that is considered to be dangerous or out of control by a parent, guardian, police officer, school, or judge. • Examples of offenses include truancy, running, away, and underage alcohol consumption.
Juvenile Delinquent	• Youth over the age of 7 and under the age of 16 who commits an act that would be a crime if committed by an adult, but is not deemed criminally responsible due to age. • Will be held accountable for actions and undergo court process in Family Court.
Juvenile Offender	• Youth age 13-15 who commits a serious crime and is assumed to be criminally responsible due to the serious nature of act committed. • Processed through the Criminal Court.
Youthful Offender	• Youth who is convicted as a juvenile offender or is convicted of a crime committed between ages of 16-18 who is granted a "youthful offender finding" instead of a criminal conviction. • Leads to reduced sentencing and sealing of criminal records.

Family Court Process

1. **Arrest**: If alleged to be a juvenile delinquent, the police can use discretion over whether to release the youth to parent/guardian with a ticket to appear in Family Court or take him/her to the county's local Department of Probation for an intake.
2. **Intake**: An intake officer from the Department of Probation interviews the youth about the alleged crime, school attendance, and his/her living situation. The officer also interviews the arresting officer, the complainant/victim, and the parents/caregiver. A Risk Assessment is administered to determine appropriate next steps, which include admitting to a detention facility, enrolling in an Alternative-to-Detention (ADT) facility, or releasing with mandatory check-ins until the court appearance. The intake officer can decide to adjust the case and divert it from Family Court to a community-based program.
3. **Initial Court Appearance:** Prior to appearance in court, a lawyer will be assigned if the youth has not already retained one. At the court appearance, the youth submits either an admission or

[1] New York State Afterschool Network (2013), The state of youth justice in New York: An overview of the juvenile justice system across the state, 1-28.

denial of responsibility (this is the equivalent of a guilty or not guilty plea), and the judge decides whether to detain or release the youth while the case is pending.

4. **Fact-Finding Hearing:** The lawyers present evidence and the judge decides whether or not the youth committed the act with which he/she is charged.
5. **Dispositional Hearing:** The judge decides the youth's disposition (which is the equivalent of a sentence). Options include probation or supervision, ATP, placement in OCFS facility (ACS facility in NYC), or release with no conditions.

Criminal Court Process

1. **Intake:** The youth is brought in for intake after arrest. He/she may be admitted to a detention facility to await court date.
2. **Criminal Court Arraignment**: The youth enters a plea of guilty or not guilty. If he/she pleads not guilty, the case is transferred to the grand jury who decides if there is sufficient evidence to put the case on trial. If the jury finds sufficient evidence, they vote for an indictment, and the case is transferred to the Supreme Court.
3. **Supreme Court Arraignment and Trial:** The youth undergoes another arraignment at the Supreme Court, followed by a trial, which determines guilt.
4. **Sentencing Hearing:** The judge assigns the sentence. At this time, the court can decide to grant a "youthful offender" finding (carries a lighter sentence).

Programs for Youth Involved in the System

Program	Description
Detention	Program for housing youth in a custodial facility while the case is open. • Typically used with youth who are determined to be at high risk for failing to appear for their court date or for reoffending before the court appearance. • Low-risk youth are usually released back to the custody of guardian. • Mid-risk are often referred to ATD programs.
ATD (Alternative to Detention)	Program for youth at mid-risk of failing to appear in court or reoffending before the court date. • Focus on allowing the youth to remain in the community. • Address the underlying issues that contributed to crime (substance abuse, mental health, family issues, etc.).
Placement	Facilities that house youth after the court finds them to be responsible for crime. • Include secure, limited secure, and non-secure levels.
Probation	Allows youth to live at home with assigned probation officer who works with the youth to help him/her return successfully to the community and avoid re-arrest.
Aftercare	Programming that is provided after the youth is discharged from placement in order to help facilitate a smooth reentry to the community. • Overseen by OCFS or the local DSS department. • There are varying levels of aftercare depending on the levels of supervision required by the court.

Alternatives to Detention

There are a number of different alternatives to incarceration for youth. These include:

Adjournment in Contemplation of Dismissal (ACOD): Provides an opportunity for the charge to be dismissed from the youth's record with clearly improved behavior. This is generally offered to a youth that may have made a "mistake or bad choice" or for youth who have committed a first offense crime. If no further offenses within 6 months means youths record is expunged and sealed. Probation supervision is often assigned to help keep the youth on track.

Probation Supervision or Community Supervision: The judge decides the youth needs supervision of probation, but does NOT assign a specific Probation Officer. The youth is expected to follow all rules at home and attend school under the supervision of the Dept. of Probation, but without specific court ordered conditions. If the youth commits another status offense, he/she will be brought back to court and the judge will make a new determination that will likely increase the severity of supervision based on the new and previous offense

Person in Need of Supervision (PINS): A petition is filed by a parent/caregiver, school official, police officer, child protective, Family Court judge or other injured party, which results in a Court Order listing conditions that the youth must file for a period up to 12 months. This program was designed Specifically for youth under 18 years old that have committed a type of "status offense". Status Offenses are violations based on the offender's status as a *minor* such as running away, skipping school (truancy), using alcohol, behavior considered 'dangerous' by parent, school, or juvenile justice system. Parents may also be required to take parenting classes. If the youth does not adhere to the Orders and Conditions listed in the PINS petition they will be brought back to Family Court.

Probation: When a youth enters Juvenile Probation they will be assigned a Probation Officer. They will be required to report to the Probation Department for a period of 12 months (every week, every other week, or once a month). They may also be required to pass drug screenings based on the type of charge they incurred

The following link provides a comic book version of the Family Court process for youth: http://www.courtinnovation.org/sites/default/files/comic_book.pdf [1]

Special Education Rights of Juvenile-Involved Youth

According to the Individuals with Disabilities Education Act (IDEA), all students, including those involved in the juvenile justice system, are guaranteed the right to a free, appropriate, public education (FAPE). Therefore, it is crucial that during the intake procedure of the juvenile court process, youth with

[11] I got arrested! Now what? A Guide to the Juvenile Justice System. Making Policy Public, Center for Urban Pedagogy (CUP). http://www.courtinnovation.org/sites/default/files/comic_book.pdf

disabilities are identified. The juvenile justice system will need to obtain a copy of the most recent IEP from the school district.[1] It is also important that juvenile justice officials verify that the youth understands the charges brought against him/her and the juvenile justice process. When a youth is re-entering the community after release from a detention facility, the court system should help ensure that there is a seamless transition back to the youth's original school district.

Assisting Youth with Re-Entry into Community after Incarceration

The smooth transition back to school after being released from a detention center is a powerful protective factor against recidivism. However, research has shown that 70-85% of juvenile justice-involved youth do not receive a high school diploma or GED during or after release.[2] One study found that only 31% of youth were engaged in either school or work twelve months after release.[3] Many are required to return to some sort of educational program as a condition of their release, but due to lack of consistent monitoring and supervision, full engagement often does not occur. Barriers and delays to re-enrollment of school include:[4]Lack of educational and other records needed for enrollment, slow identification of a suitable school for the youth, refusal of chosen school to admit the student based on criminal history, and refusal of chosen school to allow enrollment mid-semester (due to difficulty issuing partial credits).

Following re-entry, many justice-involved youth show low levels of engagement in the community.[5] The primary barriers community engagement include: insufficient healthcare coverage, difficulty navigating multiple systems, and shortage of providers in the community. Case management practitioners can play a crucial role in connecting the youth to the following services at the time of re-entry:

- Mental health treatment
- Educational and vocational supports
- Substance abuse treatment
- Healthcare
- Housing and transportation
- Pregnancy and parenting supports

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[1] Mallett, C. A. (2012). Youth with learning disabilities: Seven things juvenile courts should know. Juvenile and *Family Court Journal, 63*(3), 55-71.
[2] Cavendish, W. (2014). Academic attainment during commitment and post-release education-related outcomes of juvenile justice-involved youth without disabilities. *Journal of Emotional and Behavioral Disorders, 22*(1), 41-52.
[3] Zajac, K. Sheidow, A. J., & Davis, M. (2015). Juvenile justice, mental health, and the transition to adulthood: A review of service system involvement and unmet needs in the U.S. *Children and Youth Services Review, 56*, 139-148.
[4] Hirschfield, P. J. (2014). Effective and promising practices in transitional planning and school reentry. The *Journal of Correctional Education, 65*(2), 84-96.
[5] Zajac, K., Sheidow, A. J., & Davis, M. (2015). Juvenile justice, mental health, and the transition to adulthood: A review of service system involvement and unmet needs in the U.S. *Children and Youth Services Review, 56*, 139-148.

The following actions have been found to help facilitate a more successful transition for incarcerated youth who are returning to the community:[1]

1. Conduct a prerelease meeting 60 days prior to release to review educational progress and discuss plans for return to the community.
2. Assess family and living environment to which the youth is returning.
3. Visit the community school with the youth.
4. Finalize the educational plan for the youth 2 weeks prior to transition.
5. Conduct a formal exit interview at least 10 days prior to release.
6. Finalize transition portfolio of achievements, growth, and accomplishments during incarceration.

Employment for Youth with Criminal Records

Employment and education are seen as crucial doorways to the adult world for transition-age youth who are attempting to turn their life around following juvenile justice involvement. However, there are a number of barriers facing these youth.[2] A study conducted in 2006 by the Massachusetts Office of Public Safety found that many employers view ex-offenders as a "risky" population. Their concerns were primarily based on the belief that their company's reputation could be negatively impacted by the employment of individuals with criminal records. The same study revealed that employers were much more willing to hire offenders if they had completed a transitional employment program or received work readiness training.

The U.S. Equal Employment Opportunity Commission (EEOC) provides the following guidelines to employers in regards to hiring individuals with criminal records:

- Employers should provide applicants the opportunity to discuss their convictions and discuss the rehabilitation process.
- Criminal background checks should only be used consistent with business necessity and job-related factors.
- Employers can't bar ex-offenders from employment unless the conviction is closely related to the job, after the employer carefully considers the nature of the job, the seriousness of the offense, and the length of time that has passed since the offense occurred.

For those involved in assisting the youth with criminal records obtain a job, it is important to have as much information as possible about the nature of the conviction and any stipulations placed on the youth by the courts. The case manager should also establish a working relationship with any correctional counselors, probation or parole officers working with the youth in order to obtain records and establish

[1] Ochoa, T. (2016). Improving transition support for juvenile offenders with disabilities through a collaborative approach. *Intervention in School and Clinic, 52*(1), 14-50.
[2] Swensen, J. G. Rakis, J., Snyder, M. G., & Loss, R. E. (2014). Engaging employers and businesses in the hiring of individuals with criminal records. *Journal of Applied Rehabilitation Counseling, 45*(4), 14-24.

a working relationship with any correctional counselors, probation, or parole officers assigned to the youth.

Military Enlistment for Youth with Criminal Records

All branches of the military require applicants to meet rigorous moral character standards that are designed to minimize the enlistment of individuals who are likely to become disciplinary problems or security risks, or who may potentially disrupt order and discipline. Some types of crimes, particularly those that are considered more violent, will immediately disqualify an applicant. Other crimes will require the applicant to apply for a waiver.

Approval for waivers is made on a case-by-case basis, and the applicant will be required to provide detailed information about the "who, what, when, where, and why" of the offense. One of the considerations in determining whether a waiver is granted is often the ability of the individual to demonstrate a successful readjustment to civilian life for a period of time after release from judicial control. Letters of recommendation will also be required from community leaders such as school officials, ministers, law enforcement officials, etc.

For more information about this topic, visit www.military.com.

Module 12: Resources

Pacer Center (2013). *Students with Disabilities and the Juvenile Justice System: What Parents Need to Know,* 16 pages. http://www.pacer.org/jj/pdf/JJ-8.pdf

Pacer Center (2013). *Communication with the Corrections Center: What Parents Should Know.* http://www.pacer.org/parent/php/php-c150.p

I Got Arrested! NOW WHAT? A graphic novel guide to the Juvenile Justice System http://www.courtinnovation.org/sites/default/files/comic_book.pdf

Module 13: Community Participation

This module provides a definition of community inclusion and discusses its importance to people with disabilities. Case management practitioners are provided a set of guiding principles to center their practice on inclusion, with questions to help determine if they are fully supporting youth and families in achieving maximal opportunities for participation.

What is Community Inclusion?

Despite great advances in physical access and technology that have made schools, workplaces, and neighborhoods more accessible, there continue to be barriers to equal opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities.[1] This is true despite the fact that public policy currently emphasizes reducing the number of people experiencing exclusion from the spaces that represent the social and economic majority: typical community settings.

Community inclusion is the opportunity to live in and be part of the community and be valued for one's uniqueness, abilities and positive contribution to society. There can be no community participation without community inclusion. Inclusion is evident when a person with a disability is recognized as being "one of us" as opposed to one of "those people." Relationships within an inclusive community are reciprocal and dynamic; it is recognized that all humans (not just those with disabilities) need care and community, and all individuals both contribute to and have needs met by the community.[2]

Community inclusion encompasses the following:

- Housing
- Employment
- Education
- Health Status
- Leisure/Recreation
- Spirituality/Religion
- Citizenship and Civic Engagement
- Valued Social Roles (e.g., marriage, parenting)
- Peer Support
- Self-Determination

[1] Imparato, A., & Nygren, M. (2015). Community living and participation for people with intellectual disabilities: What the research tells us. (2015). I https://aaidd.org/docs/default-source/policy/community-living-and-participation-for-people-with-intellectual-and-developmental-disabilities-nbsp-what-the-research-tells-us.pdf?sfvrsn=0

[2] McCrary, L. K. (2017). Geel's family care tradition: Care, communities, and the social inclusion of persons with disabilities. *Journal of Literary & Cultural Disability Studies, 11*(3)10.3828/jlcds.2017.23

The following characteristics are also components of the definition of community inclusion:[1]

Presence	Participating in all settings where people without disabilities are present (boardrooms, businesses, community events, classrooms).
Choice	Having multiple experiences to draw from, selecting and engaging in activities as desired, choosing who will participate with you.
Competence	Being recognized for strengths, contributing, having opportunities to learn more.
Respect and Valued Roles	Being valued by others, being seen as a person, not being seen as a "curiosity".
Participating	Engaging with others, having a wide variety of relationships, being part of an event, not just an observer.
Belonging	A feeling individuals experience when valued by others, when others call "just to talk" or to "hang out."

Social inclusion is facilitated in a community when community members:[2]

- Grow in their relationships via community participation.
- Are able to exercise choice and control within the community.
- Experience dignity in occupying valued social roles.
- Share ordinary places through community presence.
- Contribute to community through the discovery and/or expression of gifts and/or capacities.

Community building rattles the foundation upon which the concepts for traditional service provision have been built, particularly with regard to where people with disabilities spend their day (segregated or specialized settings and programs) and who is most qualified to provide support (paid service staff).

Instead, community building presumes the creation of partnerships within and outside of the service system and fosters the development of collaborative relationships beyond the typical framework of roles and scope of work embedded in traditional service structures by reaching out to others who may be better suited to moving a person nearer to his or her targeted objective. Community building requires intentional thought and action.[3]

[1] Illinois Department of Human Services. (2011). Community inclusion: http://tucollaborative.org/wp-content/uploads/2017/04/Peer-CI-Tool-Kit.pdf

[2] Van Asselt, D., Buchanan, A., & Peterson, S. (2015). Enablers and barriers of social inclusion for young adults with intellectual disability: A multidimensional view. *Journal of Intellectual and Developmental Disability, 40*(1), 37-48. 10.3109/13668250.2014.994170

[3] Excerpted from the Person-Centered Planning Education Site, Course: Community Membership: Opportunities for Meaningful Interaction. http://www.personcenteredplanning.org/course02.cfm

Why is Community Participation Important?

Community participation is considered to be a basic human right and a fundamental principle of democracy, and as such, should be a primary focus in transition planning with youth with disabilities who may otherwise fall between the cracks once the school years are over. It is the right to have full and equal access to opportunities and experiences through which to explore, discover, and contribute to the larger community. Research has also shown that relationships and interactions within communities play a crucial role in helping individuals to develop a sense of identity, and have a significant impact on one's productivity and performance.[1] Community participation is the involvement of people in projects, gatherings and other ways through which people join together for a shared purpose.

The goal is increase community access, participation and contribution in order to increase, advance or maintain community inclusion. Inclusion efforts focus on both a) skill development to teach new and maximize existing skills necessary for participation and b) provide necessary and desired assistance and support to ensure that students have equal access to opportunities for community participation and contribution in ways that are meaningful to the student and to the community. Community participation is the outcome of enacting the principles that guide community inclusion.

Guiding Principles for Community Inclusion

The following ten guiding principles for community inclusion play a direct role in shaping the quality and integrity of the programs, services and supports that are designed and implemented with people with disabilities.[2] They lay the foundation for engaging students in opportunities that result in active, full and meaningful community participation.

Guiding Principle	**Questions for Case Management Practitioners**
1. Community options and activities are driven and guided by the student and his/her family	Has a direction been established and goals set for earning, learning and living beyond high school?
2. Services and supports promote self-determination and self-advocacy	Are opportunities to learn and practice decision-making and self-advocacy consistently part of the student's experience?
3. Inclusion goals and objectives are individualized	Has a student-centered/family-centered plan been developed?
4. Supports are provided that facilitate full and equal access, based on the student's needs and preferences	Does the student/family receive the appropriate level of assistance and support required and desired to fully and actively participate in and contribute to all aspects of community life?

[1] Denham-Vaughan, S., & Chidiac, M. (2013). SOS: A relational orientation towards social inclusion. *Mental Health and Social Inclusion, 17*(2), 100-107. 10.1108/20428301311330162

[2] Eastern Region Autism Service, Education, Research, and Training (ASERT) Center. (2010). Community Inclusion Manual *Checklist for Community Inclusion.*

5. Opportunities are created and pursued based on the student's strengths and interests	Has a comprehensive strengths-based assessment been completed and serves as the basis for educational program and transition planning?
6. Services, supports, and experiences are age-appropriate and promote the dignity and respect of the student.	Are services, supports and experiences comparable to the experiences of students without disabilities?
7. Full inclusion in typical community settings and life experiences is promoted	Does the student have the opportunity to learn about the community through situational assessments, practical experience and social connection?
8. Interdependence is fostered	Are natural supports sought and utilized?
9. Services and supports are culturally responsive	Are planning processes, service and program design and delivery culturally responsive to the student and family needs and desires?
10. Experiences provide and promote opportunities for growth	Do the activities and opportunities afforded the student and the family build on existing competence?

Checklist for Community Participation

As indicated by the guiding principles for inclusion, the identification and selection of community-based activities and settings must be based on an individual assessment of the interests, preferences, and needs of the individual. Community inclusion/participation supports and services are typically provided 1:1 in community settings, build on and enhance the student's positive reputation, and promote and foster opportunities to build solid and mutually beneficial connections and socially meaningful contributions.

There are many avenues through which community inclusion and participation can be supported by the transition planning process. Consider the following areas as examples for assisting students in thinking about and planning toward a future as a contributing member of society.

- Postsecondary education or adult/continuing education
- Volunteer activities
- Leisure and recreation activities
- Socialization activities including relationship development and maintaining
- relationships with friends and family
- Cultural and spiritual activities
- Exercising civic rights and responsibilities
- Use of typical community services available to all people

Here is a quick checklist that can help to identify the element for community participation that are already in place in the student's life, and those that may need attention.

Core Element for Community Participation	**Is this element in place and fully functional?** **Y/N**	**How is the information being used?** **What needs to be put into place?**
The student is well-informed and familiar with his or her community and has a self-directed plan for engaging and connecting to it		
The student clearly knows what his or her talents, strengths and interests are		
The student has identified employment goal(s)		
The student has identified educational goal(s)		
The student has a social network in the community		
The student has a reliable support network outside of school		
The student has the assistive technology that is needed to fully participate and contribute in community		
The student has the appropriate and necessary service supports in place		
The student has resources for and knows how to get around the community		
The student knows when and how to be a self-advocate		

Final words

Community inclusion and participation is not a program or a placement. It is the result of the provision of the right supports and services in combination with the right people in the right place. It is evidenced when people with disabilities are known, appreciated and for who they are and what they have to contribute to society…when "they" become clearly part of "we."

Module 13: Resources

Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disability put together the following toolkit to help individuals with psychiatric disabilities become more meaningfully engaged in their community. It includes worksheets for creating community resource maps: http://tucollaborative.org/wp-content/uploads/2017/04/Peer-CI-Tool-Kit.pdf

A workbook prepared by National Disability Services (NDS) that encourages professionals to think about the way they support community participation in individuals with disabilities: https://www.nds.org.au/images/resources/resource-files/CII_Community_Participation_in_Action_Guide_2016.pdf

Social participation workbook:
Escovitz, K., & Solomon, P. (2005). *Social Participation Workbook*: UPenn Collaborative on Community Integration. http://tucollaborative.org/wp content/uploads/2017/04/Social-Enhancement-Workbook.pdf

Module 14: Emerging Adulthood

Introduction

This module presents the concept of “emerging adulthood” and discusses issues that may arise for case management practitioners, such as guardianship, alternatives to guardianship, and supported decision making.

Emerging adulthood is a term that developmental psychologists have assigned to the period between age 18 and 29, in which individuals are pulling away from their families and exploring their identity in the areas of intimate relationships, independent living, and employment. The theory of emerging adulthood is based on five principles: 1) self-exploration and identity development; 2) uncertainty; 3) self-focus; 4) optimism and 5) transition.[1] During emerging adulthood fluctuation and change are considered normal and developmentally appropriate. Young adults often describe this as an "in-between" period in their life in which they experience a combination of uncertainty and optimism. Motivational interviewing is identified as an effective approach to help emerging adults explore the discrepancies between where they are and where they want to be in the future.

Individuals with disabilities often find emerging adulthood a more challenging developmental stage than their peers without disabilities. Many report a desire to be viewed by others as a person with abilities rather than disabilities.[2] They often feel underestimated and misjudged by others. Integrating their disabilities into a positive self-concept is viewed as an important process for emerging adults with disabilities. Individuals with disabilities may also have had limited opportunities to practice independence in previous developmental stages.

Postsecondary decisions

Emerging adults have a variety of options after finishing high school. The options include joining the military, entering the workforce, developing skills through an internship, apprenticeship, trade school or other job training program, or enrolling in a community college or 4-year university.

College[3]

Many factors motivate individuals to attend to college. The most common reasons that people report attending college are: 1) Freedom and flexibility for career; 2) Financial security for the future; 3) Adventure and challenge; 4) Meeting new people and making connections.

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[1] Meyer, J. M., Hinton, V. M., & Derzis, N. (2015). Emerging adults with disabilities: Theory, trends and implications. *Journal of Applied Rehabilitation Counseling,* 46(4), 3-10.
[2] Mannino, J. E. (2015). Resilience and transition to adulthood among emerging adults with disabilities. *Journal of Pediatric Nursing,* 30, 131-145.
[3] New York City Department of Education. (2011). *College planning handbook.*

HIPPA

The Health Insurance Portability and Accountability Act (HIPAA) protects the privacy and security of health information and provides individuals with certain rights to their health information. The HIPAA Privacy Rule, found in Title II of the Act, requires written authorization from a patient, or the patient's parent or legal guardian, before releasing health information to any outside party. HIPAA applies to healthcare providers, health insurance companies, and many other organizations.

Generally, a parent is the personal representative of a minor, unless that minor is emancipated, has petitioned the court for medical treatment without parental consent, or the parent has previously agreed to confidentiality between the healthcare provider and the minor patient. However, once a youth turns 18, the parent is no longer automatically considered a personal representative. For a parent to have access to medical records to assist with healthcare decision-making, the youth must sign a healthcare power of attorney.

Transfer of Rights and Age of Majority

As part of the transition process, service providers, school staff and parents should inform youth that in New York state, the transfer of rights automatically moves from parents and guardians to the youth when the youth turns 18. Parents who want to contest this automatic transfer of rights need to petition the court for guardianship, and this process takes 4-6 months to complete. Guardianship is a legal process, governed by individual state law, by which the court appoints someone (a guardian) the power to make decisions over another (a ward or respondent). In New York State, Article 17-A of the Surrogate's Procedure Act is the most commonly used method of determining guardianship for individuals with developmental disabilities .[1] The process requires either two physicians or a physician and a psychologist, the Office of Child and Family Service (OCFS), and a Surrogate Court Judge to appoint a guardian.

In recent years, there has been a growing recognition that guardianship lies in opposition to self-determination, and can hinder inclusion. Research shows that most parents pursue guardianship out of a desire to protect their child, and many are not aware that other alternatives for decision-making exist.[2] However, once a parent or other individual is appointed legal guardian, the young adult with the disability is labeled as "incompetent" or "incapacitated" and usually stripped of all rights in the eyes of the law, including the rights to vote, marry, consent to medical treatment, etc. Studies also reveal that when youth are not provided with opportunities to engage in supported decision-making they may resort to a state of learned helplessness.

[1] Healthy Transitions NY (2010). *Deciding about guardianship: Moving from pediatric to adult health care.* http://healthytransitionsny.org/wp-content/uploads/2016/08/DecidingAboutGuardianship081816.pdf
[2] MacLeod, K. (2017). "I should have big dreams": A qualitative case study on alternatives to guardianship. *Education and Training in Autism and Developmental Disabilities, 52*(2), 194-207.

Alternatives to Guardianship

In the past, many parents and caregivers applied for guardianship for their adult children with disabilities. In fact, many schools presented guardianship information to parents as a part of the transition process. However, in recent years, parents and professionals of individuals with disabilities have brought attention to the conflict that exists between the appointment of guardianship and self-determination. Self-determination is the ability of an individual to make choices and exert control over his/her own life and future Rather than transferring guardianship to another individual, proponents of self-determination encourage service providers, staff, family, and other adults involved in the life of an individual with a disability to look at alternatives to guardianship.

Alternatives to guardianship can be grouped by types of service:

1. Financial
2. Educational
3. Vocational
4. Daily living matters

Examples of Alternative to Guardianship can include the following:

1. **Family and friends**: Can be consulted for advice when decisions are made. This alternative allows individual to talk about potential options, consequences, advantages, and risks of decisions with an adult he/she trusts.
2. **Trust Funds**: Legal devices that will not jeopardize the eligibility of government benefits. As interest is accrued, the trustee can purchase services and items not covered by government benefits.
3. **Specialized Bank Accounts**: Specialized checking and savings accounts that meet the individuals need with specific safeguards such as co-signers, ceiling limits, and pour-over accounts.
4. **Power of Attorney (POA)**: Document by which any competent individual can authorize another individual to make decisions on their behalf. The POA is only allowed the powers that are specified by the individual. Document can be privately written without legal involvement.
5. **Representative Payee:** Person appointed by the agency administering funds (such as the Social Security Administration) to receive and manage the federal benefits of another. The rep payee must retain all records of expenditures made on behalf of the individual with the disability.
6. **In-home Care Services**: Can assist with medication and other medical issues as well as activities of daily living such as grooming, shopping, meals, transportation, etc. May include nurses, therapists, dieticians, etc.
7. **Living Will/Healthcare Directive:** Documents that specify the type of medical treatment an individual wishes (or does not wish) to receive when the person is unable to communicate that information.

Transition to the Adult Healthcare System

Each year, approximately 500,000 youth with special healthcare needs transition from pediatric healthcare providers to adult healthcare providers,[1] and this transition can feel overwhelming for both young adults and families. In order to understand the complexity of this transition, one must view it through the context of multiple layers of transitions that are simultaneously occurring within the life of the young adult. At the same time that the young adult is expected to transition from the pediatric to adult world of healthcare, he/she is also undergoing some normative developmental transitions associated with emerging adulthood, such as transitioning from high school to secondary education or the world of work, managing romantic relationships, moving away from home, and assuming financial independence.[2] Other demands in the young adult's life may take precedence over the healthcare transition, leading to lapses in care and possible disease progression or exacerbation.[3] In addition to navigating the complexities of multiple simultaneous developmental transitions, many youth and adults with intellectual and developmental disabilities (IDD) have health care needs that are unique in comparison to peers without IDD. They are more likely to experience co-morbid conditions such as chronic constipation, osteoporosis, hearing impairment, epilepsy, thyroid dysfunction, reflux, and psychiatric concerns.[4]

Medication management is a significant issue for many young adults transferring to the adult world of healthcare. Young adults with IDD are more likely to be prescribed multiple medications, including psychotropic medications, yet research shows that medication management is strikingly overlooked in the transfer of healthcare for young adults with IDD. A recent study found that many young adults do not have a psychiatrist overseeing the administration of their psychotropic medications, and only 24% of young adults with IDD who are on medications have ever received a psychiatric consult. Young adults also display an overestimation of their own ability to manage their medications, as evidenced by the fact that the majority of adolescents feel confident that they have adequate knowledge of their medications, yet 35-55% report non-adherence to their medication plan.[5] The reasons cited for non-adherence included forgetfulness, not having medications on hand, and concerns about side effects.

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[1] Cheak-Zamora, N., Farmer, J., Mayfield, W., Clark, M., Marvin, A., Law, J., & Law, P. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation Psychology, 59*(3), 340-348. 10.1037/a0036725

[2] Wagner, D. V., Ulrich, J., Guttmann-Bauman, I., & Duke, D. C. (2015). The process of transition from pediatric to adult diabetes care: Recommendations for US healthcare systems. *Diabetes Management, 5*(5), 379-391. 10.2217/dmt.15.31

[3] Hunt, S., & Davis, T. (2017). Preparing for transition of youth with special health care needs. *Current Problems in Pediatric and Adolescent Health Care, 47*(8), 200-207. 10.1016/j.cppeds.2017.07.004

[4] Dressler, P. B., Nguyen, T. K., Moody, E. J., Friedman, S. L., & Pickler, L. (2018). Use of transition resources by primary care providers for youth with intellectual and developmental disabilities. *56*(1), 56-78. 10.1352/1934-9556-56.1.56

[5] Andrade, D. M., Bassett, A. S., Bercovici, E., Borlot, F., Bui, E., Camfield, P., . . . Carter Snead, O. (2017). Epilepsy: Transition from pediatric to adult care. recommendations of the Ontario epilepsy implementation task force. *Epilepsia, 58*(9), 1502-1517. 10.1111/epi.13832

Along with general risks associated with chronic health conditions, there are some disease-specific risks that transitioning young adults face. For example, individuals with epilepsy occurring in childhood have a 50% risk of having seizures that continue into adulthood.[1] They also run a high risk of social isolation, unplanned pregnancy, and behavioral and psychiatric problems. Young adults with autism spectrum disorder (ASD) experience poorer overall physical health and higher prevalence of gastrointestinal disorders, sleep problems, diabetes, obesity, seizures, immune system challenges, respiratory problems, skin conditions, and food allergies.[2] They are also at higher risk for experiencing co-occurring mental health conditions such as anxiety, depression, ADHD, psychosis and Obsessive Compulsive Disorder (OCD).

While there has been a wealth of research conducted in recent years on the transition of young adults to the adult health care system, recent studies show that only 41% of young adults with special healthcare needs receive transition planning services. Barriers to the delivery of healthcare transition services include:[3]

- The amount of time required for adult providers to manage complex patients in clinic settings.
- Lack of reimbursement for time spent with patients with complex needs.
- Poor knowledge and lack of training about IDD among adult providers.
- Poorly coordinated transfer of care.
- Family and patient hesitancy to leave the pediatric setting.

Even when provided with appropriate consultation and resources regarding working with individuals with IDD, providers report concerns about their limited experience in working with the population and their lack of confidence in maintaining the knowledge base necessary for providing on-going treatment. It is often very difficult for young adults to find adult providers who accept their insurance and are experienced in working with their specific medical condition, especially when there is a co-occurring IDD diagnosis.

[1] Andrade, D. M., Bassett, A. S., Bercovici, E., Borlot, F., Bui, E., Camfield, P., . . . Carter Snead, O. (2017). Epilepsy: Transition from pediatric to adult care. recommendations of the Ontario epilepsy implementation task force. *Epilepsia, 58*(9), 1502-1517. 10.1111/epi.13832

[2] Hall, T., Kriz, D., Duvall, S., Nguyen-Driver, M., & Duffield, T. (2015). Healthcare transition challenges faced by young adults with autism spectrum disorder. *Clinical Pharmacology & Therapeutics, 98*(6), 573-575. 10.1002/cpt.254

[3] Dressler, P. B., Nguyen, T. K., Moody, E. J., Friedman, S. L., & Pickler, L. (2018). Use of transition resources by primary care providers for youth with intellectual and developmental disabilities. *56*(1), 56-78. 10.1352/1934-9556-56.1.56

Best Practices in Healthcare Transition Planning with Young Adults with Disabilities

The increased focus in recent years on researching the healthcare transition has led to a variety of best practice recommendations for coordinating care and limiting gaps in healthcare treatment. One of the most widely recommended strategies is to recognize that transition is a process rather than an event, and to begin planning as early as possible. Transition planning should address a variety of topics, and adolescents and young adults should be provided with information to help inform their decision-making related to their specific health conditions. Topics discussed should include precautions related to driving, sex, alcohol consumption, prescription and illicit drugs, safety at parties, and disclosure of diagnosis to peers and others.[1]

The Society for Adolescent Medicine recommends the following best practices for health care transition planning for adults with chronic medical conditions:[2]

- The transition should be appropriate to both the chronological and developmental age of the individual.
- The health care facility should address common concerns of adolescents (sexuality, mood, mental health concerns, substance use, and other promoting and damaging behaviors.
- The transition should enhance autonomy and personal responsibility and facilitate self-reliance.
- The transfer of care should be individualized.
- The transition process should include a designated professional, such as a coordinator or advocate, to take responsibility for the process and in collaborating with the young adult, family and medical professionals.

Research supports the benefit of **allocating a "named worker"** (or coordinator) to oversee the health care transition. This individual should be a professional, and can include a nurse, social worker, youth worker, or other health, social care or educational consultant.[3] This coordinator can serve as a link between the young adult and various professionals involved in providing care to the individual with special healthcare needs. This person can also provide support and advocacy to the young adult.

A **transition summary** is also recommended as a crucial tool in supporting young adults as they transfer from pediatric to adult care. A transition summary is a comprehensive document that includes medical, social, and care coordinating information, and it is intended to decrease the demands on the newly

[1] Wagner, D. V., Ulrich, J., Guttmann-Bauman, I., & Duke, D. C. (2015). The process of transition from pediatric to adult diabetes care: Recommendations for US healthcare systems. *Diabetes Management, 5*(5), 379-391. 10.2217/dmt.15.31

[2] Wagner, D. V., Ulrich, J., Guttmann-Bauman, I., & Duke, D. C. (2015). The process of transition from pediatric to adult diabetes care: Recommendations for US healthcare systems. *Diabetes Management, 5*(5), 379-391. 10.2217/dmt.15.31

[3] Singh, S. P., Anderson, B., Liabo, K., Ganeshamoorthy, T., & guideline committee. (2016). Supporting young people in their transition to adults' services: Summary of NICE guidance. *BMJ, 353*, i2225. 10.1136/bmj.i2225

assigned adult practitioner by summarizing information related to the young adults history of health related information.[1] The transition summary consolidates information into a printable document that can serve as a "medical transport", and can travel with the young adult throughout the transition process. While a variety of different transition summary tools have been developed, the format of a health summary typically includes:

Medical Summary	• Past medical history and problems • List of medications and history of reactions to medications • Procedures and hospitalizations • Allergies
Provider Information	• Pediatric provider(s) contact information • New adult provider(s) contact information
Functional Abilities	• ADL's • Dietary needs • Communication • Decision-making
Care Coordination	• Medical equipment needs • Pharmacy/home care companies
Social Work/Mental Health Needs	• Insurance information • Guardianship • Social support • Counseling/mental health supports
Adult Needs	• Condition-specific screening • Anticipated secondary complications of prior treatment

[1] Hunt, S., & Davis, T. (2017). Preparing for transition of youth with special health care needs. *Current Problems in Pediatric and Adolescent Health Care, 47*(8), 200-207. 10.1016/j.cppeds.2017.07.004

Module 14: Resources

This guide provides a nice overview of the rights and responsibilities of young adults in NYS, a New York State Bar Association publication, "Now That You've Turned 18": https://www.nysba.org/Sections/Young_Lawyers/Young_Lawyers_PDFs/Now_That_You_ve_Turned_18.html.

Guardianship Alternatives

Brochure about guardianship and alternatives from Health Transitions NY: http://healthytransitionsny.org/wp-content/uploads/2016/08/DecidingAboutGuardianship081816.pdf

Supported Decision-Making Resources:

The American Civil Liberties Union (ACLU) has developed a Supported Decision-Making website that includes a variety of free downloadable tools and resources, including video clips, that are very useful to understanding and implementing the SDM model. Here are just a few:

The FAQ (Frequently Asked Questions) resource provides clear, concise information ranging from "what is supported decision-making?" to "how is SDM different from person-centered planning?" to "how is SDM different from guardianship?" It is available at: https://www.aclu.org/other/faqs-about-supported-decision-making

The Brainstorming Guide to Supported Decision-Making is a great resource for assessing the degree to which the person with a disability is already making decisions that are self-determined across critical life domains, and where there may be gaps. Find this tool at: https://www.aclu.org/other/brainstorming-guide-supported-decision-making

The Guide to Programs to Implement Supported Decision-Making provides a quick reference to core federal and state programs that can be used to help people implement supported decision-making. Find this guide at: https://www.aclu.org/other/guide-programs-implement-supported-decision-making

National Resource Center for Supported Decision-Making (NRC-SDM)

The National Resource Center for Supported Decision-Making (NRC-SDM) builds on and extends the work of Quality Trust's Jenny Hatch Justice Project by bringing together vast and varied partners to ensure that input is obtained from all relevant stakeholder groups including older adults, people with intellectual and developmental disabilities (I/DD), family members, advocates, professionals and providers. http://supporteddecisionmaking.org/state-review/new-york

NYS Developmental Disabilities Planning Council (NYS DDPC)

The NYS DDPC has awarded to the Council on Quality Leadership and Hunter College to advance Supported Decision-Making across New York State for the period between 4/2016-3/2021. For information on this project go to: http://ddpc.ny.gov/supported-decision-making-0-

Healthcare Transition Readiness Assessment for Young Adults[1][2]

- ☐ I call for my own doctor's appointments.
- ☐ I organize my medical records and keep them in a safe place.
- ☐ I know or can find my doctor(s) phone number.
- ☐ I know how to get referrals to see other providers/specialists.
- ☐ Before I make an appointment, I think of questions I want to ask the doctor.
- ☐ I know where to get x-rays or bloodwork done if I need to.
- ☐ I carry important medical information (insurance card, medical alert bracelet, emergency contacts)
- ☐ I understand how privacy changes at age 18.
- ☐ I know my medical needs.
- ☐ I can describe my medical needs to others.
- ☐ I know what behaviors, situations, and other factors can impact my medical condition and make symptoms worse.
- ☐ I know my medication names and dosages.
- ☐ I know symptoms of my condition that require me to call the doctor right away.
- ☐ I know symptoms of my condition that require me to call 911 or go to the emergency room right away.
- ☐ I know where to get medical care when my doctor's office is closed.
- ☐ I know that I need to show up 10-15 minutes early to check in for medical appointments.
- ☐ I know how to find my pharmacy number and get refills on my medications.
- ☐ I have a system in place to remember to take my medications on time.
- ☐ I know how to fill out medical forms.
- ☐ I have a way to get transportation to my doctor's appointments.
- ☐ I understand my health insurance and eligibility requirements.
- ☐ I know my deductible and co-pay information.
- ☐ I understand how my medical condition will impact my future career and employment.
- ☐ I know how to access necessary accommodations at school/work.

[1] Andrade, D. M., Bassett, A. S., Bercovici, E., Borlot, F., Bui, E., Camfield, P., . . . Carter Snead, O. (2017). Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia, 58*(9), 1502-1517. 10.1111/epi.13832

[2] McManus, M., White, P., Pirtle, R., Hancock, C., Ablan, M., & Corona-Parra, R. (2015). Incorporating the six core elements of health care transition into a Medicaid managed care plan: Lessons learned from a pilot project. *Journal of Pediatric Nursing-Nursing Care of Children & Families, 30*(5), 700-713. 10.1016/j.pedn.2015.05.029

Healthcare Transition Resources:

Overview of the Family Health Care Decisions Act that was passed in NY in 2010 https://www.nysenate.gov/newsroom/press-releases/senate-passes-family-health-care-decisions-act allowing next of kin to make decisions in life-threatening medical situations when an individual is incapacitated, even if a health care proxy is not in place.

Healthcare transition guide for youth and families by the Autistic Self-Advocacy Network (ASAN): http://supporteddecisionmaking.org/sites/default/files/asan_healthcare_toolkit_0.pdf

Florida University published some workbooks for students preparing for the transition to adult healthcare: https://hscj.ufl.edu/jaxhats/docs/HCT_Workbook_18up.pdf

The Adolescent Health Transition Project created a checklist for students and parents to assess skills related to the health care transition. This can be utilized to identify skills that have already been mastered and to target skills that still need to be developed http://depts.washington.edu/healthtr/documents/healthcareskills.pdf

The Florida Center for Inclusive Communities has put together some basic healthcare forms that can be used to communicate the needs of individuals to healthcare providers.

This is a basic health care update form that can be shared with a new healthcare provider or used to update a current doctor with current information about your health. This is a great resource for students who might find it difficult to recall information during the limited time that they have with the healthcare provider: http://flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf

This form can be utilized to communicate the unique needs and preferences of the individual to staff during hospital and clinic visits. This is particularly helpful when staff may be inexperienced in working with individuals with intellectual/developmental disabilities: http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

The Center for Children with Special Needs created a 25 page downloadable health care notebook that can be individualized and placed in a binder to help keep track of crucial medical information: https://cshcn.org/pdf/teen-care-notebook-all-documents.pdf

Video (5 min, 19 seconds) featuring Katie, a 23-year-old with CP, epilepsy and other health conditions, and her transition from pediatric to adult medical care. Features interviews with Katie's mother and medical care providers. Discusses the complexities of the healthcare transition for individuals with neurological disorders : http://www.childneurologyfoundation.org/transitions/

Video featuring a social worker and nurse working with individuals with neurological conditions discussing common concerns of adolescents with complex medical conditions during the transition process. Also provides tips for parents on talking with their kids about the health care transition. http://www.childneurologyfoundation.org/transitions/

Tool from the Child Neurology Foundation to help parents of children with neurological conditions assess child's transition needs: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/C_SelfCareAssessmentParents.pdf

Youth self-assessment tool: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/D_SelfCareAssessmentYouth.pdf

Medical Summary form from the Child Neurology Foundation for youth with neurological conditions transitioning to adult health care providers: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/E3_MedicalSummary.pdf

Video for parents/professionals on preparing youth for the healthcare transition. Provides suggestions about strategies for involving adolescents in their health care to prepare for the transition: https://www.youtube.com/watch?v=cjXurYrFMZM

The New York State Institute for Health Transition Training for Youth with Developmental Disabilities website includes in-depth curriculum modules for teaching youth about various aspects of the healthcare transition as well as videos that can be watched with the student of other students demonstrating related skills: http://healthytransitionsny.org/

AASPIRE created a healthcare toolkit for individuals with ASD. Includes a worksheet/script to for the young adult to use when making a doctor's appointment https://www.autismandhealth.org/inc/forms/hc_appointment_worksheet.pdf . Also provides a checklist for what to bring to a doctor's appointment https://www.autismandhealth.org/inc/forms/hc_prep_checklist.pdf .

The site provides a tool that can be used to develop a letter for new healthcare specialists to help them understand the needs of the individual: https://www.autismandhealth.org/?a=pv&t=pv_frm&s=&size=small&p=ahat&theme=ltlc

The following websites offer tools to help develop a health transition summary . http://www.sickkids.ca/Good2Go/For-Youth-and-Families/Transition-Tools/MyHealth-Passport/Index.html (My Health Passport)

http://www.bcchildrens.ca/transition-to-adult-care/Documents/MTSGeneric.pdf (British Columbia Children's Hospital)
http://www.gottransition.org/resourceGet.cfm?id=208

Florida University published some workbooks for students preparing for the transition to adult healthcare: https://hscj.ufl.edu/jaxhats/docs/HCT_Workbook_18up.pdf

The Adolescent Health Transition Project created a checklist for students and parents to assess skills related to the health care transition. This can be utilized to identify skills that have already been mastered and to target skills that still need to be developed http://depts.washington.edu/healthtr/documents/healthcareskills.pdf

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The Center for Children with Special Needs created a 25 page downloadable health care notebook that can be individualized and placed in a binder to help keep track of crucial medical information: https://cshcn.org/pdf/teen-care-notebook-all-documents.pdf

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Tool from the Child Neurology Foundation to help parents of children with neurological conditions assess child's transition needs: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/C_SelfCareAssessmentParents.pdf

Youth self-assessment tool: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/D_SelfCareAssessmentYouth.pdf

Medical Summary form from the Child Neurology Foundation for youth with neurological conditions transitioning to adult health care providers: http://www.childneurologyfoundation.org/wp-content/uploads/2017/08/E3_MedicalSummary.pdf

Video for parents/professionals on preparing youth for the healthcare transition. Provides suggestions about strategies for involving adolescents in their health care to prepare for the transition: https://www.youtube.com/watch?v=cjXurYrFMZM

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The site provides a tool that can be used to develop a letter for new healthcare specialists to help them understand the needs of the individual: https://www.autismandhealth.org/?a=pv&t=pv_frm&s=&size=small&p=ahat&theme=ltlc

Module 15: Closeout Process for PROMISE

Preparing to Talk About Closeout

As a case manager or family coach, you serve as a role model or mentor to youth on your caseload. For some of these youth, you may provide one of the first examples in their lives of a healthy attachment figure. Research shows that the characteristics that youth seek in mentors are the same qualities that occur in healthy attachment relationships (safety and security, opportunities for growth, unconditional regard, authentic engagement, active participation, responsiveness, and empathy.) When helping relationships end, youth who have experienced previous trauma and loss or insecure attachment are particularly vulnerable to difficulties.

Discussing the termination of your working relationship may trigger a range of emotions within the youth, including feelings of abandonment, rejection, anxiety, anger, despair, confusion, fear, and helplessness. Individuals who have experienced other secure attachments in their lives may be better equipped to regulate their emotions and have a larger repertoire of coping skills to draw upon, while those who have experienced insecure attachments and/or traumatic losses may feel frantic and overwhelmed. However, as overwhelming and difficult as these emotions feel in the moment, when they are handled well and discussed openly, the process of ending a relationship in a healthy manner can be transformative for the youth. Therapeutic and constructive endings to relationships teach the youth to hold in their mind an internal representation of the departing person, while letting go of the physical presence of the individual. In the future, the youth can connect with positive internal image of the other individual when they are facing challenging situations in order to recall memories that help them to feel secure and comforted. For example, when a youth encounters a difficult task at work, he/she may engage in positive self-talk such as, “My case manager would have told me to take a deep breath and stop and think.” For youth with histories of trauma, the ending of the case management relationship may be their first opportunity to experience a non-traumatic loss.

Throughout the closeout process, the case manager will need to look for opportunities to both validate the feelings of loss and sadness that the youth and families are experiencing and redirect the focus back to the new possibilities that lie in the youth’s future. Rather than thinking of it as an “ending”, it is helpful to reframe it as a normative life transition in which both beginnings and endings are intermixed. The sadness of saying “goodbye” can be balanced with the joy of dreaming together about the possibilities that lie undiscovered in the future.[1]

While the conversation about ending your helping relationship with youth and families can be uncomfortable and difficult, and it is natural to want to protect the youth from information that he/she may find hurtful or sad, it is important to discuss the ending over time in order to allow adequate opportunity to prepare for the transition. When the termination of a therapeutic relationship takes

[1] Lanyado, M. (1999). Holding and letting go: Some thoughts about the process of ending therapy. *Journal of Child Psychotherapy, 25*(3), 357-378. 10.1080/00754179908260301

place over time, it allows both the youth and the professional to reflect on what was learned throughout the relationship. It also allows the youth and family to work through their feelings related to the change and put adequate supports in place to help prepare for the anticipated loss. After the initial conversation about the ending date of the working relationship, it is important to periodically remind the youth and family of the approaching date and engage in dialogue about how to best use the time leading up to the end date.[1] During conversations about the approaching end to the helping relationship, remind the youth that he/she played an active role in the change process and point out the strengths and resources that he/she has that will enable him/her to continue to grow after your working relationship has ended.

Due to the complex nature of some of the situations that the youth and families with whom we are working face, there may be a tendency to feel like you have failed them if you have not been able to achieve your expected goals, especially if you know that the youth/family still face significant struggles. However, rather than maintaining an unrealistic ideal that total success should have been achieved at the end of the grant, it is more helpful to ask yourself whether a "good enough" ending has been achieved. A "good enough" ending may not be perfect, and there will most likely be areas that you wish you had more time to address, but viewing your work through this context will help you to recognize that you still had an impact on the youth/family and that the time that you invested and work you completed may be a catalyst for future growth that you have not yet been able to witness. The following characteristics indicate that a "good enough" ending has occurred in a helping relationship:

- The ending is anticipated and feelings are discussed.
- The professional and individual served are able to reflect on what was accomplished and learned.
- A blueprint has been provided for the youth of a healthy ending to a relationship.
- The youth's strengths are highlighted.
- Hope is expressed for the young person's future.
- The individual served demonstrates a willingness to risk connecting with others after experiencing a safe working relationship.

The following strategies may help you to prepare youth and families for the approaching ending of your work together:

- **Point out any all-or-nothing thinking**. Help the individual measure success by steps towards future goals even if the goals are not completed. Remind them that even setbacks provide valuable lessons.
- **Help break things down into smaller parts**. Take larger goals and break them down into short-term objectives.
- **Encourage them to take responsibility for their own lives** and focus on what they can change rather than focusing on things they can't change.

[1] Goode, J., Park, J., & Parkin, S. (2017). A collaborative approach to psychotherapy termination. *Psychotherapy,* 54(1), 10-14.

- **Encourage the use of positive self-talk (both internally and externally).** Help them to reframe challenges as opportunities for growth.

Caution About Maintaining Healthy Boundaries

Within the case management relationship, case managers use therapeutic boundaries with individuals that they serve in order to define and protect the space between the professional (who has power) and the individual that is being served.[1] These boundaries can include factors such as language, time, space, money, and self-disclosure from the professional to the individual being served. During the closeout preparation process, it is important for case managers to be aware that heightened emotions and fears of abandonment may trigger youth and/or families to demonstrate an increased need for time and attention from the case manager. For example, a youth may begin reaching out more to the case manager with more frequent phone calls or requests for extra visits in an attempt to spend more time with the case manager. When this behavior occurs, it is prudent for the case manager to maintain boundaries that protect both the case manager and the individuals being served.

Warning signs that sometimes lead to more significant boundary violations include: strong feelings about specific youth or family members on your case load, gift giving exchanges, extended case management visits, and the level of self-disclosure from the professional to the individual being served. One of the most effective protections against boundary violation is engaging in supervision with someone from your agency who can help you see the situation objectively and ensure that healthy boundaries are maintained.

Case Management During Closing Out Process

Approaching the topic of closeout planning with the youth and family can seem daunting, especially if you are worried that they are going to react negatively to the discussion. Individuals that have experienced trauma and loss in the past may react more strongly to the approaching end of the project, and it can be difficult not to personalize their reactions. The best way to prepare for this conversation is to develop a plan, communicate directly and honestly with the youth and families, and seek support from a supervisor or co-worker if the discussion triggers strong emotions for you and/or the people with whom you are working. Keep in mind that this is a planned ending, and that the families were aware that they were signing up for a research project that would be ending in 2018, so while the reminder may be difficult for them to hear, it should not be a surprise. Learning to work through loss in a healthy way can serve as an opportunity for growth and healing in individuals who have experienced trauma.

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[1] Malone, S. B., Reed, M. R., Norbeck, J., Hindsman, R. L., & Knowles 3rd, F. E. (2004). Development of a training module on therapeutic boundaries for mental health clinicians and case managers. *Lippincott's Case Management : Managing the Process of Patient Care, 9*(4), 197-202. 10.1097/00129234-200407000-00007

[1] Lanyado, M. (1999). Holding and letting go: Some thoughts about the process of ending therapy. *Journal of Child Psychotherapy, 25*(3), 357-378. 10.1080/00754179908260301

During the closeout preparation process with the intervention group, the case manager/family coach will perform three primary functions with the intervention group:[1]

1. Assessment and planning for future needs.
    - Meet with the family to discuss what they have accomplished so far and what they would like to accomplish in the future. Identify any gaps between the resources that they have to meet their goals and the resources that they will need in order to achieve success.
    - Help the youth to think about their goals related to living, learning, and earning. The transition portfolios are a great resource to utilize as you work on setting goals with the youth.
    - Don't forget to assess any medical needs and help prepare for the transition from the pediatric to adult health care system, especially for youth with complex medical conditions.
2. Linking the youth and family to resources within the community.
    - Identify resources at a local, regional, state, or national level that can help the individual meet his/her needs (can include on-line resources).
    - When necessary, help individuals to make initial contact with specific agencies/programs.
    - Help the individual to prepare any documentation or other items needed to complete application/intake forms and meet eligibility requirements of agency/program.
3. Psycho-education and intervention to address immediate needs during the remainder of the PROMISE grant.
    - Provide education through direct teaching, written materials, or linkage to community resources related to the individual's disability and/or mental health condition, thereby empowering them to deal with their condition in an optimal way—e.g., info about their dx, treatment options, advocacy skills, wellness tips and strategies, accommodation information, etc.)

The focus throughout the closeout preparation process should be on empowering and engaging the youth in the management of their needs. Both long and short-term goals can be created, and these goals should be collaborative and client-centered.

Reconfiguration of Roles and Responsibilities During the No Cost Extension

The PROMISE grant has been issued a one year No-Cost Extension (NCE), during which time some of the funds that were not used due to the delayed process with recruitment and enrollment will be spent on services targeted toward the intervention group. The control group will be closed out at the end of year

[1] Weiss, M. E., Bobay, K. L., Bahr, S. J., Costa, L., Hughes, R. G., & Holland, D. E. (2015). A model for hospital discharge preparation: From case management to care transition. *JONA: The Journal of Nursing Administration, 45*(12), 606-614. 10.1097/NNA.0000000000000273

5 as planned, but information will still be gathered from this group through surveys for research purposes.

As we approach the end of year 5, both the PC and the RDS's will be phasing out the control group contact. However, the PC and RDS roles and responsibilities will shift dramatically when we enter year 6, the No Cost Extension Year (NCE). At the end of year 5, the PC will cease all services to both the CG and the IG. The CG will be provided with the on-line 211 tool for locating community resource and some other research-related contact information in their final closeout letter.

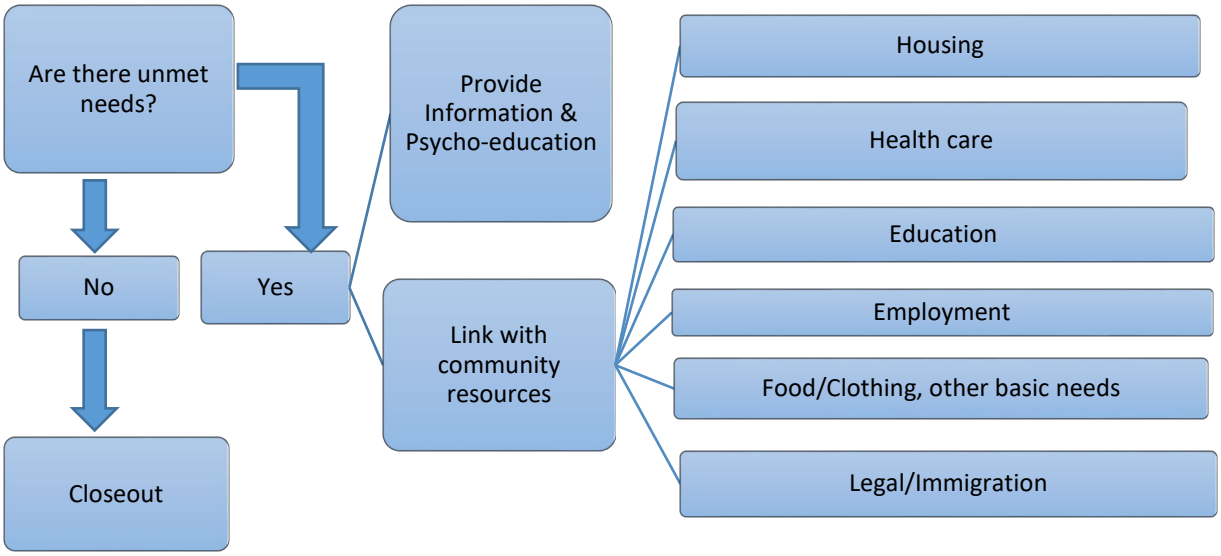
During the No Cost Extension year, providers and RDSs will continue to work with the IG, and the CM's will assume some of the responsibilities that were previously assigned to the PC's. The newly transferred responsibilities will include: linking families with community resources, providing coaching and information to families as needed, and completing the Guardian Update forms. This will require the CM's to utilize tabs within NYESS that were previously completed by the PC's (Guardian Update tab, coaching and information activities, etc.). During the NCE, an increased focus will be placed on preparing youth for emerging adulthood, where they will be managing their own health, education, employment, and daily life needs. The CM will work with youth and families to identify the goals that they want to accomplish before PROMISE services end. If necessary, additional referrals will be made to providers and other community resources to better equip youth for this transition. CM will connect the youth and family with information about adult services such as ACCES-VR, OPWDD, SSI benefits and incentives, Independent Living Centers, etc.

The goal of case management during the last year of service should be to help customize a support plan that will assist youth and families in identifying needs, linking youth and families to community supports and services to assist with unmet needs, and maintaining a path of self-determination. After holding initial discussions regarding the closeout of the grant and ending of services, the case manager should revisit the conversation as needed over time to remind the youth of the approaching ending date. During these conversations, the case manager should ask the youth what he/she wants to accomplish in the remaining time together.

During final discussions with the youth prior to closeout, it is important for the youth to take ownership of the progress that he/she made and realize that he/she played an active role in being an agent of change in his/her own life. Naming the progress made and steps taken helps the youth to mentally consolidate the gains that have been made over the last several years. Envisioning a future plan for continued growth is also beneficial in assisting the youth conceptualize the future and verbally committing to long-term change. [1]

[1] Goode, J., Park, J., & Parkin, S. (2017). A collaborative approach to psychotherapy termination. *Psychotherapy*, 54(1), 10-14.

Closeout Planning Flow Chart for IG



Information and Referral Services (I&R)

Human service professionals have come to recognize that in spite of the wide variety of resources available in the today's society regarding social service and non-profit services, many families continue to struggle with accessing and utilizing available resources. Information and referral is an organizational response that evolved as a means of helping individuals to find answers to their questions and services to meet their needs. The goals of I&R are two-fold: 1) to facilitate access to services and 2) to overcome any barriers that restrict entry to needed resources.[1]

As you prepare for the grant closeout with youth and families, it is important to assess the need for I&R services with youth and family on your caseload. In some cases, the needs will be minimal and/or families will have the skills necessary to access services in the community without your assistance. In other cases, the needs of a family may be very complex and may require multiple referrals, repeated contacts with the young adult and other members of the family, and on-going follow-up. The degree of follow-up required will vary depending on the complexity and severity of the situation.

In preparing for closeout, conversations about I&R that should be initiated with every youth and family in order to assure that they have been provided with some of the essential transition-related resources that they will need.

[1] Levinson, R. W. D. (2002). *New routes to human services: information and referral*. Retrieved from https://ebookcentral-proquest-com.proxy.library.cornell.edu

The need for I&R regarding the following resources should be assessed and discussed for each family on your caseload. It may be necessary for the case manager to help facilitate the connection between the youth/family and the service provider:

1. ACCES-VR services and application process
2. Regional Independent Living Center (ILC) services
3. OPWDD eligibility and services available across the life span
4. Parent Center services and contact information

When helping a youth or family connect with a community provider, it is helpful to find out the following information:

1. Contact information and hours of operation
2. Types of services offered
3. Whether the services offered are culturally and linguistically appropriate
4. Whether application, referral, or other paperwork assistance is needed

In some cases, if you will be referring multiple families to a specific service, it is helpful to begin establishing a simple resource binder where you can keep brochures and business cards or jot down notes. Many agencies offer websites that allow you to download brochures and other information that can be passed on to families. You can also call the organization or ask to schedule a personal visit to talk to some of the staff.

When time permits, one approach to uncovering resources within specific communities is the method of community mapping. Community mapping is an inquiry-based method that explores resources within the context of a family's culture and community.[1] The first step of community mapping involves identifying a specific location (a school or a residence) and walking or driving throughout a fixed radius around the location, observing and gathering information from any agencies or community attributes that might be utilized as a resource by specific families. When brochures and other written information are not available, an additional internet search is conducted to gather any on-line information that is available about specific resources. This information is compiled and distributed to families as needed.

2-1-1 Referral Helpline

The 2-1-1 information and referral helpline is a federally designated dialing code (just like 9-1-1) that connects callers with trained information and referral specialists who can help identify needs, search a database to find local resources that match those needs, and provide information that helps connect the callers to service providers that can help.[2] The helpline is made up of 270 state and local call centers located throughout all 50 states. Outcome research conducted utilizing data from 2-1-1 call centers shows that most individuals who call the center are looking for assistance with meeting their most basic

[1] Ordoñez-Jasis, R., & Myck-Wayne, J. (2012). Community mapping in action: Uncovering resources and assets for young children and their families. *Young Exceptional Children, 15*(3), 31-45. 10.1177/1096250612451756
[2] Boyum, S., Kreuter, M. W., McQueen, A., Thompson, T., & Greer, R. (2016). Getting help from 2-1-1: A statewide study of referral outcomes. *Journal of Social Service Research, 42*(3), 402-411. 10.1080/01488376.2015.1109576

needs (utilities, food, or housing). Upon discharging both the control and the intervention group, PC staff and CM's will provide information about the 2-1-1 helpline and services that they provide to families, and encourage families to contact them with future needs.

Community Asset Mapping Tools

Community asset mapping is a tool that has evolved in the specialized fields of sociology, psychology, urban planning, political science, etc. that focuses on gathering information and identifying resources (both formal and informal) within a given community.[1] The term is used to describe both the process of gathering information about resources and the actual product that is created when the information is documented. This information can be gathered by individuals or groups by walking through communities, by surveying communities to find out what services are being utilized, and by telephone and on-line searches. This process of gathering information helps the "mapper" discover and reflect as he/she gains a new understanding of the resources available in a specific geographical area. The information is then documented in a visual form (or "map") that shows the type and number of resources within a given area. The search can be conducted broadly, with many different types of services and organizations identified, or it could be used to target a specific type of service (such as health care providers in a specific area).

The following steps are involved in conducting a community asset map:

1. Gathering information about the needs of the population for whom the information is being gathered.
2. Scouting a specific geographical area.
3. Identifying places you wish to visit.
4. Collecting artifacts (photos, videos, brochures, etc.).
5. Writing field notes about what you saw, who you spoke with, what you learned, etc.
6. Interviewing providers and others in the community.
7. Recording your reflections in a form that shows visually what is available in the geographic area.

[1] Ordoñez-Jasis, R., & Myck-Wayne, J. (2012). Community mapping in action: Uncovering resources and assets for young children and their families. *Young Exceptional Children, 15*(3), 31-45. 10.1177/1096250612451756

Module 15: Resources

This link will take you to a guide that will help to survey available resources within the community:

http://www.communityscience.com/knowledge4equity/AssetMappingToolkit.pdf