Special Considerations

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Merrimack Center Clinically Intensive Residential Treatment Program
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> "Today you are You,
> That is truer then true.
> There is no one alive
> Who is Youer than you."
>
> Dr. Seuss

Special Considerations

This chapter recognizes that there are youth and families with unique circumstances within our systems of care who require special considerations to meet their treatment needs. In addition, special considerations are also very important in our efforts to prevent restraint and seclusion for these youth with special care needs.

Unfortunately, youth who are involved with special education and/or have intellectual and developmental disabilities are restrained at a significantly higher rate than youth who do not struggle with these challenges (Hattem, 2017, National Disability Rights Network, 2009, U.S. Department of Education, 2016). Because there is a general lack of information and limited resources on this topic, the information presented in this chapter was obtained from experts in the field who work directly with special populations.

Special populations at the Merrimack Center, an intensive residential treatment program for youth with intellectual and development disability and mental illness in Tewksbury, Massachusetts

Although the Merrimack Center serves a wide variety of youth, in recent years they have had increasing experience working with youth and

families who are refugees, immigrants, and represent many diverse cultures. Often, these youth and families do not speak English and have recently emigrated from their home country. John Tormey, MS, Program Director of the Merrimack Center, shared some of their experiences working with youth from other cultures and countries.

According to Mr. Tormey, it is imperative to respect the cultural norms of the youth and families with whom you are working. One way they begin this process at Merrimack is by conducting research on the internet about the youth and family's culture. Some helpful links are included at the end of this section of the Special Considerations chapter. Staff members at Merrimack learn about cultural norms and any possible miscommunications that might arise through cultural differences.

The following are a few examples:

- In some cultures, the "A-Ok" sign made by the index finger and thumb is considered offensive.
- In other cultures, eye contact is disrespectful.
- In the Somali culture, the left hand is considered impolite. For this reason, it is important to use the right hand to offer food or medication to Somali youth and families.

- In some cultures, mental health is viewed differently than in the West, and it is not openly discussed. It may be more helpful to focus on symptom recognition rather than labeling. Occupational therapy and other sensory interventions have been extremely helpful in working with youth and families from different cultures at Merrimack by teaching them to recognize triggers and learn self-soothing skills.

There are many examples about how important it is to recognize, respect and learn about the countries and cultures of the youth and families with whom we work. It is imperative to share this information with all staff members.

Mr. Tormey also recommended involving a professional translator if the youth and family do not speak English or if English is their second language. It is important to include additional time for translation in treatment teams and other meetings. The process of translation and allowing the youth and family time to respond is slow, but it is a critical part of effective communication. When working with a translator, it is important to be clear and direct in your use of language. At times common phrases, adages, slang, and jargon can get lost or have different and unintended meanings.

If English is not a youth's first language, it can be difficult for them to communicate that they are in crisis. In those situations, it is helpful for staff members to use simple one-word directions and hand signals. If the youth also has an intellectual disability, staff members must be patient and work closely with the youth and their family to learn what is helpful during times of crisis.

Merrimack has been working to change its culture of care over the past few years to reduce restraint and seclusion for all youth. The following are some of the changes they made and tailored to meet the needs of youth and families from other cultures.

- Merrimack implemented the Six Core Strategies©.
- Merrimack uses trauma-informed treatment strategies and a trauma-informed framework/model. They offer specific training to staff members on trauma-informed care.
- Merrimack uses applied behavioral analysis to look at the sequence and patterns of behavior and to learn what a youths' unmet need could be.
- Merrimack ensures that all staff members are aware and have an understanding of cultural differences and similarities. One way the program helps staff with this is they have information about the youth's cultural background printed out and readily available.
- Merrimack ensures that staff members have information about circumstances that resulted in refugee youth and families having to leave their native countries and come to the United States.
- Merrimack uses technology to connect with youth and families. For example, one clinician used Google Translate (https://translate.google.com/) to develop a youth's treatment plan in their native language.

Youth at Merrimack suggested that the best way to prevent restraint and seclusion is for programs to allow them to represent themselves and their culture. For example, a clinician at Merrimack worked with a youth from the Sudan to create a presentation about their culture for the other youth and staff members at the program. The youth also brought in traditional Sudanese treats to share with peers and staff.

Families working with Merrimack suggested that the most effective way to prevent restraint and seclusion is for programs to actively include them in the treatment process, to ensure that staff members listen to their input, and to have open conversations on how to help programs prevent restraint and seclusion with youth. The Building Bridges Initiative (Chapter 3 in the Resource Guide) views families as experts on their children, and it is crucial to involve them in all aspects of planning and treatment.

The Merrimack Center recommended the following resources to develop program cultures of care around working with youth and families from different countries, particularly with regard to efforts to eliminate restraint and seclusion.

The Administration for Children and Families has a list of resources for refugees and immigrants: https://www.acf.hhs.gov/trauma-toolkit/immigrant-or-refugee-populations

American Psychological Association, basic tips for working with interpreters: http://www.apa.org/monitor/2010/02/translation.aspx

Culture Care Connections provides some information on some specific cultures that are worth exploring: http://www.culturecareconnection.org/competent/index.html

The National Child Traumatic Stress Network provides some general Guidance for Mental Health Practitioners: http://nctsn.org/trauma-types/refugee-trauma/guidance-professionals

Refugee Health Technical Assistance Center provides and quick overview on the experience refugee youth may experience: http://refugeehealthta.org/physical-mental-health/mental-health/youth-and-mental-health/

Special populations at the Walden School at the Learning Center for the Deaf in Framingham, Massachusetts

The Walden School provides comprehensive treatment and educational services for children and adolescents between the ages of 7 and 22 who are deaf and hard of hearing. They often have other treatment needs, such as complex trauma, cognitive challenges, language deprivation, and behavioral challenges. The linguistic approach used at The Walden School is American Sign Language (ASL).

Karen Bishop, M.Ed., Associate Executive Director of The Learning Center for the Deaf, and Michelle Cline, MSW, LCSW, Director of The Walden School, shared some of their experiences working with the youth and families they serve at the Walden School.

The Walden School is committed to preventing and reducing restraint and seclusion and has found the following steps helpful with the process:

- At the Walden School, services are provided in the language of the youth and with an understanding and respect for their culture to be effective. Therefore, ASL is the language used at the Walden School, and it is considered essential that at least 50% of the staff members are deaf.

- The Walden School believes that youth learn through engaging in relationships with others, and Walden School staff members model self-awareness, respect, openness, teamwork, responsibility, and honesty in their day-to-day interactions with youth and each other.
- The Walden School treats each youth crisis on a case-by-case basis. Their goal is de-escalation through communication, and physical restraint is used as a last resort, only when there is a threat of imminent harm.
- Walden School does not utilize a single formula for change that applies the same expectations, rewards, and consequences for all youth. Individualized interventions are developed based on the needs of each youth and the stage they are at in their treatment.
- The Walden School believes that the youth and families are essential team members in every step of the treatment process. Their goal is to partner with them to identify strengths and needs, and work together toward the attainment of individualized educational, social/emotional, and independent living goals.

When a deaf or hard of hearing youth is restrained, the very nature of the process, holding their arms down, silences them and they can no longer communicate. The Walden school staff members are particularly attuned to monitoring youth for any signs of physical distress, because they are not able to communicate. Staff members also work out ways to communicate with youth who are trying to tell them something during a restraint. For example, youth often will have the use of one hand during restraints even though it increases the risk for staff injury.

The Walden School maintains an ongoing focus on preventing and reducing restraints. They offer trauma-informed care within a strength-

based treatment model. They continue to improve on their service offerings by adding more treatment modalities. These include trauma informed yoga classes, animal assisted therapy dog(s), and, the most recent addition, a Sensory Motor Arousal Regulation Therapy (S.M.A.R.T.) room. These help youth at The Walden School learn to understand their thoughts and feelings and teaches them to recognize their emotions before situations escalate to the point of physical restraint. Youth learn new behaviors, build self-esteem, and maximize their individual potential in a structured, supportive, nurturing, non-punitive environment. Several years ago, Walden School adopted the Residential Child & Youth Care Professional curriculum (RCYCP) to standardize training and certification for all staff members within the program. This training is the foundation of the work at The Walden School, and it is supplemented by many additional hours of training for all staff.

The system for changing behavior utilized at The Walden School is based on the belief that youth come to the program with their own unique sets of life experiences and views of the world. The youth have different strengths and needs, different likes and dislikes, and different fears and expectations. The youth have all been hurt in some way and have experienced failures in previous educational and social settings. Treatment approaches that guide youth through a process of change at The Walden School are individualized and they have respect and compassion as their foundation. There is a strong focus on relationships. Healing happens as relationships develop and grow. Staff members use their relationships and positive interactions with youth to promote healing and growth.

The use of restraint at The Walden School has continued to decrease over the years, because staff members have learned new skills. They focus on assisting youth in learning to communicate their thoughts, feelings and emotions. In addition, youth at Walden have more resources available to them that are incorporated into their daily lives. The Walden School tracks data regularly, and, when a restraint takes place, it is viewed a "treatment failure." They work to understand where treatment broke down, and how they can improve their work with the youth moving forward.

According to Ms. Bishop and Ms. Cline, The Walden School has found the most effective strategies to prevent restraint are as follows:

"Staff members demonstrate a positive attitude that consistently conveys caring and respect. We often talk about respect in terms of the students, but it has to start with us. To many of our students, adults are people who hurt children with their words, their fists, or their groping hands. To many of them, adults are people who lie and abuse power. It is our job to show, through constant modeling, that it can be different. Trust builds when a student sees a staff member can be depended on. You show up for work on time. You teach them new skills (talking nicely to others, taking responsibility for self, etc.) that you use yourself. Respect is gained through active listening, truly negotiating with students, admitting mistakes and saying I'm sorry. If we want to see these behaviors in students, then we must model them consistently in the milieu. Attitude is everything. Students learn to trust again by staff showing them the routine activities of everyday caring."

Youth at The Walden School suggested that the best way to prevent restraint and seclusion is for programs to ask them more questions, to include them in discussions, and to celebrate the accomplishments of everyone.

Families working with The Walden School suggested that the most effective way to prevent restraint and seclusion is for programs to always include them in treatment and crisis prevention planning, debriefings, and trainings.

Ms. Bishop and Ms. Cline recommended the following strategies to help other programs advance their cultures of care and prevent restraint and seclusion:

- Work together to identify what your program needs;
- Talk often about the reason restraint is harmful—sometimes just by discussing restraints, it brings the issue to a new level of awareness;
- Debrief restraints and include youth in debriefings. They will tell you how to improve!
- Bring speakers into your program to meet with and present to all staff members;
- Set up a group, including youth, to promote this culture year-round; and,
- Send youth and staff members to workshops and trainings.

Special populations at Melmark, New England

Melmark New England serves children and youth ages 3 to 22 who have diagnoses of Autism Spectrum Disorders, brain injuries, or other

neurological impairments. Primarily, youth are referred to Melmark because they have extreme behavioral challenges and have experienced multiple failed placements. It is not uncommon for youth to go to Melmark following extended psychiatric hospital admissions, with no other viable placement options willing or able to address the youth's behavioral challenges. Melmark is licensed as a day school and as a residential school. It currently has two school sites and six youth residences that operate 24/7. Melmark does not use seclusion, and it does not have time out rooms in any of its programs.

Helena Maguire, M.S., BCBA, LABA, Executive Director for Melmark New England, shared some of her experiences working with youth and families at Melmark.

Melmark's primary educational treatment approach uses the science of Applied Behavior Analysis (ABA) to analyze functions behind behavioral challenges, as well to as develop function-based behavior support interventions to improve the youth's success in school, in the residence, and at home. These interventions use highly motivating activities, preferred staff, and engaging instructional planning that breaks down learning into small components and are highly individualized.

Melmark creates an infrastructure that engages youth through positive-based interventions and ensures that staff members and families are knowledgeable and up to date with each youth's changing needs. These strategies help prevents physical restraints.

As part of Melmark's ABA model, data is consistently collected on each youth's behavioral and instructional needs. The data is reviewed each

week by the team of staff members supporting the youth and with the family. Upon reviewing the data, if the trend indicates the youth is making progress, Melmark maintains successful treatment components in place. If the data indicates that a youth's behavioral difficulties are increasing, intervention changes are made immediately to support the youth in experiencing more success.

Melmark has been able to minimize physical restraints by applying this model of data analysis and treatment changes and by providing behavioral training and physical restraint prevention training for all staff members.

According to Ms. Maguire, "*Our continued challenge remains in the fact that as new students are admitted to our programs, we are seeing a higher acuity level in their behavioral manifestations. In addition, these children are often arriving to us later in their age progression. When evaluating these variables, it is clear that given the delay in providing them with a highly specialized setting at a younger age, they have developed more intense behavioral histories that will now require more intensive supports and care to change the trajectory of their success."*

Melmark has prioritized restraint prevention since its inception 20 years ago. Prior to the changes in regulations on restraint (2016), their team spent time each month reviewing regulations, program policies and procedures, staff support structures, specialized positions, and the quality and frequency of their training programs.

Recently, given the increased needs of the youth served at Melmark, the program re-evaluated what kind of specialized, credentialed staff

members were needed to support youth. They also refreshed their training program series to ensure that staff members receive monthly trainings related to individual behavior plans of each youth, proactive physical intervention, and restraint prevention. In addition, data regarding the use of restraints are shared with all staff members and families for the youth on their team. Ms. Maguire stated, *"This heightened awareness and consistent knowledge regarding restraint prevention and restraint utilization have certainly increased our staff's capacity to understand the issues and provide the best educational treatment that has been designed."*

Melmark's most effective restraint prevention strategies are as follows:

- Melmark employs a highly credentialed and experienced workforce made up of Board Certified Behavior Analysts (BCBA's), special education teachers, and bachelor degree level direct care staff members.
- Melmark has a ratio of one BCBA for every six students.
- Melmark places an emphasis on staff training. They participate in ten days of training upon hire and monthly in-services thereafter. Weekly training focuses on individualized behavior plans and restraint prevention/intervention procedures and includes physical intervention role-plays.
- Melmark provides a great deal of staff supervision. BCBA/Special Educators are part of the youth and direct care staff members' day. They are required to be in the presenting environment for half of each day to assist, support, train and deliver direct support services.

- Melmark collects and analyzes data. They review data on each youth as a team on a weekly basis and use that data to drive programming changes to result in youth successes.
- Melmark holds monthly meetings to review restraint data. The data is used to help formulate specific strategies for youth who are struggling and to support the treating team of professionals.

Youth at Melmark New England participate in weekly team meetings, if they are able, to review their own data and contribute their thoughts about their treatment progress. They also give their input about behavior support intervention strategies they like or want to change. This collaboration is an essential part of successful work with youth at Melmark.

Families at Melmark New England meet with the treatment team each month to review their child's progress data and intervention plans. During these meetings, families receive training on individual behavior plans and restraint prevention procedures to help maintain a consistent framework of care for their child during family visits. Ms. Maguire said that most families are pleased with their child's progress and work collaboratively with Melmark to continue the efforts towards positive behavior planning and restraint prevention/reduction.

Ms. Maguire recommended the following strategies to help other programs advance their cultures of care and prevent restraint:

- Hire a highly credentialed and experienced workforce;
- Maintain a sufficient staff to youth ratio;
- Provide training for staff members when they are hired, on a monthly basis, and on a weekly basis;

- Provide staff supervision and have supervisors available during training to assist, support, train and deliver direct support services;
- Collect and analyze data. Review the data frequently as a team to drive programming changes that will result in youth successes;
- Review monthly restraint data, have discussions about the data to formulate specific strategies for any youth who are struggling; and,
- Support the treating team of professionals, the youth and the families.

Special populations at Pappas Rehabilitation Hospital for Children

The Pappas Rehabilitation Hospital for Children (PRHC) (formerly known as the Massachusetts Hospital School) is a Joint Commission accredited, pediatric, chronic care hospital serving youth between the ages of 7 and 22 in Massachusetts. PRHC is operated by the Department of Public Health. The mission of PRHC is to provide medical, nursing, rehabilitative, educational, habilitative, recreational, and interdisciplinary transitional planning services to youth with multiple disabilities.

All PRHC patients present with medically complex conditions including primary diagnoses of cerebral palsy, muscular dystrophy, spina bifida, traumatic brain and spinal cord injuries, and other metabolic/ neuromuscular disorders that require significant medical management and hospital level of care. Patients often have secondary diagnoses, including complicated seizure disorders, periventricular leukomalacia, anoxic brain damage, disorders of mitochondrial metabolism, and severe spasticity. PRHC also treats patients with rare medical conditions.

Each patient's individual treatment plan is carefully designed and rigorously followed to ensure s/he achieves the optimal level of independence in all aspects of their life.

PRHC inpatient services include:

- Comprehensive 24/7 Nursing Care;
- Medical specialties including Infectious Disease, Cardiology, Neurology, Physical Medicine and Rehabilitation, Pulmonary, Orthopedics, Podiatry, Dental, Gynecology, Complementary and Alternative Medicine, Psychiatry, and Behavioral Health Services;
- Therapeutic Services including Speech and Language, Occupational, Physical, and Recreational Therapy;
- Rehabilitation Engineering to provide adaptive equipment and assistive technology services;
- Interdisciplinary Transitional Planning program to advance independent living skill building and community integration with extensive curriculum in:
  - Personal safety and self-advocacy skills
  - Positive Choices / healthy sexuality
  - Alcohol and substance abuse awareness and education
- On-site Special Education in Institutional Setting program (SEIS) operated by the Department of Elementary and Secondary Education (DESE).

Catherine Mick, MSW, MBA, Chief Operating Officer, J.T. Jones, Ph.D., Director of Clinical Services, and Cheryl Bloomer, RN, MSW, Chief Nursing Officer at PRHC shared their experiences with the challenges

inherent in working with their patients as well as their restraint elimination efforts.

Treating youth with chronic and highly complex medical conditions that make their bodies fragile presents many challenges. Physical restraint can be complicated with youth whose bodies are not aligned as usual, youth who have severe spasticity, youth with limited respiratory capacity, or youth with skin disorders in which any physical touch may cause pain.

Given all of these medical concerns, staff members must also be keenly aware of a youth's medical equipment, such as a feeding tube, a tracheotomy, a BiPAP, or an Intrathecal Baclofen Pump, which is challenging because it is not visible to the eye. Physical restraint for these youth requires understanding their behavior and their medical diagnosis/diagnoses, which is extremely important to ensure the safety of a medically fragile youth.

Ninety-eight percent of the youth at PRHC are wheel chair dependent, which adds another complication to restraint. Restraining safely in a wheel chair is difficult, and the type of chair needs to be taken into consideration. Power wheelchairs can present with some serious concerns for both the patient and the staff. Power wheel chairs can weigh up to 350 pounds and can move at a rate of 5- 10 mph. A distressed youth heading towards the street at a quick pace can be dangerous, and, at times, staff members need to disengage a youth's wheelchair, which is akin to a mechanical restraint. If an upset angry child attempts to hit someone with his or her wheel chair, they could cause significant damage. A wheelchair that rides over someone's foot

causes injury. There is always a possibility that a wheel chair could tip over and cause injury.

Cognitively limited patients, nonverbal patients, and hearing-impaired patients also need special attention. Communication devices can be challenging for a distressed patient who is trying to say something. There are numerous communication devices on campus, which may take staff members time to learn to use. Sometimes there are miscommunications between staff members and youth as a result, but caring words and touches can be soothing and helpful.

Truly listening to patients is the best approach at PRHC. The use of storyboards and assistance from speech and language therapists helps cognitive limited patients and patients who use communication devices. When staff members present in a calm and patient manner, their interventions seem to work well. Each youth has an “All about me” poster in their rooms as a quick reference for staff members working with them. It includes use of devices, equipment, medical issues, and behavioral needs.

PRHC is always working to improve its culture of care. Some recent steps include:

- All PRHC patients participate in a comprehensive Positive Behavior Support (PBS) Program to develop social skills, respectful peer engagement, and strategies to improve behavioral success. In addition, over the past several years, PRHC has expanded patient participation in Complementary and Alternative Medicine services, which has greatly assisted in providing self-regulation skills to use when anxious or upset.

- Over the past few years, an increasing number of patients have been admitted to PRHC with histories of trauma and anxiety disorders. PRHC has increased trauma-informed care training for all clinical staff, across all shifts, to meet their needs.
- Policies and procedures have been developed and implemented to include specific interventions on wheelchair mobility concerns. For example, if a child is driving their wheelchair too fast, they receive rehabilitation-engineering education. They practice driving safely at a reasonable speed, stopping when needed, and using ceiling mirrors.
- PRHC policies, procedures, and practices also include directives on timely staff and patient debriefings following a restraint. A senior administrative team reviews each restraint incident to assess the effectiveness and appropriateness of the intervention.
- This year PRHC added more staff members to their First Aid Support Team (FAST). They used the Commonwealth's Employee Assistance Program for debriefing to help staff members who worked with a particularly difficult patient who required restraint and was diagnosed with extreme post-traumatic stress disorder. PRHC currently contracts with a traumatic stress professional to conduct critical stress debriefing with PRHC staff on an ongoing basis.

Historically, restraints were rarely used at PRHC. However, their patient population has changed, and the youth at PRHC have many more challenges than in the past. PRHC now works with clinically and medically complex youth who are often suffering from the effects of trauma. The restraint issue is more relevant for PRHC now than in the past.

PRHC has increased their use of positive support plans to help youth build coping and self-soothing skills. Staff members also help youth make use of therapeutic breaks, which are valuable tools. Staff members work to notice early signs of escalating behaviors in youth, and, if needed, a behavioral health staff member meets with the patient and assists her/him in using his/her coping strategies.

Youth at PRHC have given a strong message to the clinical staff members about how to prevent restraint. These youth with multiple disabilities have asked staff members to "listen and be respectful of our needs and wants." They are saying, "Don't treat us like a disease. We have a voice about what we need"

Families working with PRHC suggested that the most effective way to prevent restraint is for the program to know their child, listen to their child, and create an individual plan for their child.

PRHC recommends that programs interested in preventing and reducing their use of restraint and seclusion should continue to seek out resources to enhance their knowledge of best practices and work across disciplines to develop a broader and deeper understanding of the issues youth, families, and treatment providers are facing.

Conclusion

It is imperative to consider the specific needs of youth and families served in any treatment or educational setting. However, there are youth who have unique needs and require even more specialized interventions and treatment. Several groups were discussed in this

chapter, including youth from other countries, youth who are deaf or hard of hearing, youth with neurological impairments, and youth with complex medical and emotional problems. In the next edition of the Resource Guide, this chapter will be expanded to include additional groups of youth and families who require special considerations as well as more resources.

Special Considerations

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