

## Overview

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“ Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has. ”

Margaret Mead

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# Overview of *Resource Guide*

## Introduction

**F**or the last six years, the Commissioners of the Massachusetts Department of Mental Health (DMH) have supported a formal initiative to reduce and eliminate the use of restraint and seclusion in child and adolescent treatment programs. This commitment by DMH leaders demonstrated their determination to decrease the use of coercive interventions in inpatient and intensive residential treatment settings and their belief that these approaches were unacceptable.

With this support from the highest level of DMH administration, key staff from the Department's Licensing and Child and Adolescent Divisions embarked upon the journey to improve the care of children, protect them from further life trauma within the mental health system, and support nurturing care to facilitate healing in these programs.

This *Resource Guide* was written to document much of what has been learned since the inception of this project and is meant to capture a portion of the creativity, innovation, and skill that many of our inpatient and residential staff developed as part of their efforts to meet the goal of preventing the use of restraint and seclusion.

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We wish to acknowledge the members of the provider community in Massachusetts who are responsible for leading the way nationally in changing culture and raising the bar in terms of care standards and staff expectations. Mental health workers, nurses, physicians, occupational, art and recreation therapists, and social workers have shared their programmatic improvements, new approaches, and transformative practices that have made a difference in the lives of the children and families.

## Setting the stage: State & national framework

The goal of hospital and residential treatment for children and adolescents and their families is to help them achieve personal growth, recovery, and healing. Treatment should focus on helping children (by “children” we mean both children and adolescents) develop skills to manage themselves safely by emphasizing strengths, developing skills, and working with families to address difficulties.

Caring for children with emotional difficulties and mental illness and assuring their safety is very challenging, and programs have typically used external controls and coercive interventions for behavior management. These interventions, such as strict consequences, seclusion, and physical and mechanical restraint (S/R), are often traumatizing and harmful for children.

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DMH, as the Massachusetts state mental health authority, and the National Association of State Mental Health Program Directors (NASMHPD), as a nationally recognized organization representing the public mental health system in fifty states and territories, is committed to changing inpatient and residential treatment environments from coercive to collaborative settings. This shift in focus emphasizes the core values of respect, nurturance, and empowerment and underscores abilities rather than pathology (LeBel, Stromberg, Duckworth et al., 2004; NETI, 2006).

The purpose of this *Resource Guide* is to provide suggestions and information and share what has been learned as programs adopt a strength-based framework for children, adolescents, and their families. The guide will attempt to describe ways to make and sustain significant programmatic changes with the goal of creating non-violent, trauma sensitive treatment cultures.

Through its statutory authority, DMH licenses and provides regulatory oversight to acute psychiatric units in private and general hospitals and Intensive Residential Treatment Programs (IRTP's). It also monitors long-term inpatient facilities, Clinically Intensive Residential Treatment Programs (CIRT's), and IRTP's through its operational or contractual role.

In 2001, DMH undertook an initiative to promote strength-based care and reduce the use of S/R in licensed and contracted child and adolescent hospitals and intensive residential treatment programs. The project was developed and led by DMH staff in

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the Child/Adolescent Licensing divisions. Their work was based on extensive research, site visits to programs that had eliminated or had very low rates of S/R, and consultation with national experts in establishing and implementing strength-based, trauma-sensitive, and non-violent treatment approaches (LeBel, Stromberg, Duckworth et al., 2004).

DMH staff provided clinical support, teaching, technical assistance, and regular feedback to support working partnerships that transcended the traditional model of authority. The goal of the effort was to help programs shift from an external management paradigm to a paradigm emphasizing skills in the service of self-management for children. Many programs in Massachusetts participating in this initiative have had significant reductions in the use of S/R, and some have eliminated these practices altogether. Although these initial results are impressive, there is a need for ongoing training, supervision, and quality management to sustain these changes over time.

The DMH Child/Adolescent Initiative obtained a great deal of useful information by assessing the different paths that individual hospitals and residential programs took towards achieving their goals. It was striking that all of the programs that significantly reduced or eliminated the use of S/R made changes in their program philosophies, practices, and policies.

Many programs found that they had to review and reframe the way they approached their work of caring for and providing treatment for children. These new ideas and practices

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emphasized helping children become more competent by teaching them self-management skills and providing them with opportunities to practice these skills.

While Massachusetts was working on its initiative, a number of other mental health programs for adults and children throughout the country also began to work toward reducing the use of S/R. In 2002, the National Association of State Mental Health Program Directors (NASMHPD), through its National Technical Assistance Center for State Mental Health Planning (NTAC), was given the resources to create a national training initiative called "Creating Violence Free and Coercion Free Mental Health Treatment Environments for the Reduction of Restraint and Seclusion" (NETI, 2003). Mental health leaders from Massachusetts contributed what they learned from their programs to support the development of this national initiative.

Nationally, the President's New Freedom Commission on Mental Health issued a report and guidelines in 2003 designed to transform the way we care for people with mental health needs (New Freedom Commission on Mental Health, 2003). Massachusetts identified a number of areas that needed improvement in its programs that dovetailed with many of the recommendations in this report. This *Resource Guide* was created to support programs that want to become part of this national movement to provide better services to children and families.

This *Resource Guide* and the New Freedom Commission Report promote emerging promising practices and

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interventions, sensitivity to trauma, respecting and empowering children and families, and focusing on resiliency. The children and families we serve deserve a renewed commitment to strength-based care, and programs can accomplish this by establishing and sustaining affirming, trauma sensitive, non-violent treatment cultures.

## Purpose of the *Resource Guide*

This *Resource Guide* was designed to provide administrative, clinical, and direct care staff with a menu of approaches, tools, and treatment strategies that can be used to establish positive treatment cultures. It is a compilation of effective strategies that were used in Massachusetts programs to reduce and/or eliminate S/R to date. The interventions that are described in this *Resource Guide* are not an exhaustive list, and it is important to note that new ideas about improving program practices are evolving as the Massachusetts programs continue to advance and make changes and as other programs across the country join in the effort.

This *Resource Guide* discusses core interventions that are meant to provide readers with a basic understanding rather than an in-depth or step-by-step implementation plan. There is additional material at the end of each chapter for more information about each topic.

The *Resource Guide* was originally written to support hospital and residential programs, but the interventions have been found to be effective in day programs, partial hospitalization

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programs, and other treatment settings. It is intended to be useful for staff members of all disciplines.

The *Resource Guide*:

- provides information and tools that support organizations, leaders, clinicians, and direct-care staff in implementing strength-based care and reducing/eliminating the use of coercive interventions;
- addresses administrative considerations that are vital to sustaining changes in philosophies of care and program treatment cultures;
- introduces the concept of strength-based care, describes its value in treatment settings, and provides examples of adaptable interventions and current best practices;
- focuses on empowering and collaborating with children and families and suggests tools and strategies for accomplishing these goals;
- emphasizes valuing families and provides guidelines for becoming more “family friendly”;
- addresses the impact of trauma on children and suggests treatment strategies for use in inpatient and residential treatment that include but are not limited to individual crisis prevention tools and sensory-based treatment approaches;

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- emphasizes a multifaceted approach in creating a supportive environment, from innovative use of physical space to creating partnerships between children, families, and staff members;
  - includes references to emerging promising practice literature that links the reduction of coercive interventions to treatment benefits and clinical outcomes;
  - contains narratives from clients about their experiences of S/R;
  - includes information on legal limitations and liability in the use of S/R; and
  - draws on state-of-the art knowledge from national and local experts in key areas related to improving inpatient culture.

Program leaders may want to introduce the guide to staff members, explain its purpose, and encourage them to read it and learn about the different elements that provide the foundation for strength-based treatment cultures.

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### Overview

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# Leadership

## Creating Culture Change

**Kevin Ann Huckshorn, RN, MSN, CAP, ICADC**

**Janice LeBel, Ph.D.**

“ Some are born great, some  
achieve greatness, and some  
have greatness thrust upon ‘em ”

Shakespeare, from *Twelfth Night*

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# Leadership

This chapter has been extracted and synthesized from the National Association of State Mental Health Program Directors' (NASMHPD) National Technical Assistance Center (NTAC)'s curriculum on eliminating treatment violence and coercion. This curriculum is part of the NTAC National Executive Training Institutes (NETI) and has been taught to more than 3,000 people from 48 states and territories in the United States as well as states within Australia and New Zealand. The Department of Mental Health thanks Kevin Ann Huckshorn, RN, MSN, CAP, ICADC; Executive Director of NTAC, for the generous use of this material.

**T**he National Executive Training Institute (NETI) has been advancing the national initiative to reduce S/R. In 2002, experts from around the country met to identify core strategies to make culture and practice change. The experts, most of whom had already successfully reduced or eliminated seclusion and restraint in their respective states or facilities, agreed that leadership was the single most important core strategy in this culture change process.

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## How can leaders create culture change to reduce S/R?

Simply put, leaders have the power, the role, and the authority to make the changes that are necessary for S/R reduction/elimination success, such as:

- Making and keeping S/R reduction a high priority
- Creating a plan for S/R reduction/elimination
- Reducing or eliminating organizational barriers
- Providing the necessary resources
- Holding people accountable for their actions
- Identifying and valuing champions who are committed to this work

## What are the key leadership principles to creating culture change?

### **1. Commitment**

Programs that want to create violence-free, strength-based, collaborative treatment environments must have leaders who are dedicated to these values and willing to make changes to existing policies, procedures, and practices to make that happen. This process can be difficult and time-consuming. It requires commitment, resources, and patience.

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Changing culture and practice generates a lot of anxiety. People may feel nervous, unsure, or skeptical. This is a natural part of the process. But leaders must hold the staff member's anxiety and be willing to model the same behavior that is expected of staff members – utilizing a style of management that empowers and supports all staff.

## **2. Mission, vision, and values**

Many program leaders in Massachusetts, other parts of the United States, and in other countries have revised their:

- mission statements
- vision statements, and
- core values/principles

as the first step in their strategic planning process. Generally speaking, these revisions include incorporating language that reflects the desire to establish affirming, trauma-sensitive, non-violent, strength-based treatment cultures that promote collaboration rather than control. This step is generally followed by the development of an organizational position statement about the goal of the reducing and striving to eliminate S/R practices.

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Program mission statements reflect the core purpose of the program and should be inspiring and easy to communicate. Program vision statements are broad statements that describe the program's aspirations for the future. Bill Anthony, cited in the NETI Leadership module (2006), states:

**“A shared organizational vision is like a magnet, it attracts people with its special characteristics.”**

Mission and vision statements can be communicated to staff members in many ways, such as the use of metaphors, anecdotes, personalized accounts of S/R, and experiences with trauma-informed care. Mission and vision statements are important because they define who the organization is, help energize staff members, and mobilize them to work toward a common goal. They also provide a sense of purpose to staff members, children, families, and the community.

### **3. Clarifying organizational values**

Once a program vision has been established, program leaders must set clear goals for reducing and striving to eliminate S/R based on the program vision. They must also create a program culture that identifies and lives by the key values of violence-free, coercion-free care. Many programs in the Massachusetts initiative have moved from being rule-based, institutional, impersonal, and, at times, coercive, to providing person-centered care based on respect and meeting the unique needs of each individual.

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This is the point in the change process when programs conduct a comprehensive reality check and start to reexamine:

- Program policies
- Program procedures
- Treatment activities
- Rules
- Schedules
- Historic practices
- Traditions, beliefs, and unspoken rules that persist

Basically, everything must be reconsidered, reevaluated, and measured against the new program values of creating a strength-based, non-violent, respectful and caring culture that facilitates S/R reduction/elimination.

This is when you ask yourselves, “Is what we say, actually what we do?”

*Practice what you preach - examples*

<b>Value:</b>	Individualized Person Centered Care
<b>Practice:</b>	Everyone goes to bed at 9:00 PM and lights out
<b>Change:</b>	There is a range of bedtimes to accommodate differences in bio- rhythms, nighttime difficulties, and preferences.

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<b>Value:</b>	S/R only used for imminent danger
<b>Practice:</b>	Any kind of property destruction, threats, physical acting out results in S/R use
<b>Change:</b>	Children who engage in one time only hitting, break furniture, kick a staff person, throw something, or otherwise act out and then calm down are not put in seclusion or restraint but addressed in treatment team.

<b>Value:</b>	Program is trauma-informed
<b>Practice:</b>	Trauma not formally assessed or in treatment/crisis plans. Environment gives mixed message: rules posted, no welcome sign, institutional décor/color, metal detectors, searches, locked/alarmed doors, S/R rooms
<b>Change:</b>	Soften environment & reflect trauma awareness in treatment and program operations.

*Using respectful language that recognizes the person*

“Person-first” language is the preferred language for person-centered care and explicitly refrains from using labels and terms that are distancing, dehumanizing, institutional, and not recovery-oriented, such as: units, wards, line staff, in the trenches, non-compliant, manipulative, attention-seeking, an actress, etc. Person-first language is respectful and reflects the philosophy of how we speak about something is indicative of how we feel about and value it.

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Person-first language encourages individualized, respectful descriptions that do not label. For example it is better to say someone “has schizophrenia” rather calling them “schizophrenic.” People are not their diagnoses. Person-first language reminds us that the people we serve are, just like us, sons, daughters, friends, neighbors, employers, employees, students, teachers, and so much more than their illness or the challenges they face.

*Examples:*

- At **Central Louisiana State Hospital in Alexandria, Louisiana:** Adolescents who are hospitalized at Central Louisiana State Hospital are referred to by their given name and called “students” by all the staff. Their policies and procedures refer to “students.” The hospital leadership believes this is an important way for everyone to remember that the adolescents are there to learn, and the job of staff is to teach, support, and coach.
- At **South Florida State Hospital in Pembroke Pines, Florida:** Adults who are hospitalized at South Florida State Hospital are referred to as: “*persons served.*” This may seem different – but all the staff use this language to describe every person who is hospitalized at that facility. This is what consumers said they preferred to be called. It also reminds staff of their role, to help and serve the people in their care.

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## 4. Using human technology! Empowering, supporting, and supervising staff

It is important for program leaders to empower the staff members who provide care to children in their programs. This entails sharing the program mission and vision, and providing the skills, information, authority, and resources necessary to carry out their responsibilities.

This can be done through on-going training, education, support, and supervision as well as involving staff members in program decision making. The goals are for staff members:

- to become empowered to negotiate with and empower the children so that they can provide choices that are “win-win,” and
- to value the avoidance of trauma and re-traumatization more highly than compliance with program rules.

Weekly supervision and on-going training opportunities provide staff with the tools and information that they need to care for and treat the children in the program. It also ensures that new standards are well-integrated into the program culture and sustained over time.

To create a positive caring culture, training for staff must include trauma-informed care, understanding the impact of trauma on children, assessing traumatized children, learning and practicing verbal de-escalation techniques, utilizing individualized crisis prevention (Safety Tools), and eliminating power and control struggles with children.

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Changing a program culture also means changing the staff culture. This can be accomplished if staff:

- understand the reason that change is needed
- are willing to try to do things differently
- are given new tools to use and understand how and when to use them
- receive ongoing supervision and feedback about their performance
- feel empowered and supported

Other ways to help staff feel like an important and active part of this change process is to have staff members:

- attend good training programs
- visit other successful programs
- spend time conceptualizing, implementing, and overseeing the program's strategic plan and change initiatives
- bring their skills and talent to the program! Lead poetry classes, teach yoga, coach a sport, and organize music groups, boy/girl scout troops, chess clubs, etc.

## 5. Using data to inform practice

Leaders should use data to inform their efforts to reduce S/R in their programs. They should gather historical data (six months to a year) to use as a baseline and then set realistic goals for reduction of S/R.

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There are a number of variables that are important to gather and track to analyze events as part of a reduction/elimination plan, including:

- Unit/Day/Shift/Time of Day
- Age/Gender/Race
- Date of admission/diagnosis
- Attending physician
- Pattern of staff involved in events
- Number of grievances
- Precipitating events
- Safety issues justifying S/R

Data must be used to monitor the program's progress, share with staff, inform new practices, and to identify training needs. Data must be posted, visible, used, and common knowledge among the staff. Measuring S/R is a clear way that programs can explicitly see what they are doing and what works and what does not.

Many programs around the country actively use their data:

The Merrimack Center BIRT in Tewksbury, Massachusetts has been using an advanced data program that creates real-time charting of acuity and allows staff to see what is really happening in the program and with each adolescent, in the moment, and over time.

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In Pennsylvania, the adult state hospital system issues monthly S/R reports electronically which are emailed to a national listserv of within-state and out-of-state interested parties. They share aggregate data to ensure transparency, one of the goals of the New Freedom Commission Report, and to vigilantly measure what they are doing and where they are going as they plan to eliminate S/R in all 8 state hospitals by January 1, 2007.

At Fulton State Hospital in Missouri, every unit has a S/R Bulletin Board maintained by consumers and staff. Staff members post the data and offer unit-to-unit consultation to their peers. Consumers post their experiences in S/R and write thank you notes to staff who helped them avoid S/R. Written recommendations are offered from the “Peace Club” about how to “keep the peace.” Data helps keep everyone focused around this common goal of increasing safety and decreasing S/R.

Some states, such as California, embrace transparency by posting S/R data from their inpatient systems on their state’s web site at:

<http://www.dmh.cahwnet.gov/Reports/Seclusion&Restraint/default.asp>

## **6. Leaders develop a S/R plan**

To effectively implement an organizational and cultural change process, the initiative has to be planned, written down, and be part of an overarching strategic action planning process.

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In Massachusetts, the importance of developing a strategic plan to prevent S/R was part of the Child/Adolescent S/R Prevention Initiative since its inception. Now, this planning requirement is included in the new DMH regulations governing S/R (104 CMR 27.12: Prevention of Restraint and Seclusion and Requirements When Used), which were promulgated on April 3, 2006.

The new regulations require facilities governed by the regulations to develop and implement a plan to reduce, and wherever possible, eliminate the use of S/R. The DMH regulations offer an important degree of specificity and detail to help every facility frame their S/R prevention effort.

The NTAC NETI curriculum offers an overarching framework that leaves customization to the state/facility or treatment setting. They recommend that the plan should:

- Adopt a prevention approach;
- Utilize Performance Improvement Principles (CQI) with action steps, responsible parties, goals, timeframes and the names of individuals responsible for action steps within the plan;
- Involve a stratified, multi-disciplinary team with all levels of staffing represented;
- Be shared, and the team should meet on a regular basis to review data, measure progress and update the plan and action steps;

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- Identify a realistic, measurable goal and core strategies to be implemented;
  - Include the people we serve in the planning and implementation of the initiative. We have much to learn about what works, what doesn't, and how consumers and families think we can improve the care we provide. While consumer involvement can be challenging with short lengths of stay, it is still possible to solicit input in creative ways.

**Example:** The Hunt Center in Danvers, Massachusetts creatively solicits input and feedback from families and visitors with an attractive form positioned right at the entry way. We need the voice of consumers - they are our customers.

**Example:** At Tewksbury State Hospital in Tewksbury, Massachusetts, three of the consumers who posed the greatest treatment challenges for staff were asked to make up an expert advisory panel for their S/R strategic planning effort. Some of Tewksbury's most important and useful recommendations came from consumers who could share exactly what helped, what didn't, and what strategies would be more effective.

## Summary

Program leaders are responsible for creating and maintaining a caring treatment culture that reduces and strives to eliminate S/R, violence and coercion.

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This requires rethinking and likely redrafting portions of mission and vision statements and agency values with all staff members. It requires a thorough review of all program policies and procedures to assess for congruence between what programs say they do and actual practices and to be sure these important documents reflect the new values and the direction of the program. This process also includes developing and regularly reviewing job descriptions and staff competencies, supervising annual performance reviews, overseeing program and agency operational goals, and measuring program outcomes.

Program leaders must anticipate the natural tendency for staff members to return to past treatment practices, particularly when stressed. Past practices are more familiar and comfortable. It is important for leaders to create systems that can quickly recognize and respond to any departures from the revised program values and goals.

Supervision is an important way to teach and reinforce new skills and to recognize and reward staff members' successes and hard work. Formal evaluation systems should be developed to assess whether staff members have learned the skills necessary to meet the new expectations and are using them regularly with all of the children.

Most importantly, leadership carries the responsibility for sustaining the effort and keeping it going! *It takes a long time and hard work to change thinking and practice... this is marathon work!*

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### Leadership

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# Strength-Based Treatment

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“ It is only with the heart that one can see rightly; what is essential is invisible to the eye. ”

Antoine de St. Exupery  
from *The Little Prince*

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# Strength-Based Treatment

**T**raditionally, most inpatient and residential programs use a pathology-based approach to treatment, where there is considerable focus on the psychiatric diagnosis. While the child's diagnosis is important, an overemphasis on pathology may cause the staff to view children as the problems they present rather than the people they are. A new movement in mental health is person-centered care, where staff members are encouraged to respect and partner with children and their families instead of focusing on limitations.

Treatment programs that use strength-based practices view each child as a unique individual with strengths, capacities, and challenges. Resiliency research studies have found that when children successfully overcome challenges and achieve positive outcomes, their accomplishments are usually a direct result of their strengths (Davis, 1999; Grotberg, 1995; Wolin, 1993; Bernard 2004).

In strength-based treatment, staff members teach children and families new skills to deal with problems rather than respond to disruptive or problematic behaviors with coercive interventions. This approach allows children and their family to be active participants in their treatment.

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## Moving towards strength-based care

Programs that want to move toward a strength-based treatment model must evaluate the attitudes and beliefs of their staff members and specific program practices to ensure they emphasize collaboration rather than control.

The following are examples of how strength-based practices can be incorporated:

- **Identify strengths from the start** – Staff members should identify the child’s talents and strengths from the initial assessment. Three areas to look at are interpersonal characteristics (e.g., honest, funny), everyday living skills (e.g., grooming and cleanliness), and talents in specific areas (e.g., sports, academics, art, music) (Grotberg, 1995). Once the child’s specific strengths are recognized, staff can create opportunities where the child can participate in activities that match his/her talents.
- **Look for opportunities for praise** – Staff should be committed to finding various ways throughout the day to give children praise for their accomplishments. It can be as simple as reminding them that they are special and using empathy statements that are specific and sincere. Staff should reward positive behavior and create opportunities to showcase the children’s accomplishments (i.e., bulletin board of artwork).

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- **Encourage mutual appreciation** – Staff members should create an atmosphere where children acknowledge their own strengths and successes as well as the strengths of their peers and staff. Staff should establish an atmosphere where children are encouraged to express their feelings and negotiate with staff.
  - **Share strengths with family** – Staff members should share something positive about a child every time they speak with the child’s family and point out the strengths the family possesses. Staff should also maintain a positive outlook about the future and share it with the child and their family.
  - **Staff Meetings** – Staff should actively observe children’s behaviors and have an understanding of how the use of praise affects their behavior. They should provide feedback to their co-workers and work together on how to be more effective in incorporating strength-based care ideas in their program.

Please see the *Promising Practices* chapter for more information.

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## Positive outcomes resulting from the use of strength-based approaches

Programs in Massachusetts have experienced some or all of the following positive outcomes after implementing strength-based treatment approaches:

- Children view themselves in a more positive manner and feel more confident as a result of frequent and sincere praise by staff members. When a child's self-esteem improves, he/she may focus less on negative thoughts.
- The overall level of problematic behaviors decreases when staff members increase their use of praise with all of the children in the program (Furst et al., 1994).
- Children, families, and staff feel more hopeful about the future.
- Staff members find it more enjoyable and rewarding to work in a program where the focus is placed on enhancing strengths rather than controlling behavior.
- Length of stay is shorter in programs that use collaborative practices with children and families.

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## Strength-based treatment beliefs

### **SBT:**

- Is collaborative
- Rewards positive behaviors
- Teaches new skills and provides opportunities to practice these skills
- Emphasizes discussion and negotiation
- Provides the child with choices
- Views the child as resilient
- Views the child's parents or adult supports as caring and competent
- Is committed to understanding the child on *multiple* dimensions

### **SBT does not:**

- Rely on control
- Focus on reacting to negative behaviors
- Utilize confrontation and rigid limit setting
- Implement sanctions and punishments
- View the child through his/her limitations
- View parents or adult supports as obstacles to recovery
- Assess the child on a single dimension

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## Moving from Control to Collaboration

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If the person you are talking to doesn't appear to be listening, be patient. It may simply be that he has a small piece of fluff in his ear.

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*Pooh's Little Instruction Book,*  
inspired by A.A. Milne

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# Moving from Control to Collaboration

**M**any treatment programs operate with an inherent philosophy that providers know what is best for the child, and that the child's behavior needs to be externally managed. This philosophy enforces an "us vs. them" mentality and creates harsh boundaries and distance between staff, children, and their families. Ross Greene, Ph.D. identified that staff control issues and reinforcement of rules were found to precede the majority of incidents of S/R (Greene, 2004). Below are four "slippery slopes" that may create problems when programs overemphasize control (Adapted from NETI Training Manual, 2004; Morrison, 1989).

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**Slippery Slope 1:** The primary focus is on the needs of staff members rather than the treatment needs and goals of the clients. Treatment activities are organized around what is convenient.

**Slippery Slope 2:** Rules become very important and inflexible. Compliance and containment are valued and are sometimes mistaken for clinical improvement. There is a lack of recognition of client re-traumatization if and when it occurs.

**Slippery Slope 3:** Minor rule violations by children lead to control struggles with staff members. Privileges become a source of greater control struggles because staff members threaten to take them away when children don't comply or exhibit behavioral challenges.

**Slippery Slope 4:** Inexperienced or under-trained staff members bully children into compliance based on subjective observations about their behavior. Some programs reward staff for maintaining safety and having quiet shifts but do not realize that the results may have been achieved by using coercive methods.

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Fortunately, there is a newer trend in treatment settings that focuses on minimizing the use of controlling practices in inpatient and residential treatment programs. These practices shift the emphasis from controlling behavior to forming collaborative partnerships with children and families. The underlying philosophy of the collaborative treatment approach is based on treating children, families, and staff members with dignity and respect.

Staff members view children as capable human beings and encourage and value input from children and their families in decision making. They respond to challenging behavior with empathy, active listening, and interventions that engage the children in finding solutions (NETI, 2004). Several treatment programs in Massachusetts that have significantly reduced S/R rates have also embraced collaborative approaches (LeBel, Stromberg, Duckworth et al., 2004).

## Collaborative problem solving

Ross Greene, Ph.D., a well-known child psychologist in Massachusetts, developed a specific treatment model for children and adolescents, called *Collaborative Problem Solving* (please see the short description in the *Promising Practices* chapter). This approach focuses on understanding the child's behavior as a statement of frustration and recognizes that the circumstances that elicit the behavior are beyond the child's ability to manage.

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The focus of the model and interventions is to engage in a problem-solving process to create greater understanding and help the child and family develop the skills to manage stressful situations (Greene, 2005). By using a collaborative and respectful approach, parents and staff members have found that they are often able to avoid power struggles.

## Case example using a collaborative approach

<b>Staff:</b> “You are being restrained daily. How can we help you stay out of the safety coat?”
<b>Adolescent:</b> (firmly): “I <i>want</i> to be restrained.”
<b>Staff:</b> “We have to think of other ways to help you feel safe. (pauses) Would a sleeping bag help?”
<b>Adolescent</b> (thinks for a moment): “Can I have the kind that gets tight at the end?”
<b>Staff:</b> “Yes, do you also want to use a weighted blanket on top?”
<b>Adolescent</b> (brightening): “Yeah...when can you get the bag for me?”

## Applying a collaborative problem solving approach - One unit’s success

The Cambridge Hospital Child Assessment Unit (CAU) in Cambridge, Massachusetts adopted Ross Greene’s *Collaborative Problem Solving* approach, which helped them move from a culture of control to a culture of collaboration.

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This approach helps staff members view a child's behavior as the result of an inability to tolerate frustration and recognize the child's difficulty with flexibility.

Staff members learn specific ways to interact with children to decrease "meltdowns" and to identify the pathways that lead to "meltdowns." Staff members emphasize teaching new skills to children so they can experience more success.

One psychiatric resident who worked on the unit wrote, "When the leaders of the CAU started to think about changes, their first step was to change the mission from safety and containment to nurturance and teaching" (Harris, 2003).

## Examples of how programs can develop collaborative practices:

### 1. Empowering staff members:

- **Staff empowerment:** Staff members should feel empowered and encouraged to make decisions that will help children gain control or calm down, even if they go against expected programmatic routines (allowing a child to stay up past bed time to talk, allowing a child to be late to class because he/she feels stressed, or allowing a child to leave a meeting and walk outside to calm down).

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- **Staff are trained to use a collaborative approach:**  
Staff members should participate in on-going training in the areas of sensitivity, avoiding power struggles, and using collaborative approaches such as negotiation, alternative dispute resolution, conflict resolution, and collaborative problem solving.
  - **Staff interactions:** Staff members should listen to each other's ideas, model mutual respect, and involve each other in programmatic decisions. Once staff members work collaboratively, there is a natural transfer to their work with children and families.

## 2. Make use of strength-based and skill-enhancing treatment practices

- **Showcase strengths:** Bulletin boards and program materials use words that emphasize strength, collaboration, choice, and empowerment.
- **Give children a voice in their care:** Children are encouraged and supported in taking active roles in their own care. Staff brainstorms with children about rules, activities, and incentives; staff and children work on weekly menus together; and family/child advocates are invited to help prepare the children and families for treatment meetings.

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- **Staff members encourage family involvement:**  
 Staff encourage family members to take active roles in their child’s treatment, decision making, and planning. Meetings are scheduled based on family availability, there are open visiting hours, and the program provides support and education for family members.

## How to turn coercive statements into collaborative statements

Coercive/Control	Collaborative
“I told you to go to your room, now!”	“Taisha, I am sorry I cannot talk right now because there is an emergency I have to address on the phone. Would you mind waiting in your room, or would you rather sit down in the office and wait?”
“Everybody line up, it is time to go to dinner. No talking when walking.”	“We will be going to dinner in a few minutes. Remember, we must walk through halls quietly because people are working. Can some of you share with the new staff, Katie, some of the ways we try to be respectful when we walk to dinner?”

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Coercive/Control	Collaborative
<p>“Be quiet, it was not your turn to talk.”</p>	<p>“Erik, I am so glad you want to participate. Do you think you can wait until it is your turn to share your ideas?”</p>
<p>“No, you cannot do your laundry another day. Get up and start your laundry now.”</p>	<p>“Rasheed, I can understand that you want to finish your chess game. Do you want to do your laundry after the game or do you want to stop the game and ask Dean if he will trade with you? We only have the machines for two hours, so he’ll want to start if he is going to trade.”</p>
<p>“No, you cannot stay back from art class.”</p>	<p>“I noticed you were acting different today. Are you sad or upset about something, or are you not feeling well?”</p>
<p>“No, you cannot just leave community meeting.”</p>	<p>“I know it is hard for you to sit for a long time. I have the same problem. I use a squeeze ball whenever I get antsy. Do you think that would help you, or do you think using your mantra would help you feel comfortable staying longer?”</p>

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<b>Coercive/Control</b>	<b>Collaborative</b>
“If you don’t participate in group, you will lose points.”	“Wow, you usually love group. Do you want to talk about why you do not want to participate today?”
“If you don’t take your medication, you will lose your privileges.”	“I am really concerned about you feeling good. Do you think your medication is not working, or is it making you feel bad or different?”
“Are you questioning my authority?”	“From the way you responded, it sounds like I might have been too forceful when I told you to stop watching TV. Lanette, if we are going to make the movies in time, we need to leave now. I know you wanted to go. Do you still want to go or do you want to stay and watch the program?”

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## Positive outcomes in programs using collaborative approaches

The following positive outcomes have been noted in programs in Massachusetts that are using collaborative treatment approaches:

- Decreased use of S/R
- Relationships are nurtured between staff, children, and families
- Staff members use empathy and support to help children participate in the program to the greatest extent possible. They use a variety of tools to help children stay calm and in control
- Children and staff learn new ways to solve problems
- Staff recognize that all behavior is meaningful, and challenging behavior indicates that a child's needs are not being met. They work to understand what the child is trying to communicate through his/her behavior. Staff think about how they can respond to the behaviors, using concepts such as "giving a child a flashlight because he is lost in the dark," "helping a child succeed by taking away roadblocks," or "acting as a tour guide to support a child out of a mess."
- After a difficult behavioral episode, staff members tell the child, "I am sorry you were upset and we did not help you stay calm. Can you think of something we could have done to be more helpful?"

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- Staff, children and families all feel more satisfied with the program.
  - Children have reduced lengths of stay in out-of-home programs that actively partner with families (Stroul & Friedman, 1986).

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## **Giving People a Voice, Choice, and Role**

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“Empowerment is not a program. It is a core condition for quality. You can't give, bestow, grant or authorize, delegate or impose empowerment. You create conditions to develop it.”

Steven Covey

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# Giving People a Voice, Choice, and Role

## Overview

**M**ost experts in the medical and mental health fields emphasize the importance of the people we serve being full partners in making decisions about their treatment needs. The concepts of collaboration, partnering, and empowerment (which is defined as, “To give authority or power to” by Merriam-Webster (1997)) have become a focus for adult and child mental health movements.

The Center for Mental Health Services and several states (e.g., New York, Vermont, Massachusetts) recognized the need to create empowerment opportunities for children and adolescents with serious emotional disturbances (SED). Subsequently, treatment programs have begun to hire young consumers as advocates and as participants in work groups and task forces. Programs have also begun to financially support practices that promote partnerships and empowerment of children, such as peer mentors, youth support groups, statewide youth leadership conferences, youth leadership courses, and weekend youth retreats.

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## How to begin

Although many programs that care for children have treatment philosophies that recognize the importance of fostering independence, actual program practices often rely on control and encourage children to conform to rules of group living. Many staff members have personal belief systems that children should be seen and not heard, and that children develop problems as a result of having too much freedom.

Moving from a treatment culture that emphasizes control to one where staff members work collaboratively with children requires a great deal of work. Program leaders must reassess their mission, vision, and values, and review practices and make changes to promote values of empowerment, inclusion, and partnership with children and families.

Programs that promote empowerment and partnerships view themselves as “being on the same team” with the children and families they serve. They willingly give over some authority to and share decision-making with the children, taking their age, developmental ability, interests, and needs into consideration. Younger children may have more limited input into daily choices and treatment options than older children.

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Programs that promote empowerment:

- Involve children in making decisions about their treatment.
- Involve children in making decisions about aspects of programming.
- Involve children by giving them leadership roles in the program.
- Teach children skills related to leadership, decision-making, and empowerment.
- Ensure that staff members are committed to including children and families in decisions about care.
- Ensure that staff members are competent in teaching skills that help empower children and families.

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## Program practices that promote empowerment and partnerships with children

There are many changes that programs can make to promote empowerment and partnerships, including:

- Hold a series of staff training sessions on how to partner with and empower children.
- Contract with a youth leadership trainer to provide children and staff with experiential training on youth leadership. Provide an interesting and challenging youth-oriented or youth-responsive leadership curriculum, such as ropes courses or adventure-based/experiential learning courses, which the children are involved in on a weekly basis.
- Involve children in programmatic changes by inviting a group of staff and children to visit other programs that have incorporated empowerment and partnership practices and share what they learn. Allow the children to help strategize about needed changes within the program.
- Solicit input from children formally by including them in programmatic decisions and understanding that even small choices can be empowering such as: planning menus, time of group activities, asking where they want to sit as well as other aspects of the program.

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- Involve children in discussions about expectations, privileges and consequences, and allow them input about the program’s accountability mechanisms. Many programs use privilege/point/level systems but a growing trend in Massachusetts programs is moving away from these depersonalized, coercive practices to child/youth centered care where teaching/reparation are individually-driven, not part of a one size fits all approach. Children’s mistakes should be used as opportunities for learning and should be addressed as “teachable moments.”
  - Ensure that the child and family have input in decisions about the child’s privileges. Home visits, time spent outdoors or in activities, regular snacks and opportunity to visit with family members should never be taken away because of misbehavior. If harmful behavior/interactions are a concern, the program and the family can work together to develop a specific plan, but family visitation is a right, not a privilege, unless there is a clear protective concern.
  - Set up treatment planning and treatment review practices that fully involve children in their treatment, and include what they see as their difficulties and where they need the most help.
  - Create a child-friendly physical environment including positive inspirational messages, creative signs and posters that promote partnership, empowerment, youth leadership, and self-determination.

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- Frequently point out individual strengths of children and talk with them about how their strengths will help them be successful.
  - Have youth empowerment and leadership opportunities that create a formalized voice for children, such as student government, a youth advisory council, youth representatives to the executive committee, youth co-leading groups and activities, or a mentoring program. Many programs pay children a stipend to assume these leadership roles to underscore the importance and value of the task/effort.
  - Utilize a social skills curriculum that can be adapted to different developmental levels. It should focus on empowerment, leadership skills, assertiveness training, problem solving, making choices, making decisions, being responsible, offering suggestions/feedback, saying no, disagreeing with others, reporting whereabouts, building trust, honesty, expressing concerns, etc.

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## Expected outcomes for programs that promote empowerment and partnerships with children and their families

Programs that promote empowerment and partnerships with children and their families often find positive changes, including:

- The program uses less seclusion and restraint.
- Children become more confident and learn skills related to decision making, leadership, and self-determination.
- Staff members, children, and families feel more satisfied with the program.
- There is less tension between staff and families because families feel important and valued rather than marginalized and blamed.
- Staff members feel empowered and less threatened, and they view their role as supporting, teaching, and partnering, rather than one of making decisions and controlling.
- Staff members find themselves spending more time proactively teaching and talking, thereby focusing on the positive, and less time reacting to problems, thereby not focusing on the negative.

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- Programs are more meaningful to children if they offer a wider variety of child-friendly groups and activities. Children are then more likely to enthusiastically participate.
  - Children have leadership roles in many areas of the program, such as leading groups, checking chores, participating in student council, and being youth advisors to the program executive team.
  - Programs promote youth empowerment interventions, which have been found to produce empowerment and health outcomes, including stronger self-efficacy, increased participation in social activities, and improved mental health and school performance (Wallerstein, 2006).

## Involving people in their treatment— Client roles in treatment settings

In her 2007 guidebook entitled *Paving New Ground, Peers Working in In-Patient Settings*, Gayle Bluebird identified and highlighted hospitals in the United States that have successfully developed roles for peers (Bluebird, 2007). She reported that peers work in many different capacities across the country: as advocates, counselors, educators, and evaluators in public and private facilities, and that the possibilities for their involvement are endless. Involving peers has the potential to create culture change in every aspect of treatment. Although Ms. Bluebird wrote about adult roles, there are also many opportunities for

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treatment programs to create roles for children and adolescents to help them become more active in program decision-making and program planning.

## Peer roles for children and adolescents in Massachusetts treatment programs

The Massachusetts Department of Mental Health (DMH) provides children and adolescents with opportunities for involvement in DMH programs, projects, and events. DMH values their input and perspectives and pays youths for the time that they spend on these projects or in identified roles. What follows are some of the creative positions that youth have held that help to enhance DMH services offered:

- **Youth Advisors**

This role is broad and implemented differently in different settings. Youth Advisors have helped to serve as peer supports. In addition, they also:

- give tours to potential residents and their families,
- critique unit rules/activities,
- interview prospective staff,
- participate in developing program materials, and

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- solicit input from their peers to present to staff regarding a range of issues from food, to scheduling, to group efforts outside of the program (i.e., organizing bake sales for fire victims, participating in the Heifer Project, adopting a needy family at holiday time, donating to Toys for Tots, etc).

Youths in several DMH treatment programs also participated in developing program handbooks with pictures and information for youth and families being offered services by the programs. The youth had brainstorming sessions where they discussed important aspects of the program and information about the program to include in the handbooks. Youths also gave tours to a photographer and gave input about how to represent the program pictorially.

At the final stages of the project, youths act as a review committee for the handbook project by reviewing and making final suggestions for changes and improvements in the final product. Youths were paid for the time that they spent assisting with this important effort.

- **Youth Council / Student Council Representatives**

The Youth Advisor role has also been more formalized and organized through unit/program Youth Councils or Student Councils. The Councils usually have full peer community membership, and peer leaders are selected/elected and serve as representatives of the

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peer community in order to provide formal feedback and input to unit/program leaders. Youth Advisors and Youth Council representatives are compensated for their time and contributions.

- **Youth Rights Officer**

This role has been implemented in some adolescent treatment programs as a way for young peers to educate each other about their rights in these settings. This role does not take the place of a unit/program Human Rights Officer, rather it supports the program's human rights efforts. Typically, the Youth Rights Officer will help to reinforce the information already provided by the unit/program's Human Rights Officer by reviewing, in their own words, the rights they have in the treatment program.

The Youth Rights Officer also helps to administer a brief Human Rights quiz to the new peer, reviews the results with the Human Rights Officer and the peer, and helps to explain any misunderstandings. Concerns about significant human rights issues are not the responsibility of the Youth Rights Officer and serious concerns, if raised, are referred to the unit/program leadership and the Human Rights Officer. It is preferable for there to be more than one Youth Rights Officer, so they can support one another.

The unit/program's Human Rights Officer trains, supervises, and meets frequently (at least weekly)

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with the youths in this role. Youths apply for the position, participate in an interview process with the Human Rights Officer, and are paid a weekly stipend for their service.

- **Youth Human Rights Committee Member**

This role is currently implemented in Massachusetts statewide treatment programs. Youths participate in bi-monthly evening dinner meetings with peers from other programs to talk about human rights issues, general concerns, treatment needs, environment of care matters, etc. The Committee is facilitated by the Director of Child/Adolescent Human Rights and the Coordinator of Interagency Activities, and every youth is paid for their participation.

- **Teen Mentors**

Student graduates of a creative arts service are hired as Teen Mentors for this program. Teen Mentors fully participate as junior leaders and help to support younger peers during rehearsals, activities, outings, and performances. They provide the important service of role modeling and coaching. The Mentors participate in an array of creative arts activities (set design, dance, singing, painting) with their younger peers and also serve as program ambassadors with new youth and their families who are referred to the program.

The Teen Mentors also contribute to the creative process, offer tours of the studio, help explain the

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program, and provide reassurance, support and enthusiasm for the program to their mentees. Teen mentors are paid for their work.

- **Resident Support Team**

The Resident Support Team was designed and implemented in a long-term, secure, adolescent residential program as a very early intervention approach to a problem resolution. It was not and is not used as a crisis intervention approach. The intent is for senior peer leaders to be educated and supervised by a program clinical leader in how to mediate disputes or conflict and listen and provide support to peers. The Resident Support Team is used when an adolescent would rather seek support from a peer than talk to a staff member. Team members are educated about situations that must be reported to and involve program leaders. Team members apply for the role, are interviewed by a clinical leader, and, once hired, are paid for their work. They receive ongoing supervision while participating on the Team.

- **Youth Speakers**

Youths from inpatient, intensive treatment programs, and program graduates participate in conferences, grand rounds, roundtables and other events where youth perspective and expertise is needed. Youths are prepared for their public speaking engagement in advance which includes parent/legally authorized

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representative approval, meeting and discussion with program leaders about the nature of the event, and rehearsal sessions to practice public speaking and responding to questions.

- **Research Assistants**

Youths have been trained and paid as interviewers and research assistants for Consumer Quality, Inc., a mental health consumer-operated research, evaluation and quality improvement organization. Youths have also participated as Focus Group members to advocate for needs and improvements in youth mental health services in both the inpatient and community settings.

There are many creative ways to involve youth in their treatment programs. Youth involvement and empowerment is beneficial because it leads to the acquisition of new skills, it helps build self-esteem, and it gives young people the rewarding experience of offering something to others.

Even very young children can take on the role of a “buddy” to help a new child feel more comfortable and learn about a treatment program. Children can help keep their environment attractive and safe by performing “environmental rounds” with an adult to assess areas of needed repair. They can make decorations, paint murals, and plant flowers to contribute to an attractive program environment. Children can take on leadership roles in program meetings, they can give feedback to

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program administrators, and they can even take on roles that involve learning specific job skills.

One adolescent in a Massachusetts residential treatment program was “stuck” and unable to move to his next residential program due to a lack of available beds. Program staff creatively offered him a paid position in the administrative office where he learned secretarial skills and performed tasks that were very helpful to the Administrative Assistant. This job enabled him to feel that he was still making progress and moving towards his goals while he was waiting to move to another program.

## Young adult roles

The Transition Age Youth (TAY) Initiative at the Massachusetts Department of Mental Health was established to help young persons, ages 16-25, embark on a positive life path into adulthood toward the goals of obtaining personal stability, community housing, employment, and positive family/social relationships. Several young adult roles were created through the TAY Initiative:

- **Youth Councils**

Youth Councils are comprised of youth and young adults who meet monthly and participate in various activities related to mental health. It is also an opportunity for clients to express their needs and voice their concerns

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for mental health services. A Statewide Youth Advisory Council has also been created in which youth and young adults serve as an advisory board to the TAY Initiative. Council activities range from co-chairing meetings, learning advocacy and leadership skills, participating on advisory boards, creating public service announcements and websites about mental health stigma, and involvement with community service projects.

A Statewide Youth Advisory Council has also been created in which youth and young adults serve as an advisory board to the TAY Initiative and provide formal feedback and input to DMH on young adult services and programs. Youth are provided stipends for attending meetings.

- **Statewide Youth Coordinator**

The Statewide Youth Coordinator is responsible for coordinating the development/activities of the Statewide Youth Advisory Council, advocating on behalf of youth and young adult needs, organizing a venue for youth to express their voice (e.g., website development, *YouTube* videos), and coordinating efforts as they arise between youth, providers and DMH. It is a full-time, paid position.

- **Writing Collective Project**

A writing project was created for young women who were no longer eligible for DMH child and adolescent services due to their age and did not qualify for adult services. These authors wrote first person accounts of

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their transition experiences in “Youth in Transition Writing Collective: Recovery Stories Written by Inspiring Young Women.” The youth writers received stipends for their stories.

- **OTHERS (Other Teens Help Everybody Respect Self)**

The OTHERS is a youth group run by young people between the ages of 13 and 21 sponsored by the Parent/Professional Advocacy League (PAL) in Worcester, Massachusetts. The group serves as an educational and social support group for youths with mental illness.

Some of the group’s projects have included: development and distribution of public service announcements on mental health stigma; participation on a radio show discussing mental health; participation on a local Substance Abuse committee; involvement with a tobacco prevention campaign; advocating at the Massachusetts State House for mental health services; and, volunteering with community service projects (i.e., sponsoring a family in need, volunteering at an animal shelter). The youth meet twice a month, and they are provided with dinner and transportation to and from the meetings.

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## Peer roles for adults across the United States

There are a number of hospitals and treatment programs in the United States that have been active and creative in developing adult peer specialist roles. Some interesting roles are described in Ms. Bluebird's *Paving New Ground, Peers Working in In-Patient Settings*.

- **Peer Drop In Centers**

Some hospitals in Florida and Pennsylvania have programs that have developed peer run drop in centers operating on the grounds of state hospitals. Peers in these settings provide a place for clients to get away, relax, play games, have refreshments, form social relationships, and strengthen their skills of independence.

- **Peer Bridgers**

New York State developed the concept of "Peer Bridgers," which are teams created to help people transition from hospital to community when they are ready for discharge. A number of crisis centers around the country are also beginning to hire peers to support people who come to the emergency room in crisis.

- **Peer Run "Living Rooms"**

In Arizona, Recovery Innovations of Arizona, has peer-run "Living Rooms" in crisis centers, where people can

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stay up to ten days in a comfortable, recovery-oriented setting instead of being admitted to a psychiatric hospital.

- **Peer Support in Developing Hobby and Interest Groups in Hospitals**

Ms. Bluebird reported that one of the chief complaints of adults in inpatient psychiatric facilities is lack of interest and boredom with groups that are offered. At Riverview State Hospital in Maine, a peer specialist team provides a wide variety of art and hobby groups based on the interests of the people that they serve.

- **Peer Specialists on Inpatient Units**

Peer Specialists are consumers in recovery who are employed by inpatient units to participate in treatment team meetings, facilitate support group meetings, provide individual support, and to assist with discharge transitions to the community. The Peer Specialists also work to help bridge the hospital/community transition for clients and coordinate community supports.

- **Peer De-Briefer Position**

Massachusetts was the first state to create a peer specialist position of de-briefer as a professionally paid staff job in a state psychiatric hospital. A de-briefing is a process that assesses a crucial event, such as a restraint, by reviewing the sequence of events and talking with involved clients and staff members. The de-

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briefers then make recommendations as part of a team process about how similar events can be prevented in the future.

Clients are often more comfortable talking with a peer who has had similar experiences, and such conversations may lead to changes in the person's treatment plan as well as a decrease in incidents of restraint and seclusion. Massachusetts was one of eight states that recently received a federal grant to eliminate restraints and seclusions in state inpatient facilities.

DMH hopes to hire peers for De-Briefer/Patient Liaison positions in each of its inpatient facilities.

▪ **New, Emerging Roles**

There are a number of peer roles that are being developed across the country such as

- Peer Support Team Specialist,
- Peer Mediator,
- Resident Rights Officer,
- Consumer Advisor, Service Advisor
- Consumer Affairs Director,
- Trauma Specialist, Recovery Specialist,
- Peer Mentor,
- Crisis Prevention and Intervention Worker,
- Parent Coordinator,
- Program Evaluator,
- Wellness Educator, Vocational Educator.

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## Family roles

Parents and families can participate and provide support in various roles to increase awareness of familial needs, provide a parent and family perspective, advocate for their family members who have serious emotional disturbances or mental illnesses, and assist DMH and its providers in being family-friendly and family-driven.

Listed below are a few ways that parents and families can become involved in the care and treatment of their loved ones.

Please also see the document “AARC Position Paper – Redefining Residential: Becoming Family Driven” (AARC, 2006) provided at the end of the *Valuing Families* chapter for more ideas on family involvement and participation.

- **Members of Councils & Advisory Boards and Committees**

Parents and families participate as members on councils and advisory boards. As members of councils, parents assist in policy, planning and program development.

Parents participate on a number of boards, including: the Department of Mental Health’s *State Mental Health Planning Council*, the Executive Office of Health & Human Service’s *Children’s Behavioral Health Advisory Council*, the Professional Advisory Committee on Children’s Mental Health, DMH Area and site boards, the Statewide Advisory Council on Special Education, and

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committees focused on specific topics (i.e., school-district based Parent Advisory Committees on Special Education). Parents are also involved in proposal review committees.

- **Parent Coordinator (a.k.a. Family Support Specialist)**

Parent Coordinators provide support, information, and resources in the community for parents and families. They coordinate and conduct events for parents, such as parent support groups, conferences, trainings on mental health topics and on advocacy. They provide feedback to the state in the form of parents' perspectives by organizing focus groups and by assisting families in responding to surveys and requests for information to improve aspects of care.

- **Parent Peer Partners/Mentors**

Parent Partners are parent peer mentors. They can provide an adjunct clinical role. They support parents of children with SED in many ways, ranging from assisting parents in navigating and understanding the mental health system, the special education system, and insurance systems to strategizing about the day-to-day challenges of parenting a child with SED.

- **Presenters/Speakers**

Parents and families have been invited as speakers to present the family perspective in mental health settings.

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At a DMH provider forum in 2007, parents talked about forming provider and family partnerships and the importance of collaborating and including families in all aspects of a child's mental health treatment and care.

- **Support and Information for Brothers and Sisters (SIBS)**

Sponsored by the PAL Central Mass chapter, SIBS is a support group designed for sisters and brothers (between the ages of 5-14 years old) living with siblings who have emotional, behavioral or mental health challenges (PAL, n.d.). Parent support coordinators in other parts of the state also organize short-term or ad hoc events for siblings.

## “Building Bridges”

With the leadership and support of SAMHSA, a national summit of leaders, providers, families and youth was convened in Nebraska in 2006. The purpose of the meeting was to better integrate and link residential and community-based services and supports with the goal of supporting the transformation of children's mental health.

A Joint Resolution was developed that envisions a comprehensive, flexible family-driven and youth-guided array of culturally competent and community-based services and supports, organized in an integrated and coordinated system of care.

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The resolution underscores the importance of families, youth, providers, advocates, and policymakers sharing responsibility for decision making and accountability for the care, treatment outcomes and well-being of children and youth with mental health needs and their families.

This resolution was signed and supported by many leaders, states, and provider organizations and promotes the spirit and values identified in this *Resource Guide*. The “Building Bridges” Shared Core Principles can be found at <http://www.systemsofcare.samhsa.gov/hottopics/docs/BuildingBridgesJointResolutionFinalDraft82806.doc>

## Additional resources

The following resources are included at the end of this chapter:

- A sample staff competency on partnering with children
- SAMHSA descriptions of youth guided, youth directed, and youth driven treatment
- A sample Recovery Assessment that has been used on adult inpatient treatment units.

# Sample Staff Competency on Partnering with Children

Programs can use the following questions to assess whether staff members are learning to empower and collaborate with the children in their care:

Do the staff:

- Display voice tone and body language that denotes care and respect at all times;
- Communicate in a manner that reflects a belief in the strengths and abilities of each child. Examples include:
  - Frequently asking children about their thoughts/ideas by saying things like, “You are a smart young man, tell me what you think should be done in a situation like this.”
  - Asking for cooperation and/or participation rather than making demands
  - Actively providing choices for the child to consider, rather than just giving directions
  - Using words that promote partnerships, such as, “You are my partner on this, right? We can work to solve this problem together.”

- Demonstrate an understanding of the importance of giving children choices, focusing on empowerment, and supporting the child in developing self-determination, self-advocacy, and leadership skills;
- Actively provide opportunities for children to learn youth leadership and self-determination skills by:
  - Giving them opportunities to make choices
  - Helping them actively participate in setting treatment goals and making long term plans
  - Asking for their input in creating program rules, incentives, activities, and groups
  - Encouraging them and providing opportunities for them to express their concerns and discuss any problems or disagreements regarding consequences
  - Providing them with opportunities to take responsibility for themselves, their belongings, their surroundings, and their lives
  - Providing appropriate developmental freedom, such as allowing them to select their own friends, giving them permission to participate in activities, permitting them to choose their own activities during free time; and allowing them to learn from their own mistakes

- Encouraging their participation in activities that develop empowerment, like participating in unit committees, participating in new-staff interviews with peers, becoming a peer-mentor with younger/newer children in the program;
- Teach the children skills related to leadership, self-advocacy and self-determination, such as problem solving, making choices, making decisions, being responsible, offering suggestions, saying no, disagreeing with others, reporting whereabouts, building trust, honesty, expressing concerns, etc. (Goldstein et al, 1980).

**We proposed that the process of moving from youth guided, to youth directed, to youth driven happens at 3 levels: youth involvement at the individual youth level, the community and policy making level. This list illustrates what should be happening at each stage in the process as the young person makes their transition into adulthood. \*\* Youth should be young people who have experience as consumers and are or would be the youth served in a system of care community.**

## **Youth Guided**

<u><b>Youth Guided Individual</b></u>	<ul style="list-style-type: none"> <li>• Youth is engaged in the idea that change is possible in his or her life and the systems that serve him or her.</li> <li>• Youth need to feel safe, cared for, valued, useful and spiritually grounded.</li> <li>• The program needs to enable youth to learn and build skills that allow them to function and give back in their daily lives</li> <li>• There is a development and practice of leadership and advocacy skills, and a place where equal partnership is valued.</li> <li>• Youth are empowered in their planning process from the beginning and have a voice in what will work for them.</li> <li>• Youth receive training on systems players, their rights, purpose of the system and youth involvement and development opportunities.</li> </ul>
<u><b>Youth Guided Community</b></u>	<p>Community partners and stakeholders have:</p> <ul style="list-style-type: none"> <li>• An open minded viewpoint and there are decreased stereotypes about youth.</li> <li>• Prioritized youth involvement and input during planning and/or meetings.</li> <li>• A desire to involve youth</li> <li>• Begun stages of partnership with youth.</li> <li>• Begun to use language supporting youth engagement.</li> <li>• Taken the youth view and opinion into account.</li> <li>• A minimum of one youth partner with experience and/or expertise in the systems represented.</li> <li>• Begun to encourage and listen to the views and opinions of the involved youth, rather than minimize their importance.</li> <li>• Created open and safe spaces for youth</li> <li>• Youth are compensated for their work.</li> </ul>
<u><b>Youth Guided Policy</b></u>	<ul style="list-style-type: none"> <li>• Youth are invited to meetings</li> <li>• Training and support is provided for youth on what the meeting is about</li> <li>• Youth and board are beginning to understand the role of youth at the policy-making level</li> <li>• Youth can speak on their experiences (even if it is not in perfect form) and talk about what's really going on with young people.</li> <li>• Adults value what youth have to say in an advisory capacity.</li> <li>• Youth have limited power in decision making.</li> <li>• Youth have an appointed mentor who is a regular attendee of the meetings and makes sure that the youth feels comfortable to express his or herself and clearly understands the process.</li> <li>• Youth are compensated for their work.</li> </ul>

## **Youth Directed**

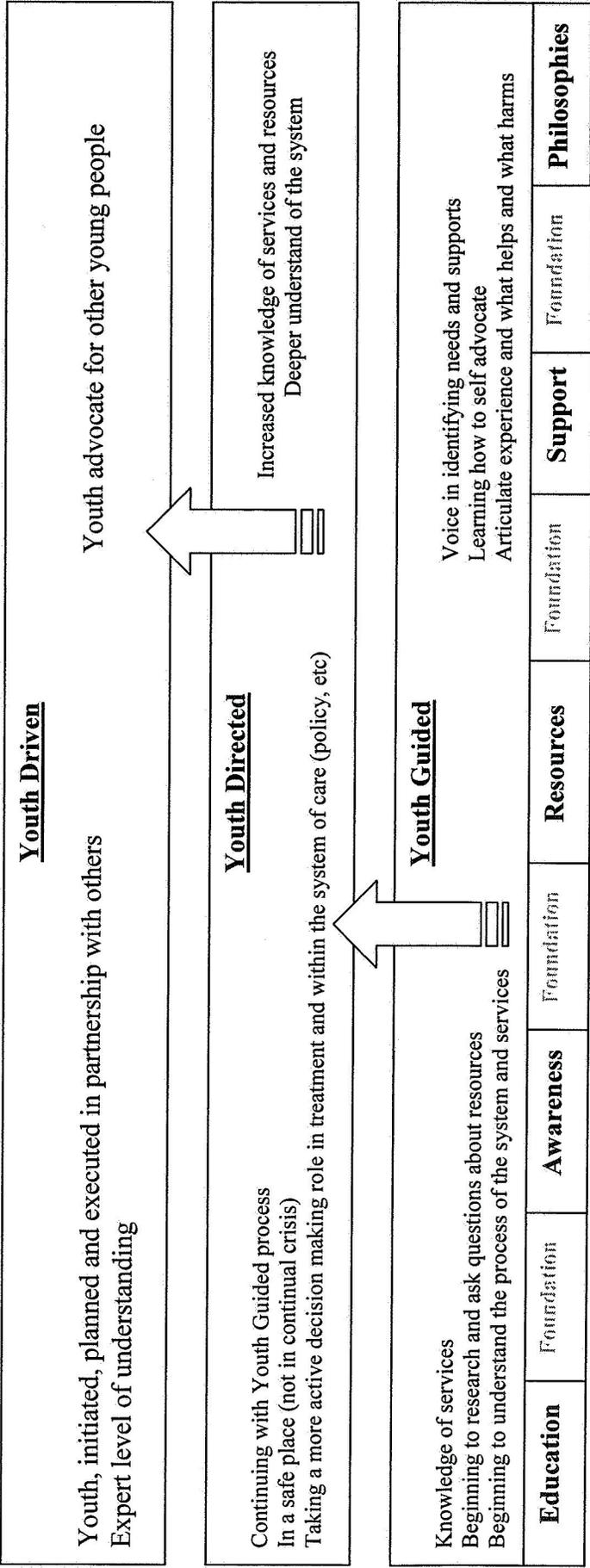
<p><b>Youth Directed Individual</b></p>	<p>The young person is:</p> <ul style="list-style-type: none"> <li>• Still in the learning process.</li> <li>• Forming relationships with people who are supporting them and are learning ways to communicate with team members.</li> <li>• Developing a deeper knowledge and understanding of the systems and processes.</li> <li>• Able to make decisions with team support in the treatment process and has an understanding of consequences.</li> <li>• In a place where they can share his or her story to create change.</li> <li>• Not in a consistent period of crisis and his or her basic needs are met.</li> </ul>
<p><b>Youth Directed Community</b></p>	<ul style="list-style-type: none"> <li>• Youth have positions and voting power on community boards and committees.</li> <li>• Youth are recruiting other youth to be involved throughout the community.</li> <li>• There is increased representation of youth advocates, and board and committee members throughout the community.</li> <li>• Everyone is responsible for encouraging youth voice and active participation.</li> <li>• Community members respect the autonomy of youth voice.</li> <li>• The community is less judgmental about the youth in their community</li> <li>• Youth are compensated for their work.</li> </ul>
<p><b>Youth Directed Policy</b></p>	<ul style="list-style-type: none"> <li>• Youth understand the power they have to create change at a policy making level.</li> <li>• Youth are in a place where they understand the process behind developing policy and have experience being involved.</li> <li>• Youth have an enhanced skill set to direct change.</li> <li>• Youth have understanding of the current policy issues effecting young people and be able to articulate their opinion on the policy.</li> <li>• Policy makers are in a place where they respect youth opinions and make change based on their suggestions.</li> <li>• All parties are fully engaged in youth activities and make youth engagement a priority.</li> <li>• Youth receive increased training and support in their involvement.</li> <li>• There is increased dialogue during meetings about youth opinions and action is taken.</li> <li>• There is increased representation of youth and a decrease in tokenism.</li> <li>• Equal partnership is evident.</li> <li>• Youth are compensated for their work.</li> </ul>

## **Youth Driven**

<p><b>Youth Driven Individual</b></p>	<ul style="list-style-type: none"> <li>• The youth describes his or her vision for the future.</li> <li>• The youth sets goals for treatment with input from team.</li> <li>• The youth is aware of his or her options and is able to utilize and apply his or her knowledge of resources.</li> <li>• Youth fully understands his or her roles and responsibilities on the team.</li> <li>• The youth and all members of the treatment team are equal partners and listen and act upon youth decisions.</li> <li>• The youth facilitates open lines of communication and there is mutual respect between youth and adults</li> <li>• The youth is able to stand on his or her own and take responsibility for his or her choices with the support of the team.</li> <li>• The youth knows how to communicate his or her needs.</li> <li>• Youth are mentors and peer advocates for other youth.</li> <li>• Youth are giving presentations based on personal experiences and knowledge.</li> <li>• The youth is making the transition into adulthood.</li> </ul>
<p><b>Youth Driven Community</b></p>	<ul style="list-style-type: none"> <li>• Community partners are dedicated to authentic youth involvement. Community partners listen to youth and make changes accordingly.</li> <li>• Young people have a safe place to go and be heard throughout the community.</li> <li>• There are multiple paid positions for youth in every decision making group throughout the system of care and in the community.</li> <li>• Youth are compensated for their work.</li> <li>• Youth form and facilitate youth groups in communities.</li> <li>• Youth provide training in the community based on personal experiences and knowledge.</li> </ul>
<p><b>Youth Driven Policy</b></p>	<ul style="list-style-type: none"> <li>• Youth are calling meetings and setting agendas in the policy making arena</li> <li>• Youth assign roles to collaboration members to follow through on policy.</li> <li>• Youth hold trainings on policy making for youth and adults.</li> <li>• Youth inform the public about current policies and have a position platform.</li> <li>• Youth lead research to drive policy change.</li> <li>• Youth have the knowledge and ability to educate the community on important youth issues.</li> <li>• Youth are able to be self advocates and peer advocates in the policy making process.</li> <li>• Youth are compensated for their work.</li> <li>• Community members and policy makers support youth to take the lead and make changes.</li> </ul>

## Youth Guided

Youth Guided means that young people have the right to be empowered, educated, and given a decision making role in the care of their own lives as well as the policies and procedures governing care for all youth in the community, state and nation. This includes giving young people a sustainable voice and the focus should be towards creating a safe environment enabling a young person to gain self-sustainability in accordance to their culture and beliefs. Through the eyes of a youth guided approach we are aware that there is a continuum of power and choice that young people should have based on their understanding and maturity in this strength based change process. Youth guided also means that this process should be fun and worthwhile.





SOURCE 01 STUDY # ID # \_\_\_\_\_  
INITIALS: \_\_\_\_\_ DATE COMPLETED \_\_\_\_\_

NEUROPSYCHOLOGICAL  
HIGHLIGHTS

WISHES AND DREAMS

CURRENT PLAN

SOCIAL HIGHLIGHTS

STRENGTHS AND SKILLS

THE HIDDEN ASSETS

SOURCE 01 STUDY # ID # \_\_\_\_\_  
INITIALS: \_\_\_\_\_ DATE COMPLETED \_\_\_\_\_

**OTHER POTENTIAL  
UNTAPPED RESOURCES**

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**PROPOSED STRATEGIES**

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## Valuing Families

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“

There are two lasting bequests we  
can give our children. One is roots.  
The other is wings.

”

Hodding Carter, Jr.

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# Valuing Families

## Defining family

**F**amilies exist in many different forms and perform various roles in the lives of children. In this *Resource Guide*, the word “family” may refer to biological families, adoptive families, step-families, extended families, foster families, and/or other individuals or group of individuals who play a significant role in the life of the child. The implication of this broad, inclusive definition of family is that treatment providers need to work with significant people in the child’s life (with permission from the legal guardian) that may extend beyond those who have legal responsibility for the child (DMH, 1997).

The treatment provider’s task includes working with the people who have legal responsibility for the child and other individuals with significant connections to the child at whatever level of involvement meets the child’s treatment needs. For example, it may not be appropriate to involve foster families in all of the ways that other kinds of families are involved. Depending on the specific circumstances of the relationship, foster families may or may not have the same kind of history or future together that other kinds of families have.

It is also important to acknowledge that some children do not have families, and treatment programs should work with the Department of Social Services to identify individuals in

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the community who can provide non-professional, nurturing relationships for these children (DMH, 1997).

## The Massachusetts perspective

The Massachusetts Department of Mental Health (DMH) believes that it is essential for treatment providers to understand that all families are unique and have special needs and responsibilities. For example, step-families and blended families have become increasingly common. Adoptive families face particular challenges. Many children are closely connected to grandparents or other relatives in addition to or instead of parents. Some children live with foster families because of protective issues in their primary families, and other children have no permanent families.

It is important to note that families also differ in their cultural, ethnic, and racial backgrounds, their traditions, and in ways of expressing these differences. “Service Providers need an awareness and acceptance of cultural differences, an awareness of their own cultural values, an understanding of the ‘dynamics of difference’ in the healing process, a basic knowledge about the client’s culture, and the ability to adapt practice skills to fit the client’s cultural context.” (CASSP, 1989; DMH, 1997)

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## Collaborating with families

DMH defines collaboration as “the formation of a working relationship between service providers and families that has as its joint goal the fostering of joint decision making in regard to the child or adolescent.” In addition, “Collaboration with families is a means to an end—the end being to deliver the most appropriate and effective services possible for the child or adolescent and his or her family” (DMH, 1997). DMH outlined the following values and beliefs to govern the collaboration process (DMH, 1997):

- The family should be the child’s most significant care giver, when applicable and appropriate.
- Parents/caretakers are experts about their own child and family.
- All families have strengths and weaknesses.
- Treatment providers should have respect for the diversity of families in terms of race, ethnicity, culture, religion, education, and socioeconomic status.
- Programs should foster partnerships with families and adjust program operations to increase each family’s ability to participate as an equal partner.
- Treatment providers can be valuable consultants to families.

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DMH uses the following collaboration principles when it contracts with organizations to provide services for children and families in Massachusetts (DMH, 2000):

- Parents/guardians should be viewed as the partners of professionals in the treatment of children with mental health problems.
- Parents/guardians have had the day-to-day responsibility for child-rearing and will be significant supports for their children throughout their lives. They have the need and the right to full information about their child's problems and the range of interventions and supports that are available.
- Parents/guardians and professionals have different perspectives and can benefit from input from each other. Policies, services, and supports should be designed and evaluated with input from parents/guardians and treatment professionals.
- Parents/guardians have valuable information to share with each other, and formal or informal parent groups provide opportunities for emotional support.
- Parents/guardians have the right and responsibility to advocate at the local state and national levels to secure services for children with mental health needs.

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## An evolutionary process

Out-of-home treatment programs traditionally focused on treating children safely within the program and often viewed families as dysfunctional. Programs need a long time to shift from viewing families in negative ways to seeing their strengths. When a program decides to make this change and become “family friendly,” all aspects of the program must be reviewed and modified accordingly.

The *Valuing Families in Residential and Inpatient Programs* article at the end of this section provides a number of suggestions for working with families in a respectful and inclusive manner.

Treatment programs can readily take the most important first step, which is to ensure that staff members respectfully treat all family members as equal members of the treatment planning team. In addition, program managers can teach staff members the basic values of family-driven care, such as helping the treatment teams focus on the positive qualities of children and families and teaching active listening. Incorporating these practices into treatment environments will help move programs toward the goal of building collaborative parent/professional teams.

The chapter on *Strength-Based Treatment* in the *Resource Guide* provides more suggestions for working with children and their families.

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## Researched recommendations

In the *Learning from Families, Systems of Care: Promising Practices in Children's Mental Health, 2001 Series*, the writers cited research that linked professional/parent partnerships with good treatment outcomes. The writers stated:

“Parents’ views and opinions about the professional with whom they and their child worked determined their view about the program’s overall quality and effectiveness. The implication is that parents’ positive opinions about their child’s provider often correspond with their belief that the services themselves are effective.

In addition, when parents perceived their provider as helpful, they also believed that the provider had a high level of regard and concern for the child. This research also reinforces the belief held by others in the field that communication and feedback are essential in establishing positive relationships.

Open communication on the part of the provider was equated with helpfulness by the parents. Specifically, professionals who took the time to respond to parents’ expressed desire for information on treatment alternatives for their child were considered to be the most helpful” (Worthington et al., 2001).

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## Successful practices in Massachusetts

A number of programs in Massachusetts have changed their practices to enhance their partnerships with families as part of their initiatives to implement strength-based care and reduce the use of S/R. A few examples of these practices include:

- Having a cheerful sign at the entrance that welcomes family members
- Having open visiting hours for family members so that they can visit any time, including during dinner, at bedtime, before school, etc.
- Scheduling treatment reviews at the convenience of the family
- Holding treatment reviews and therapy meetings in the family's home and not at the residential or hospital program
- Hiring a full or part-time family advocate to support family members
- Having a protocol to help family members prepare for treatment review meetings so they can be full participants
- Connecting families to parent support networks

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## Cambridge Hospital, Child Assessment Unit

The Child Assessment Unit (CAU) of Cambridge Hospital, located in Cambridge, Massachusetts, is a 13-bed inpatient psychiatric unit for children and adolescents.

Staff at the CAU have worked hard to make their program more family friendly by implementing an “Open Hours” visiting policy (described below), seeking and valuing family input in the care and treatment of the children, and conducting treatment meetings with hospital staff (Regan, Curtin & Vorderer, 2006) at times that are convenient for the family.

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The CAU posts the following information in their program:

**Cambridge Hospital, Child Assessment Unit  
OPEN VISITING HOURS**

The Child Assessment Unit encourages parents and guardians to spend time on the unit with their child. We want your involvement and collaboration in the treatment of your child. We do not have fixed times that parents may visit. The unit is open to parents and guardians.

- Your participation is vital to our being able to provide the best possible care of your child.
- We welcome you sharing information with us as well as asking questions about our treatment.
- We encourage you to spend time on the unit based on your schedule.
- We encourage you to feel free to help your child “settle” at bedtime and to assist your child with daily living skills if they need help.
- We welcome your observations and feedback.
- We want you to join our team.

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## Positive outcomes from partnering with families

Stroul and Friedman developed the *Child and Adolescent Service System Principles* in 1986. This is a system of care philosophy that involves developing a coordinated network of services and treatment providers to meet the multiple and changing needs of children with serious emotional disturbances (Stroul & Friedman, 1986) and their families. Since this time, experts in the field of child mental health have recognized the importance of partnering with families. There are many positive outcomes associated with programs that actively partner with families, including:

- reduced lengths of stay in out-of-home treatment programs
- increased parent satisfaction with treatment services
- improved sense of parental self-efficacy, which corresponds with an increased investment in their child's treatment and treatment outcomes (Worthington et al., 2001)

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## Additional resources

The following are included at the end of this chapter:

- The article, Valuing Families in Residential and Inpatient Programs: Guidelines for Helping Residential and Inpatient Programs Become Family-Friendly.
- A Working Definition of Family Driven Care by the Federation of Families for Children's Mental Health.
- A position paper from the American Association of Children's residential Centers (AARC) entitled: Redefining Residential: Becoming Family-Driven.

# VALUING FAMILIES IN RESIDENTIAL AND INPATIENT PROGRAMS

## Guidelines for Helping Residential and Inpatient Programs Become Family-Friendly

Ms. Caldwell is currently working with family advocates throughout the country on revising and updating the "Valuing Families" guidelines. With the advent of 'family-driven care', many of the recommendations in this document have evolved. When families are full partners and family and youth team meetings are utilized to determine the needs of the family and youth while the youth is in out-of-home care, then families and youth determine the services and supports they will receive. Additionally, some terms used in the document are now outdated. For instance, the use of behavior management has been replaced with behavioral support. Although this document provides foundation areas for out-of-home programs to consider, the MA DMH expects an updated version of this document will be available in the Spring of 2007. *(September 2006)*

The attached document was developed in conjunction with staff from the New York State Office of Mental Health (OMH), family members and staff from programs licensed by OMH. More importantly, this document was the result of multiple meetings with many family members of children who were in residential, inpatient or day academic programs for children with special needs. Family members gave their time and shared both their good and their painful experiences. This is really a document that outlines strategies, which if used by programs, would best ensure full cooperation and support by family members. This document is dedicated to all families who have struggled to raise a child with special needs, who have struggled to be heard, and have struggled to maintain their self-esteem and respect when working with 'professionals'.

These guidelines were primarily written by Beth Caldwell and Erlinda Rejino, with feedback, help and support from E. Persons, K. Hayes, M. Johnan, S. Schlosberg, S. Thaler, J. Windsor, G. Wood, P. Albertine, A. Nicholson & L. Mappes. The guidelines were updated and revised by Ms. Caldwell in April 2001.

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## **VALUING FAMILIES IN RESIDENTIAL AND INPATIENT PROGRAMS**

### **Guidelines for Helping Residential and Inpatient Programs Become Family-Friendly**

#### **Area #1: Philosophy / Practices**

The mission statement of each program should support a commitment to an ecological approach in which children are considered within the context of their family and families are considered within the context of their culture and extended community. The philosophy of each program should clearly indicate that the program's primary mission is to help parents ensure that the needs of their children are met, and their own needs, relative to helping their child, are met. The program philosophy should spell out that the program is neither taking the place of the parents, nor providing superior care - rather, the agency is a vehicle to support the parent in parenting his/her child. The philosophy of each agency/program should clearly articulate that respect for individual children, their families and their culture is best conveyed in a flexible environment which provides a number of different treatment and support alternatives and involves the child and the family in choosing their own treatment, education and support options.

The program philosophy should recognize the great diversity in family types, strengths, and weaknesses. Program philosophy should stress staff sensitivity to the fact that families come in different sizes, composition, and sexual orientation.

Additionally, program philosophy should commit itself to searching for extended family and family friends for children who may not have apparent families. It is important for programs and their staff to recognize that residential placement is time limited; the program goal is to help ensure the child will be successful in his/her home community. To accomplish this, identification and/or development of support networks and consistent contact with the home community are essential.

Program policies and procedures should clearly reflect the value of family involvement and input in all of the areas listed below:

#### **A. Environment**

All areas of the environment (residence, grounds and offices) should exude a warm and welcoming attitude toward children and their families. Some of the indicators in this area include:

- ◆ Decorations that reflect the cultural diversity of staff, children and their families.
- ◆ Comfortable furniture.
- ◆ Service areas, which all are handicapped accessible.
- ◆ When guests come on-site, hospitable offerings of toys, food, coffee, etc., are made available to suit the needs of individual families.

- ◆ Space is available for private conversations and visits between children and their families, including areas for young siblings to play.
- ◆ Parking spaces are available for families.
- ◆ Space, where families can gather to provide support, information, and conversation to one another, is available.

**B. Agency Marketing Materials**

All materials developed by the program to market itself (brochures, referral forms, etc.) should reflect that families are valued. Indicators include:

- ◆ Children are described in the context of the family.
- ◆ Families are mentioned in the first paragraph of materials.
- ◆ Materials are available in the primary languages used by the families the program serves.
- ◆ Materials are written in a clear and elementary manner that is understandable, regardless of education level.
- ◆ Videotapes are available to help all families understand the programs, particularly for families who do not read.

**C. Family Support and Involvement**

Opportunities for family involvement and input should be made available at all levels of program life. Family involvement in treatment planning is crucial and is the focus of another section. In addition to treatment planning, programs can provide additional supports to families and affirm their value as partners in treatment. Indicators of family support and opportunity for family involvement include:

- ◆ A Family Advisory committee, which may be composed of past and current service recipients. The purpose of the advisory group is to provide a consistent vehicle for communication.
- ◆ Family handbooks which include simple, but clearly written program descriptions and listing of rules, with pictorial cues.
- ◆ A buddy system which places parents in contact with another parent from the beginning of involvement with the program.
- ◆ Several choices for families who would like to participate in the life of and oversight of the program. The choices should vary in the amount of time required and type of participation (i.e., serve on a committee, help teach a vocational class, help run a support group).
- ◆ Program offers open house for schools and other systems involved with the child and family.
- ◆ With parental permission, the program should have regular phone contact with support agencies in the child and family's home community, and the program should send written updates and other materials to the home agencies involved with the child and family.
- ◆ Program offers parents an opportunity to feel empowered in their child's life. For example, rather than giving donated gifts to the children from the agency on holidays, the agency should allow the family to choose gifts from the donations and give them to the children themselves.

- ◆ Program networks extensively and educates child-serving systems and community groups regarding program services and goals.
- ◆ The program hires or contracts with a Parent Advocate. (A parent who is paid by the program to ensure that all aspects of the program are family-friendly and that the program offers appropriate support services to families.)
- ◆ Educational opportunities are available for families regarding decision-making and advocacy.
- ◆ Education and support is regularly offered to families in the areas of helping their child, helping themselves in handling their child, and managing the-extra stress and demands put on their lives.
- ◆ For families who live more than a 45-minute drive from the program, families are connected with support/educational opportunities offered in their home communities.
- ◆ Ongoing efforts are made to identify additional family supports needed in the program.
- ◆ All family education and support offerings are offered at times convenient to parents (e.g. evenings, Saturday morning or Sunday afternoon to coordinate with a home visit pick-up or return).
- ◆ Families are consistently involved in the evaluation of the program on both a short-term (e.g. requesting feedback on meetings, visits) and long-term (confidential consumer survey) basis.

**D. Family Contact is a Right, Not A Privilege**

The program recognizes and respects the diversity of families by defining family broadly, and involving kinship family members, as well as other supportive members of the child and family's home community during the child's stay at the residential program. The right to family/kinship contact should be reflected in a flexible, individual approach to determining decisions about contact with the child. Individual families should be involved in decisions regarding at least each of the of the following areas:

- ◆ The frequency of phone calls to and from the family.
- ◆ The frequency of visits to the residential or academic program.
- ◆ The frequency of home visits by the child and staff,
- ◆ Letters to and from the family.
- ◆ Friend and sibling contact.
- ◆ How and when the parents want to be notified of events in the child's daily life in the residential or academic program.
- ◆ How the child should recognize and celebrate family occasions (birthdays, anniversaries, funerals) and holidays (e.g., make cards, go home, send presents).

The program should promote family visitation both on site and in the home community. The program should have policies, which provide at least the following supports for visitations:

- ◆ Help with transportation.
- ◆ Child care at the program site.
- ◆ Flexible funds to address individual family need (e.g., "Sunday clothing" for a family with limited resources who would like to visit a residential program).

### **E. Home visits by Program Staff**

Visits by staff members to the family home are crucial in efforts to identify treatment and support needs, and to better understand the culture of the family and community to understand family dynamics. Some indicators in this area include:

- ◆ First home visit occurs early in placement (e.g., within two weeks of placement).
- ◆ Home visits occur regularly.
- ◆ Family option to refuse a home visit.
- ◆ All levels of staff have opportunity to participate in home visits.

### **F. Agency Language Excludes the Use of Disparaging Terms Describing Families**

All agency materials, and language used by all staff should promote respect and sensitivity to families. Materials and language should avoid "professional jargon" that may not be understood by family members. All staff should be careful to avoid the use of labels. There should be a commitment to training modalities that encourage re-thinking about language issues (e.g., dysfunctional family to "challenged" family)

## **Area #2: Staffing**

### **A. Hiring Practices**

Agency hiring practices are crucial to the selection of staff who value families and whose attitudes will support the development of a partnership with the family. The following areas should be structured to select staff members willing or able to learn how to work with families:

- ◆ Screening.
- ◆ Interviewing (Family-Friendly Attitudes).

### **B. Staff Training**

One of the best ways to ensure that staff stay in touch with the needs of families is to hear it directly from the family members. Family members should be a part of the training team whenever family issues are the focus. In addition, all staff should be expected to attend some family support group meetings to increase their sensitivity to the diverse needs of families.

The following areas should be addressed in initial and in-service staff training programs:

- ◆ Emphasis on valuing families and family involvement in treatment, support, and planning.
- ◆ Cultural Issues.
- ◆ Children and family rights.
- ◆ Sensitivity to placement and separation issues, including grief and loss, for family members.
- ◆ Sensitivity training regarding the diversity of families and family issues.
- ◆ How to do a home visit, including:
  - Flexibility to participate in family activities;
  - Reasonable dress; and
  - Relaxed, not always formal interactions with family.
- ◆ Respect for family bonding and the family's role as the primary caretaker for the child.
- ◆ Language usage when interacting with-families.

- ◆ Communication skills: listening and understanding; and conveying concerns.

Additionally, staff needs to understand that families interface with many staff, sometimes more than 50. They need to view themselves as only one person of the many whom give the child and family feedback and advice. Staff should also be aware that families might need supports throughout their child's life. The services will need to be flexible and within the context of a long-term plan.

### **C. Supervision and Support of Staff**

Programs and agencies must support their staff efforts to work with families in numerous ways. Regular supportive supervision of staff is one of the best ways for an agency to gauge and, if necessary, improve staff attitudes and abilities in working with families. Families want to be assured that all of the staff interfacing with their child understands his/her needs and background. Families also appreciate staff who show sensitivity and concern. Agencies should incorporate the following practices into operation:

- ◆ There should be weekly supervision of staff, which includes information regarding each child's progress/targets and family interface.
- ◆ Processing time should be available to support staff in their own expressions of unfamiliar/uncomfortable family interaction (e.g., participation in an unusual ritual with a family).
- ◆ Program staff should be knowledgeable about other resources and systems of service involved with each family
- ◆ All staff should have the opportunity to read each child's record and discuss the child and family's treatment/service plan and supports with a supervisor prior to working with a child.
- ◆ Direct-care staff should attend treatment/service-planning meetings to give input and to gain further understanding of each child, or should be thoroughly briefed after each meeting.
- ◆ Paid Parent Advocates should occasionally attend staff meetings and treatment/support meetings.
- ◆ Administrators and supervisors should articulate and model values, beliefs, policies and practices that maintain morale.
- ◆ The learning environment should be responsive, flexible, and adult-oriented.
- ◆ Staff should participate in evaluating their own performance and developing an individualized learning plan with specific targets, timetables and goals.
- ◆ Staff should attend workshops and conferences, which focus on "family-friendly" ideas.
- ◆ The agency should establish standards and indicators for staff, which delineate competency-levels, in working with families.

### **Area #3: Admission/Discharge**

#### **A. Referral and Pre-Placement**

A family's first program contacts during referral and pre-placement is a critical time in the development of a trust relationship. Program policy and procedures should address at least the following areas:

- ◆ A buddy system which places parents in contact with another parent from the beginning of involvement with the program;
- ◆ Parents receive a copy of the referral information;
- ◆ A letter of introduction regarding the initial interview and pre-placement process is sent to the parents;
- ◆ Pre-placement visits are scheduled at the parents' convenience;
- ◆ Families are included in making the decision that their child needs a residential or special academic placement and have a choice in placement options;
- ◆ Agency policy is clear regarding when an interview and pre-placement visit occur;
- ◆ Pre-placements are only done if there is a strong possibility for admission; and
- ◆ Overnights, for residential programs, are a part of pre-placement.

The social amenities for the initial child and family visit should be clearly outlined for staff; these should include at least:

- ◆ An approach that acknowledges that each child and family is special and deserving of respect;
- ◆ A tour of the program site;
- ◆ At some point in the initial contact, a statement that clearly says, "You know your child best";
- ◆ Defer to family in decisions during the visit (i.e. would they like the child to be a part of conversations/what snacks can be offered the child);
- ◆ Feedback should be sought from the family throughout the visit (Are they getting the information they need? What do they have questions about?);
- ◆ The family should be given written information regarding the program before they leave;
- ◆ Families should be provided with the name and number of a person they may contact with questions;
- ◆ Families should be given the name and number of another parent they can contact with questions;
- ◆ Follow-up phone calls should be made to ensure the family had all questions answered; and
- ◆ Personal notes should be sent to the - family and the child telling them how much they enjoyed meeting them and stressing individual strengths noted.

#### **B. Admission Process**

After the child and family have been accepted for admission to the program, the following items should be addressed:

- ◆ The family should help choose the date and time for admission.
- ◆ The transition into the program should take the needs of family and child into consideration.

- ◆ The transition should consider individual family needs, with an individual assessment of additional support, time and information that may be needed. Individual families may need extra support the days before, day of, and days after admission.
- ◆ A specific agency contact person should be clearly defined for the family.
- ◆ There should be a plan for enhanced communication with the family during first few days - at a time convenient to family.
- ◆ There should be an attempt to make the admission day as non-threatening as possible. For example, creating an admission activity, like a child requested-meal, which includes the child, his/her parents, siblings and close extended family.

### **C. Discharge**

Agencies must be focused on discharge and the return of the child to the family and home school and community. In order to facilitate a rapid return home, agencies must:

- ◆ Start Discharge Planning during the pre-placement and admission process.
- ◆ Plan for Precipitous Discharges - that is, develop contingency plans which will ensure support to the family and the safety of the child in the event of unplanned separations.
- ◆ Devote the resources and time needed to identifying and working with community supports in each child's home community in the areas of education, recreation, and relationships.
- ◆ Planning for how these will be maintained or developed while the child is in placement is important, and efforts must be increased prior to discharge and throughout the transition to home process. These efforts are especially crucial in cross-region and cross-county planning.
- ◆ Ensure that the transition to the home community is gradual.
- ◆ Ensure staff are able to provide ongoing support to families, specific to the needs of each child and family throughout the child's stay-and after discharge.

## **Area #4: Treatment and Support Services - Planning and Implementation**

### **A. Planning for Treatment and Support services**

Treatment/service and support planning in academic and residential programs must involve the family and the child's support network in order to be effective. This planning must focus on the development of skills and supports that are usable at home, at the home school and in the community. Indicators of family-focused treatment/service and support planning include:

- ◆ Assessments that identify all family strengths and resources.
- ◆ Reality-based treatment/service and support planning.
- ◆ Goals and objectives which are skill-based and outcome driven.
- ◆ The offering of a menu of alternative interventions to families and children.
- ◆ Identifying or finding child and family-specific supports in the program and in the community and helping the child and family remain connected to those supports while in the program.
- ◆ Specific interventions that help promote the skills needed in the child's community life, not focus on skills that are most useful in the residential or academic program.

Two key questions programs must ask themselves and families regularly are:

- ◆ Are families involved in all decisions?
- ◆ Are behavioral systems used in the program simple? Are they easily understood and able to be used by families in the *home*?

**B. Family Involvement and Input in Treatment Planning**

Agency policy should clearly communicate that family participation in treatment and support planning is expected and fostered in at least the following areas:

Parents' preparation for treatment planning meetings should include:

- ◆ Meeting with parents before the treatment planning meeting;
- ◆ Definition of a real role in the treatment team for parents, i.e., report at each meeting on visits and contacts.
- ◆ Give copies to family of materials relevant to the meeting.
- ◆ Family assessment of whether different program techniques and intervention can easily transfer to their home-life and routine.
- ◆ The family should specify who they would like to have at the planning meeting.
- ◆ The treatment planning meetings should focus on goals and objectives, strengths and discharge criteria.
- ◆ Treatment planning meetings should be scheduled with the family's convenience as primary consideration.
- ◆ Program policy must be clear as to whether family must be present before it is considered a treatment-planning meeting.
- ◆ Staff language should be clear, positive and avoid the use of labels. Meeting should be jargon free.
- ◆ Consideration should be given to meeting space, seating, support to families during meeting, and how the treatment plan is written.
- ◆ The initial identified needs for both the child and family must be continually re-evaluated.

**C. Behavior Management Systems**

Behavior programs (level system) should be individualized for both the needs of the child and the parent, flexible and geared to ease of use in the discharge/home setting as opposed to behavioral control in the residential or academic setting.

- ◆ Families should be asked how much they want to be involved in ongoing programming of their child. Do they want to be involved if a child is sad, displaying precursors to acting-out behavior, acting-out?
- ◆ The child and family should be given a list of options for meeting identified needs (e.g., learning self-control can be accomplished by voluntary time-out when upset, by requesting to call home, by writing in a journal, by punching a pillow) and choose or develop a new option that best suits their needs.
- ◆ The child and family should choose what types of restrictive interventions they prefer if the child loses control (e.g., time-out, physical hold, medication, punching a pillow).



# Working Definition of Family-Driven Care



Version 12 – June 2007

## Definition of Family-Driven Care

Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- ✓ Choosing culturally and linguistically competent supports, services, and providers;
- ✓ Setting goals;
- ✓ Designing, implementing and evaluating programs;
- ✓ Monitoring outcomes; and
- ✓ Partnering in funding decisions.

## Guiding Principles of Family-Driven Care

1. Families and youth are given accurate, understandable, and complete information necessary to set goals and to make choices for improved planning for individual children and their families.
2. Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes.
3. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf and may appoint them as substitute drivers at anytime.
4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports and allows families and youth to have choices.
6. Providers take the initiative to change practice from provider-driven to family-driven.
7. Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families and where family and youth run organizations are funded and sustained.
8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9. Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families and work to eliminate mental health disparities.
10. Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes.



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**AACRC Position Paper**  
**Redefining Residential: Becoming Family-Driven**  
Adopted June 2006

**Preface from Parent Advisor Board Members of AACRC** *Redefining Residential: Becoming Family-Driven* is a vision for family-driven care. We are excited to have been asked to collaborate with AACRC in creating this document, as the association continues a series of policy papers that highlight new trends and promising practices in residential care. While our discussions at times were difficult, they were a necessary component of building mutual understanding and respect in our parent-provider partnership. The process of creating this paper is a good example of what ideally would happen on a daily basis in partnering with families in the care of their children. The collaborative work and open dialogue that created this document are essential elements of “becoming family-driven”. This beginning dialogue must be continued if the redefinition of residential and true system transformation for our children individually and collectively is to become a reality. We hope that with this paper family-driven care has finally arrived, long overdue.  
*Martha Globus-Rodriguez (New Jersey), Ron Sipress (Oregon), Joe Anne Hust (California)*

This paper represents current thinking of the American Association of Children’s Residential Centers (AACRC) regarding the importance of family-driven care for youth placed in congregate facilities. AACRC is the longest standing national association focused on the needs of children in residential treatment and their families.

**Overview**

Residential treatment as a field has struggled with how to effectively respond to the familial needs of the youth in care. In the past the field tended to be youth centered, with family work as one of many identified treatment issues, typically focused on the youth’s response to his/her parents and siblings. Parents’ involvement ranged from none at all to very active involvement in their child’s care; however in general the rights of family members to have access to and be central to their child’s treatment was subject to contingency and question.

Residential treatment has not been alone in this clinical heritage; a dismissive approach to families of children with mental and behavioral disorders has also tended to characterize the culture of the child welfare, mental health, education, and juvenile justice communities. Nonetheless residential has a unique and unfortunate legacy of ambivalence about parents, rooted in its history as a service modality that evolved from the orphanage model. In its genesis the field was imbued with the residues of parent surrogacy, an orientation strongly reinforced by the prevailing mindset across the other child serving systems and training institutions- that parents were the cause of the child’s problems. Residential became defined, and defined itself, as a placement, in which the staff individually and collectively took the place of parents in the day-to-day life of the child. The understanding and empathy offered the children was not consistently afforded to the parents, many of whom faced stigmatization and adversarial approaches.

In the last two decades, the thinking about family involvement across the child serving systems has begun to change. The Child and Adolescent Service System Program (1985) envisioned a central role for families in community systems of care for children with mental health problems. Wraparound, family decision making, and parent-professional partnerships have emerged in child welfare, education, medical, and juvenile justice arenas, as well as in mental health. Such service configurations have recently been supported by the research and heralded in salient mental health public policy studies, including the Surgeon General’s and the President’s New Freedom Commission reports. Research specific to residential care has also consistently identified improved child outcomes when parents and families are more involved. The response from the field to these developments has been slow but not insignificant, as residential centers across the country increasingly design processes and practices for more inclusion of parents and family members in the care of their children. The result has generally been improved outcomes for children and families.

Yet there remains a great deal to do. Residential facilities are faced with redefining their roles in local community systems of care and with the challenge of making the changes necessary to incorporate and support parents and families, often without additional resources, and within a framework of restrictive funding regulations. Many programs have been encountering this implicit or explicit expectation. For some it is transformative, but the task is complex and requires a shift in focus from treating the child in the context of the setting to treating the child in the context of the family and community. The complexity is compounded in responding to those children whose parents' rights have been terminated, who have bounced from temporary placement to temporary placement, and who consequently lack any real attachment to a community. This paper will review the emerging definition of family-driven care in children's mental health and discuss issues related to its implementation in residential programs. Some innovative practices will be referenced and organizational implications addressed.

### **Redefining Residential – Transforming to Family-Driven Care**

AACRC, in a position paper entitled "Redefining Residential 2005", addressed the importance of residential programs reengineering themselves to become integral parts of local systems of care, and encouraged facilities to adopt and adapt transformative practices in keeping with the research and changing external environment. Of these, the move toward adopting and embracing family-driven care offers particular promise and leverage.

Family-driven care is defined by the Federation of Families for Children's Mental Health ([www.ffcmh.org](http://www.ffcmh.org)): "Family-driven means families have a primary decision making role in the care of their own children .... This includes: choosing supports, services, and provider; setting goals; designing and implementing programs; monitoring outcomes; partnering in funding decisions; ..." The definition delineates principles and characteristics of family-driven care, most notable of which is that "administration and staff....share power, resources, authority, responsibility, and control..." with families and youth.

There are many important reasons for residential facilities to embark on a path toward family-driven care.

- Children love and value their parents. The biological connection and the drive to heal any disruptions in attachment are powerful. To not explicitly and overtly value a child's parents may inadvertently symbolize not valuing the child. This can compromise the child's self-esteem and jeopardize treatment effectiveness. More importantly such an approach devalues the family relationship, a biological lifetime constant. Even youth who have been estranged and separated from their families often seek reconnection with family at some point in their lives. A treatment climate of shared responsibility, open communication, strengths-focus, and equal partnership facilitates healing and growth.
- The challenges children present in residential care often have genetic/biological components as well as environmental precursors. Children who have suffered trauma in their lives, regardless of source, often see themselves as helpless at the hands of external circumstances, for which they tend to blame others, including their parents. Marginalizing the participation of parents, in attitude or practice, causes staff to be caught up in the blame cycle, reinforcing the parents' sense of shame or guilt and making it difficult for the children to recover. Conversely, engaging with the family as full partners creates the opportunity for resolution of the losses and grief the child and family have experienced. Ensuring parents have the primary decision-making role supports or, in some instances helps them reassume, their parental responsibilities.
- Parents and families provide important information and feedback. An approach that engages them equally creates a shared responsibility for growth and change. It provides the opportunity for staff to work together with parents and to utilize family members' experience and expertise. This yields an increased ability to understand the child within the context of his/her family, culture and community, and to develop realistic expectations, plans, and supports. The family is affirmed in having their strengths recognized and valued; the staff benefit from having support and assistance and from being relieved of the implicit, at times self-imposed, responsibility to be the ones who will "fix" the child. Family-driven care is a partnership.
- Parent-professional partnerships promote success. They overcome the fear, stigma, lack of support and encouragement, resource limitations, cultural dissonance, misunderstandings, and resistance that parents and professionals alike often experience with each other. They lead to shorter lengths of stay and more efficient utilization of resources.
- Parents are strong and effective voices, advocating in pragmatic and realistic ways for the needs of children on quality improvement, planning, and governance bodies. As political partners with professionals, parents are powerful advocates for the full continuum of care, inclusive of residential, and for efforts to meet the needs of children and families in local communities.
- The research in residential treatment consistently shows that the processes and outcomes of care improve in correlation with the degree of family involvement.

Residential programs have taken notable steps toward family-driven care, and it is probably safe to say that an evolutionary process has been occurring over the past decade. However, old habits, including mental habits,

die hard. So despite the evolution that has occurred in the field, there still tends to be collective mindsets in the system and within individual organizations that diminish the importance of meaningful family involvement. The problem is exacerbated by residential's accustomed role as the placement of last resort. By the time families encounter residential providers, the parents are often angry, mistrustful, and/or hopeless, perhaps as a result of their experience in the system, but nonetheless tending to reinforce the "old" mindset where it exists. It is incumbent upon residential programs to develop a culture and practices that help staff to avoid or overcome this mindset and learn how to negotiate working relationships with families at the beginning of treatment in a way that establishes "ground rules", while engaging each family in quite the same manner as each "new" child, as possessing unique strengths upon which to draw in addressing their own particular challenges.

### **Making and Sustaining the Move Towards Family-Driven Care**

Becoming family-driven has been described as "a journey", one that involves constantly addressing the belief systems of the staff, through leadership involvement, training, ongoing dialogue with family members, and self-monitoring (quality improvement). Organizations can consider encountering this challenge at multiple levels of partnership that bring alive the promise of family-driven care. For example:

- **Care** – At the care level parents and/or family members can facilitate treatment planning meetings, work with staff in the milieu, shadow staff in facility and community settings, be the key decision maker in treatment plans, and be consulted over the phone at moments of impasse. Wraparound teams can be configured within residential programs and then follow the family and child back into the community. Focusing consistently on validating strengths can help parents and families reinforce and develop competencies, at times not identified in referral material or even clearly recognized by themselves. Listening carefully to and learning from parents and families can lead to better understanding of the child, increased cultural responsiveness, opportunities to address the needs of siblings, and the identification of respite and crisis plans for when their children return home.
- **Hired Parents** – Many organizations are hiring parent advocates and parent partners as employees. These individuals can perform a variety of functions within the organization, for example family outreach, staff training, liaison, wraparound facilitation, and mentoring of other parents.
- **Program** – At the program level parents have valuable contributions to offer into quality improvement activities, clinical policy, outreach, hiring, and many other arenas of organizational life. They can provide real life feedback regarding the strengths and gaps of the program.
- **Governance** – At the governance level parents are valuable members of Boards of Directors, and offer critical input into strategic planning and resource allocation.
- **System** – At the system level parents can have important voices on advisory committees and interagency collaboratives. Parents understand the importance of a full array of services and, in telling their stories, have a powerful influence on policy makers.

Such multi-level partnerships can help establish and reinforce a culture of family-driven care. They are more readily supported if the organization has made the leadership commitment to become family driven and can dedicate budgetary resources to supporting parent travel, paying stipends, or hiring parents as paid staff. The Board of Directors and CEO can ask themselves a series of key questions in assessing readiness to move in this direction, for example:

- ✓ *Do the staff of the organization act, speak, and interact in ways that truly welcome, support, affirm, and incorporate the perspectives and wishes of parents?*
- ✓ *Do parents have to be "invited" into the organization or is it a baseline assumption of staff that parents are reciprocal partners?*
- ✓ *Is the organization committed to redefining itself as providing an intervention within a community continuum rather than as a placement of last resort?*
- ✓ *Does the organization believe that sharing decision-making, leadership, and power with parents yields better outcomes for children and youth?*
- ✓ *Is the organization willing to implement training and other practices that culturally reinforce the importance of parents and families in day to day actions, discussions, and care planning?*

The responses to these questions can drive strategic planning and practice innovation. Changes in practice, even incremental, can and do lead to positive results.

The implementation of family-driven care in residential facilities is a transformational step that promises to yield better outcomes, increasingly shared responsibility, and exciting and rewarding partnerships between professionals, families, and communities. Agencies that have begun the path of innovation have reaped the reward of making their collective work more exciting and somewhat easier. Residential programs are urged to consider taking these steps and to develop practices to sustain them. For further information regarding AACRC, its position on family-driven care, or resources, please contact our national office at 1-800-332-2272.

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## Trauma-Informed Care

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Remember there's no such thing as a small act of kindness. Every act creates a ripple with no logical end.

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Scott Adams

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# Trauma-Informed Care

Why is an understanding of trauma important?

**T**he prevalence of childhood exposure to trauma is startling, and it is well-documented that undiagnosed and untreated traumatic experiences in childhood may subsequently lead to serious psychological impairments not always obviously related to the traumatic events. To treat childhood psychiatric and behavioral symptoms appropriately, it is important to understand how the effects of traumatic exposure manifest in children and adolescents and to ensure that our treatments reflect our understanding (van der Kolk, 2005; van der Kolk et al., 2005; Spinazzola et al., 2005).

According to the American Academy of Child and Adolescent Psychiatry (AACAP), all children experience stressful events at some point in their lives that affect them emotionally and physically. Children usually react briefly to mild stress and then recover without additional problems. However, a child who experiences an overwhelming or catastrophic event, or series of events (as in domestic violence, child physical or sexual abuse, or neglect), may develop ongoing difficulties attributable to the trauma, including post-traumatic stress disorder (PTSD), complex PTSD, or Disorders of Extreme Stress (DESNOS). AACAP states, "A child's risk of developing PTSD is related to

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the seriousness of the trauma, whether the trauma is repeated, the child's proximity to the trauma, and his/her relationship to the victim(s)." A child who is threatened or abused repeatedly by an immediate family member, who also witnesses other family members being mistreated, who is often left at home alone to care for himself or herself, who suffers other traumatic experiences as a result of the lack of supervision (being molested by a babysitter, bitten by a dog, hurt in a preventable accident) will be at risk for more severe PTSD symptoms or trauma related disorders that appear behavioral but, in fact, reflect the impact of trauma and neglect (AACAP Facts for Families, 1999).

## What is a "trauma"?

- "Psychological trauma is the unique individual experience of an event or of enduring conditions in which the individual's ability to integrate his or her emotional experience is overwhelmed (i.e., his or ability to stay present, understand what is happening, integrate the feelings, and make sense of the experience), or the individual experiences a threat to life, bodily integrity, or sanity." (Saakvitne et al., 2000)
- "Traumatization occurs when both internal and external resources are inadequate to cope with external threat." (van der Kolk, 1989)

Trauma can include many different kinds of events and conditions: from invasive medical procedures and treatments

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to accidents, death of a parent or sibling, exposure to neighborhood violence or natural disaster, domestic violence, threats of family violence (whether acted upon frequently or intermittently), physical and sexual abuse, and traumatic neglect (inadequate food and/or care). Trauma is also relative, that is, an event that is stressful for a four-year-old (such as being left alone and unattended for several hours) might be traumatic for an infant. In addition, the perception that one's life is in danger might also be relative. For example, a mother might know that her enraged husband will not harm the children, but the children might perceive his rage and aggression as life-threatening.

There have been numerous studies on the prevalence of trauma. One study estimated that as many as 90% of adult clients who receive public mental health services have trauma histories (Mueser et al., 1998). Another study revealed that 34-53% of these clients reported childhood sexual or physical abuse (Kessler et al., 1995). In addition, 3.9 million adolescents have been victims of serious reported physical assaults and almost 9 million have witnessed acts of severe violence (Kilpatrick et al., 2001). Between 3.5 and 10 million children have witnessed the abuse of their mother, and up to half are of them are victims of abuse themselves (Edleson, 1999). Though not described in these studies, millions of other children are exposed to neighborhood violence, illness or death of a parent, severe accidents or injuries, and invasive medical treatments, all of which can also result in traumatization.

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## Warning signs of trauma

The role of trauma in causing and perpetuating the symptoms that we observe in children is a very new concept in the world of mental health. In fact, until 1980, there was no diagnostic category for trauma-related symptoms. Even when the diagnosis of PTSD first appeared in the DSM, it reflected the symptoms seen in combat veterans or Hurricane Katrina victims better than the symptoms of childhood trauma.

Children rarely have flashbacks and nightmares, for example. Their attempts to “avoid” traumatic recall look on the surface much more like behavioral avoidance than post-traumatic reactions. Their physiological hyperarousal is more likely to manifest as aggressive or self-harming behavior than as a strong startle response or difficulty sleeping, and their sleep difficulties are likely to be either hidden because of the shame or because they manifest simply as resistance to bedtime. The idea of trauma as a contributor to underlying oppositional, anxiety, bipolar and depressive disorders is so new that therapeutic environments have not yet incorporated practices reflecting the likelihood that traumatic or neglectful experiences are likely to be the cause of any child’s symptoms.

Children who experience repeated trauma struggle with its consequences in many different ways and may develop any number of obvious trauma-related symptoms, including intense fear, helplessness, anger, sadness, or horror; intrusive memories of the traumatic event; avoidance of any stimuli

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related to the event; and hypervigilance and increased arousal. They may show intense psychological distress at exposure to anything that resembles an aspect of the event. They may have difficulty falling asleep or concentrating and may be easily startled. Some children may become less responsive emotionally, more listless, depressed, withdrawn, and more detached from their feelings. They may become emotionally numb and unresponsive or even develop dissociative symptoms (AACAP Fact for Families, 1999; Cook et al., 2005; Teicher et al., 2002).

A child dealing with the aftermath of trauma may also experience symptoms less clearly related to the trauma, including headaches or stomachaches, sudden and extreme emotional reactions, difficulty falling or staying asleep, irritability or angry outbursts, and difficulty concentrating. The children may also engage in repetitive “play-like” behavior that unconsciously re-enacts the trauma (e.g., sexualized play, aggressive behavior with peers or toys, acting out critical or humiliating treatment). Children who have been traumatized are likely to be guarded or anxious, easily angered, and highly reactive. These children are often highly sensitive to authority or hierarchical relationships, and they may have difficulty following rules or taking responsibility for their behavior, and they may make the same behavioral mistakes over and over again. A sense of “being threatened” can quickly lead the child to an emergency stress response and loss of control over aggressive impulses, resulting in attempts to harm him or

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herself, acting aggressively toward others, or engaging in verbal abuse.

Traumatized children most often exhibit these behaviors unintentionally, without awareness of the connection to the trauma, or they experience the behaviors as logical responses to their sense of being threatened.

## Understanding “trauma logic”

“Trauma logic” is the kind of logic that only makes sense if you make the trauma-related assumption that nothing good is going to happen and no one can be trusted. If the norm is that something bad will happen (it’s just a question of what and when), then you will go a long way to get more control over that inevitability.

If professionals are not trained to recognize the connection between symptom and trauma, it should not be surprising that the children themselves fail to make those connections. For children, there is an additional obstacle: both lack of memory and loyalty play a role in children’s lack of disclosures. Even when they are invited to disclose, loyalty to family members and fear of loss, rejection, or retaliation if they tell discourages revelation. In addition, traumatic memory is so unreliable that they may not clearly remember what happened. A famous study by Linda Williams (1995) of adults with documented abuse histories (in the form of emergency room records) found that approximately a third had no memory of

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these documented incidents and another third of those who did remember the experiences reported having forgotten for significant periods of time.

The challenge for mental health professionals, even when they are frustrated and befuddled, is to assume that all human behavior is meant to be adaptive. “Radical acceptance” means that all behavior, no matter how bizarre, is at least a failed attempt at adaptation. This idea fits better with the newer explanations of human behavior from neuroscientists which demonstrate that our behavior reflects our brain development and our brain development is dramatically affected by attachment and environment (Shonkoff & Phillips, 2000).

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The following are two examples of how behavior that was adaptive at one time is no longer useful and potentially harmful for these children:

An adolescent girl who was sexually abused by a stepfather and neglected by her alcoholic mother seeks out sexually explicit or dangerous situations now. Re-enactment behavior almost always has an adaptive purpose: this teenager is seeking out a situation that she learned was bound to happen anyway, no matter what she did. Believing that sexual exploitation is inevitable, initiating the sexual contact gives her increased control over the timing and circumstances, the only control she could have had as a child. In addition, seeking out the only positive attention she may have ever known might give her some hope of connection or protection.

A 12-year-old boy was abandoned by his father and severely neglected and beaten by his mother who has Bipolar Disorder. He now steals from his peers and makes himself the scapegoat in social situations. If the only attention he received from his mother came when he acted out or irritated her, he is now likely to behave as if all human beings would do what he learned to expect from her, and making himself the “bad guy” offers more control, more predictability. If you are convinced of your unlovability, as a child with his history would have to be, and assume that others will never like or include you, why not pull the plug on positive relationships while you still can? If you are convinced that others have not had the losses you have had, that they have gotten the things they needed and wanted, and then you steal from them, you reclaim your loss.

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These are examples of “trauma logic.” If we use “trauma logic,” we will communicate to children that their behavior must have some logic that we don’t understand, and that they must be trying to solve a problem rather than create one. And if, instead of reacting to the inappropriateness of the behavior, we can be curious about its own logic and creativity, then we will start to invite the children to be more curious than impulsive.

Because of our concerns about safety and risk management, many mental health professionals are reluctant to initiate these discussions with children. We become anxious that we will encourage or reward the behavior. But the world of neuroscience tells us differently: safety and risk management depend upon the ability of the frontal lobes to exert top-down managerial control over impulses and actions.

If we encourage curiosity about behavior, not by asking, “Why did you do it?” but by assuming, “You must have had a good reason, even if that reason doesn’t make sense right now,” then we wake up the frontal lobes and increase their ability to observe and plan. If we *react* to the behavior by either imposing a consequence or asking “Why?” questions, we do the opposite of what we intended, and the frontal lobes shut down as feelings of shame or anger increase.

Ironically, it is actually better risk management to assume the best than the worst! It is our frontal lobes that are in charge of safety and good judgment, and curiosity is the key to bringing them on line.

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## The neurobiology of trauma

Even at birth, we are “hardwired” to respond to threat or danger with specific physiological responses that maximize our chances of survival. When we perceive a threatening stimulus, our bodies mobilize emergency responses. Adrenaline activates the sympathetic nervous system to speed oxygen to muscle tissue preparing us to flee or fight, while other neurochemicals mobilize the parasympathetic nervous system to prepare us for other alternative survival responses, such as freezing, submission, and compliance.

In childhood, fight against a parent figure or flight from home and family are not usually available options, and therefore parasympathetic freezing and compliance often come to be habitual ways of responding to potential danger for children. Over time, with repeated experiences of actual or threatened abuse or neglect, the development of specific brain pathways governing personality and emotional development may be profoundly affected. These pathways include those that enable a person to recognize and respond appropriately to danger, to interpret new experiences, to process information, to self-regulate, to control impulses, and to form memories.

Under ordinary conditions, these emergency responses shut down after the danger has passed. However, for people who are exposed to severe and ongoing trauma, the body often loses its ability to shut down the emergency response, resulting in either a continuous state of hyperarousal (as evidenced by

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behavior that is anxious, guarded, explosive, aggressive, reactive, hyperactive) or prolonged states of hypoarousal (associated with numbing, robotic compliance, passivity, disconnection, loss of pleasure or motivation). The survival responses that helped the child to adapt to a threatening environment tend, with overuse, to become post-traumatic symptoms and habitual problematic responses.

Human development is shaped by a dynamic and continuous interplay between biology and experience. In a traumatogenic environment, certain cues become associated with potential danger and cause the survival responses to be turned on in anticipation of abuse or threat (for example, when the front door opens, when a raised voice is overheard in the next room, when a particular model of car driven by the abuser is observed).

This sensitivity to *threat cues* helps to increase the chances for optimal survival but results in later difficulties with *stimulus discrimination*, which is the ability to differentiate a potential future threat from reminders of past trauma. As a result, trauma victims often become very reactive to sensory input directly or indirectly associated with past traumatic experiences. The body responds as if the stimulus represents a life threat with sympathetic responses of panic, adrenaline rush, and hypervigilant and/or hyperactive reactivity, or, with parasympathetic shutdown, numbing, floating away, or blanking out. On the surface, others may perceive the victim as either over-reacting or under-reacting, without realizing that these

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responses are the body's re-enactment of mobilization for danger (van der Kolk et al., 1996; Saxe, Ellis, & Kaplow, 2006).

As an additional complication, the child may not be aware of any connection between these reactions and the episodes of neglect and abuse he or she experienced. The ability to remember what happened and put it in context is impaired during a traumatic event or in a threatening environment. When the sympathetic nervous system prepares for fight or flight, the frontal lobes and the hippocampus (the parts of the brain responsible for witnessing events and organizing the memories) shut down to enable us to respond immediately and instinctively. The result is that the child is left with the emotional and body responses to the event disconnected from the knowledge that they occurred.

These responses do not "carry with them the internal sensation that something is being recalled. We act, feel, and imagine without recognition of the influence of past experience on our present reality" (Siegel, 1999). Caregivers struggle with understanding the intense and often extreme responses of traumatized children, and the children themselves do too. Asking the child, "Why did you do that?" usually only elicits guesses or excuses that further frustrate the child and the caregiver.

Inpatient and residential treatment programs provide services for many traumatized children. Some of the children are identified as traumatized at admission, but some are not, either because the trauma has not been reported or because the

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reported events have not been seen as potentially traumatic. In Massachusetts, a review of client histories in 2001 revealed that 84% of the children in continuing care inpatient hospital units and intensive residential treatment programs had reported histories of trauma (DMH Record Review, 2001).

In another study of 100 adolescents on inpatient units, 93% disclosed having a history of trauma and 32% were diagnosed with PTSD (Lipschitz et al., 1999). Children are often admitted to hospitals and residential programs because they are struggling with problematic behaviors connected to their histories of trauma, such as suicidal or parasuicidal behavior, self-injury, aggression toward others, passive aggressive behavior, loss of interest, and deep despair. Despite the large number of traumatized children in residential and hospital programs, most settings have not provided their staff members with the necessary training to offer trauma treatment or trauma-informed care.

## Assessment of trauma risk

To provide specialized trauma treatment, programs must be able to identify the potential or actual traumatic exposure of each child at intake. This goal is best met by conducting an initial assessment of a child's trauma history, with a particular emphasis on identifying any risk factors or triggers that may result in dangerous behavior. Without such an assessment, it is impossible to provide trauma-informed treatment.

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Ideally, trauma assessments should include the following information:

- The type of trauma
- The age at which the trauma occurred
- The perpetrator of the trauma
- A description of related symptoms
- A description of the most common triggers that activate the symptoms

At the same time, trauma assessment must reflect the Hippocratic principle, “Do no harm.” For example, it is important to keep in mind that talking about traumatic events triggers trauma-related sympathetic and parasympathetic responses and may create an internal sense of threat for the child. It is also threatening for children to be asked to reveal “secrets,” to “tell on” their parents, or to discuss events that they may not remember or associate with degradation and humiliation. In general, it is more helpful to get a general idea of the type of trauma and the identity of the perpetrator from the child, rather than detailed information, and to elicit the more detailed information from other sources. It is also important that the assessment focus on what happened to the child, rather than on what is wrong with him/her (Bloom, 2002). The assessment becomes part of the treatment when it is used to reassure the child that his or her symptoms have meaning, that they make sense as responses to traumatic experience or as ways that the body is expressing fear and dread.

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Finally, it is of utmost importance to assess the child's current situation relative to safety. Treatment providers must ascertain whether the child is still actually or potentially being subjected to abusive relationships or circumstances and ally with non-abusive family members and collaborate with protective child welfare agencies.

## Trauma-informed care

Understanding the impact of trauma on children is relatively new in the mental health field, and few hospital and residential treatment programs have provided adequate training and supervision for staff members about it. Without specific knowledge about trauma and skills for working with its effects, it is hard to provide trauma-sensitive interventions. For example, interventions that punish aggressive behavior resulting from traumatic triggering often exacerbate a child's trauma symptoms, because the punishment triggers more sympathetic activation and can result in more aggression and/or hypervigilance.

In the past twenty years, treatment providers and researchers have begun to more fully understand how trauma affects people on many different levels. Trauma-informed care is the provision of treatment that recognizes the consequences of trauma for children and offers interventions that address both the behavior or symptom and its underlying post-traumatic cause. It is an emerging practice that can dramatically improve the prognosis for traumatized children in mental health

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treatment settings. Trauma-informed care principles have been developed by synthesizing current research on trauma, what is known about effective treatment practice, input from trauma survivors, and by differentiating re-traumatizing and strength-based interventions. A strength-based perspective assumes that maladaptive behavior arises in a context where that behavior was once adaptive. For example, a child's aggressive behavior developed at a time where he/she lived in a violent neighborhood, he/she was neglected, and he/she witnessed his/her mother being beaten. In fact, these behaviors, when understood contextually, are actually "valiant attempts" to cope (Bloom, 2002).

Trauma-informed care systems share key principles with strength-based philosophies, including (NETI, 2006):

- Recognizing that children who have been neglected, experienced significant loss, witnessed violence, or been physically or sexually abused are likely to suffer from severe behavioral problems representing symptoms and memories of the trauma
- Conducting routine and thoughtful trauma assessments is essential to treating traumatized and neglected children
- Identifying treatment setting variables and program practices that are inherently re-traumatizing and will therefore exacerbate the symptoms even if the behaviors are controlled

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- Acknowledging that all program staff must be trained to work with traumatized children and provided with ongoing training and supervision on assessment and treatment
  - Valuing and involving the child and family in all aspects of care and creating opportunities for control or mastery for children who have experienced the overwhelming loss of control
  - Using neutral and supportive language because most physical and sexual abuse is accompanied by verbal abuse and the use of neutral language ensures that symptoms will not be excessively triggered in program settings
  - Using neutral and supportive language that does not blame or excessively pathologize the child.
  - Creating personalized and flexible plans for each child in the program ensures that the trauma symptoms and behaviors are being addressed proactively (see *Safety Tools* chapter of the *Resource Guide* for more information)
  - Providing training for staff members that teaches them to use mindfulness skills to increase their ability to observe, stand back, and collect information rather than reacting immediately to children's behavior and symptoms

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- Supervising staff members to help them refrain from behavior and interactions that might be construed as coercive or controlling by children, families, and other staff members, such as using a sarcastic tone of voice, joking about the children, arguing, making threats, being critical or taking away privileges unnecessarily.

## Programmatic approaches to trauma-informed care

Implementing a trauma-informed treatment model requires organizational commitment at all levels. It is important to provide staff members with the training and resources to conduct thorough trauma assessments, to provide appropriate treatment, and to avoid re-traumatizing practices within the program. Commitment to trauma-informed care requires appropriate training of key administrators and staff members in trauma-specific treatment and resources for systems modifications and performance improvement processes. Depending on the setting, program cultures may require significant changes, because trauma-informed care models minimize the use of coercion and control by emphasizing prevention, articulating de-escalation preferences, and using Safety Tools.

Programs that embrace trauma-informed care practices promote partnerships between staff members and children, rather than labeling children as manipulative, needy, or attention-seeking, and value collaboration over compliance.

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In addition, programs that are trauma-sensitive tend to have lower rates of S/R than programs that use more coercive treatment interventions. Interventions that are more authoritarian may or may not achieve more behavioral compliance in the short term but run the risk of exacerbating trauma symptoms in the long run and interfering with internal skill development.

Not only is commitment to understanding the role of trauma crucial for the successful implementation of trauma-informed care but also commitment to the avoidance of practices that exacerbate trauma symptoms and can be re-traumatizing for the children that staff are trying to help. Unfortunately, our bodies and nervous systems cannot differentiate between an adrenaline response evoked by something currently dangerous and an adrenaline response triggered by some small trauma-related cue. For example, a number of frequently occurring environmental variables found in most child settings involve stimuli that can be very traumatically activating for children: arbitrary or unexpected exercise of authority, lack of choice, humiliation, directly or indirectly being labeled “bad,” being pressured to disclose feelings, being the center of attention (or *not* being the center of attention), isolation, groups of people, having to make eye contact, punishment, raised voices or angry expressions, kind or caring gestures, S/R, and time-out procedures.

Depending on whether the child’s experiences have included more neglect compared to abuse or more abuse compared to

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neglect, one child may be more easily triggered by threat cues and another by neglect cues. A child with a history of being locked in a closet would likely find the experience of seclusion reactivating and devastating. A child who was held down and sexually abused might find physical restraint terrifying and overwhelming, reminiscent of the experience of an adult holding and hurting him/her. If the child grew up in a large family, groups may be more triggering; if the child grew up in isolation, being alone may be more intolerable. If the child's exposure was to physical violence, loud voices and sudden movements might be triggering.

### **A Case Example**

Andrew is a 12 year old boy admitted to a residential program for a variety of behavioral and emotional problems: aggressive acting out at school, sexualized play with a younger sister, explosive outbursts at home, hitting and biting himself, and difficulty in relationships with both peers and adults. The program staff found him extremely difficult even in his initial intake interview. Andrew became agitated in response to questions and attempted to run out of the room and assault other residents, resulting in a staff member having to restrain him. Staff members experienced him as “manipulative,” “cold and uncaring,” “having no respect for authority,” and “scary.”

In addition, Andrew responded poorly to attempts by staff to connect to him in a positive way, acting out in response to praise and seeming to sabotage himself each time he began

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to do better, which led to staff members becoming frustrated and avoiding him altogether. Lost in his treatment was the history with which he came to the program: severe neglect in early infancy by his drug-addicted mother, sexual abuse by at least one of her boyfriends, and physical tormenting by his two older brothers.

As the staff were helped to connect this history to Andrew's behavior, it became clearer that his "cold and uncaring" and "scary" behavior represented fear and emotional withdrawal, an adaptive response to his childhood environment; the lack of respect for authority stemmed from fight/flight responses that were triggered each time he was arbitrarily told to do something; his difficulty with praise and success reflected the experience of having been "groomed" for the sexual abuse with positive attention and gifts.

As staff responded to Andrew by positively re-framing his symptoms ("Of course, you aren't sure you can trust us," "Wow, you sure are good at hiding your feelings when you are upset—you must have had a lot of practice"), using language and tone of voice that signaled calm instead of authority, providing psychoeducation appropriate to his age, and giving him opportunities to contribute input on his behavior plan, Andrew began to exhibit fewer outbursts and an improved ability to regulate his reactions to stimuli.

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In the previous example, Andrew's acting out behavior could be tracked to particular trauma-related cues: feeling "trapped" (triggered by any type of confrontation with staff or even in routine meetings), feeling vulnerable (triggered by intimacy, by being treated kindly, attempts to connect with him, being asked to disclose feelings), feeling "bad" or "wrong" (triggered by understandable staff or peer reactions to his behavior).

Even though some triggering is inevitable despite the best, most informed care, the staff's acknowledgement of the role of triggering can be helpful in increasing the child's level of awareness and control over future reactivity. If reactive behavior is labeled as "triggered," even if the child is held responsible for it, then self-awareness and compassion can be facilitated, decreasing the likelihood of the reactivity occurring again or occurring at the same level again.

For Andrew, this intervention entailed reminding him that talking to staff about his behavior did not mean he was trapped, that he could leave and come back if he needed to, as well as reassuring him that being asked to take responsibility for his behavior did not mean he was "bad," and reminding him that it was triggering for him to have to talk about his reactions. Last but not least, staff made an effort to connect with him in a way that was friendly but reserved to decrease the relational triggering and to avoid asking him to be directly vulnerable, while also acknowledging that, of course, he might have some strong feelings.

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**The National Child Traumatic Stress Network (NCTSN)** is an organization dedicated to raising the standard of care and improving access to services for traumatized children, their families, and communities throughout the United States. NCTSN develops and disseminates effective, evidence-based treatments, collects data for systematic study, and helps to educate professionals and the public about the impact of trauma on children. NCTSN provides information on current empirically supported treatments and promising practices for treating traumatized children ([www.nctsn.org](http://www.nctsn.org)).

## Principles of trauma-informed care

Implementation of the following suggestions will pave the way toward more effective, trauma sensitive care in inpatient and residential settings (Hodas, 2006; NETI, 2006).

Where possible, staff members should be given the opportunity to visit programs that have successfully developed and implemented trauma-informed care practices to observe how the practices actually work.

- The first step in implementing trauma-sensitive programming is to review the **organization's mission and values** and reframe them to emphasize the importance of trauma-informed care and to ensure that all components of the program support a trauma-sensitive focus.

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- Each treatment program should have a written **philosophy of care** that incorporates trauma sensitivity and spells out how it is integrated into all aspects of the child's daily routine and treatment. Appropriate trauma-sensitive practices must be incorporated into group programming and milieu activities.
  - Programs should provide on-going **training for all staff** members in childhood trauma, trauma-informed care, and trauma treatment models. Use of role play and other experiential techniques can increase understanding of the "emotional logic" of apparently illogical, unsafe behavior.
  - It is particularly important for all staff members to be trained in how to conduct **trauma assessments**. Consultation and training by trauma experts can help clinicians to be trained to conduct assessments based on verbal reports from the child, verbal reports from non-offending parents and caregivers, treatment records, and information from the child's drawings and play.

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- In addition, training on translating assessments into **treatment planning** is equally important. Although problematic and risk-taking behaviors are characteristic in traumatized children, good training and supervision can help staff members intervene in ways that support treatment of trauma symptoms rather than simply responding to the behavior. Programs should strive to provide treatment planning and interventions that resolve behavioral problems and address the underlying trauma issues.
  - Specific **modalities** can enhance the effectiveness of trauma-informed care, such as the use of comfort rooms and sensory interventions, caring relationships, positive adult and peer role models, self-esteem building activities, and activities that develop specific skills. Please see the chapter on *Sensory Approaches* and the section on *The Importance of Physical Environment* in the *Resource Guide* for more detailed information on sensory strategies and comfort rooms.

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- Given that trauma represents a failure of safety for children, it is especially important that trauma-informed care includes the development of **Safety Tools** specific to a particular program population. An awareness of each child's personal triggers, early warning signs, and an ability to teach a child to recognize his/her triggers and symptoms provides a repertoire of coping skills to effectively manage the feelings that arise. Please refer to the *Safety Tools* section of the *Resource Guide* for several sample Safety Tools.
  - Sensitivity to children's histories of trauma and neglect as manifested in the use of respectful and therapeutic **communication strategies**, such as active listening or contextualizing acting out behavior. (For example, listening empathically to a child's excuses for a mistake, rather than immediately correcting him, or reassuring a child with a history of physical abuse that his mistake or acting out will not result in physical punishment.)

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- Despite good intentions and policies, hospital and residential programs for children with trauma histories will still inevitably expose children and staff to upsetting incidents. It is important to have a comprehensive **debriefing** procedure in place to use after these incidents that includes specific protocols for how to address the needs of any children and staff members who were traumatized or re-traumatized by the incident. Meticulous reviews of these events can provide information that leads to learning and change and prevention of further re-traumatization.

## Seclusion/restraint (S/R) and trauma

Although S/R techniques have been used routinely for decades in residential and inpatient settings, trauma experts tell us that the use of S/R and other control-oriented treatment practices is re-traumatizing for both children and adults. Trauma treatment and research experience both testify to the importance of avoiding re-traumatization as a first priority in treatment.

Although triggering of traumatic activation cannot be completely avoided, as discussed above, it must be kept to a minimum in order to avoid the reactivation of trauma-related symptoms. It is impossible for programs to meet the treatment needs of these children without attention to trauma-informed practices that provide the highest standard of care. There are a number of trauma-informed care practices that have been well researched, and they have been found to support trauma

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recovery and symptom improvement and to reduce the frequency of inappropriate child behaviors. Please see the *Promising Practices* chapter in this *Resource Guide* for more details.

Use of trauma-informed care practices in residential and inpatient treatment programs have been reported to result in a number of positive outcomes, such as:

- Staff members make every effort to prevent the use of S/R
- Staff members understand the complex bio-psychosocial and developmental impact of trauma
- Staff members are less likely to respond punitively or be judgmental in response to difficult behaviors
- Staff members are able to respond early to potentially problematic behaviors so that children gain internal controls and the program environment feels safer
- The tone of the milieu is quiet, calm, positive, and respectful, and the program is an appealing place for staff members and children
- Children, families, and staff members are more satisfied with the quality of the care provided at the program
- Behavioral incidents are avoided by using calming and collaborative approaches with children, such as collaborative problem solving, de-escalation strategies, conflict resolution, negotiation, and offering choices.

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- The children and staff gain greater understanding of how behavior relates to trauma experience
  - There are fewer assaults on staff members and fewer injuries of children and staff members (LeBel & Goldstein, 2005)
  - Staff understand their own trauma reactions and vulnerabilities
  - Rates of staff turnover are lower and morale is higher (LeBel & Goldstein, 2005).

## Providing care for staff members

Vicarious re-traumatization is the term used to describe a staff member's individualized process of internal change as a result of working with traumatized children, and it includes a number of feelings and subsequent mechanisms for coping with these feelings. "Vicarious re-traumatization is an inescapable effect of trauma—an inevitable hazard of working with trauma survivors." (Saakvitne et al., 2000)

This secondary traumatization results not only from exposure to the details of traumatic experiences but also from the experience of fear and helplessness in the face of trauma-related dysregulation and risky behavior.

When feelings of anxiety or stress become overwhelming for the caregiver, vicarious re-traumatization can result, affecting their sense of identity, their beliefs, their ability to feel

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connected with others, their sense of safety, their desire for closeness, and their feelings of safety and control.

It is essential for staff members to pay close attention to their needs when working with traumatized children and to develop healthy strategies for ensuring that these needs are met.

If staff members have difficulty recognizing the personal toll resulting from the exposure to trauma, they will not be able to see how it affects their responses to the children, such as over-reacting to a child's behavior out of fatigue and frustration, acting out of anger, and using rigid methods of control, including S/R.

Given the incidence of traumatic events in the general populations (60% of men and 51% of women in Kessler et al.'s 1995 study), organizations must be made aware of the reality that many of their own staff members have experienced trauma themselves. Attention to signs of trauma symptoms in staff members should be part of the supervisor's responsibility, and ideally guidelines should be in place to ensure that staff members can access support. Senior psychiatric administrators in trauma-sensitive programs can ensure that staff members are supported in understanding children with trauma symptoms and that they also have support for themselves and a context for their feelings and reactions to the children in their care.

Staff members should be encouraged to take time off, pursue personal interests, and to seek outside assistance, if necessary, to cope with the stress inherent in working with

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traumatized children. It is important to provide staff with support to self-reflect and to develop their own self-care strategies. Staff can even develop their own Safety Tools. Supervision and consultation can also be helpful. Senior staff can offer days away for regenerating and renewal that are enjoyable, playful, and fun, such as picnics, softball games, yoga, meditation, and organized potluck meals.

Conceptual understanding of the feelings and reactions engendered by work with highly symptomatic traumatized children increases the ability to stand back and mindfully observe it, rather than react to it, which is a key ingredient in preventing vicarious traumatization.

## Additional resources

The following resources are included at the end of this chapter

- Diagnostic criteria for PTSD (DSM-IV, 1994)
- Proposed diagnostic criteria for Complex Trauma/DESNOS (van der Kolk et al., 1996)
- NASMHPD Position Statement on Services and Supports to Trauma Survivors
- The MA DMH monograph Series on Treatment of Individuals with a History of Trauma

# Post Traumatic Stress Disorder (PTSD)

## Diagnostic Criteria from Diagnostic and Statistical Manual for Mental Disorders, 4<sup>th</sup> Edition(DSM-IV)

A. The person has been exposed to a traumatic event in which both of the following were present:

(1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.

(2) the person's response involved intense fear, helplessness, or horror.

**Note:** In children, this may be expressed instead by disorganized or agitated behavior.

B. The traumatic even is persistently re-experienced in one (or more) of the following ways:

(1) recurrent and intrusive distressing recollections of the event, including images, thoughts, and/or perceptions.

**Note:** In young children, repetitive play may occur in which these or other aspects of the trauma are expressed.

(2) recurrent distressing dreams of the event.

**Note:** In young children, there may be frightening dreams without recognizable content.

(3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and/or dissociative flashback episodes, including those that occur on awakening or when intoxicated).

**Note:** In young children, trauma-specific re-enactment may occur.

(4) intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

(5) physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:

(1) efforts to avoid thoughts, feelings, and/or conversations associated with the trauma

(2) efforts to avoid activities, places, and/or people that arouse recollections of the trauma.

(3) inability to recall an important aspect of the trauma

(4) markedly diminished interest or participation in significant activities

(5) feeling of detachment or estrangement from others

(6) restricted range of affect (e.g., inability to have loving feelings)

(7) sense of a foreshortened future ( e.g., does not expect to have a career, marriage, children, or a normal life span)

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by at least two of the following:

- (1) difficulty falling or staying asleep
- (2) irritability or outbursts of anger
- (3) difficulty concentrating
- (4) hypervigilance
- (5) exaggerated startle response

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than one (1) month

F. The disturbance causes clinically significant distress and/or impairment in social, occupational, and/or other important areas of functioning.

*Acute:* Duration of symptoms is less than three (3) months

*Chronic:* Duration of symptoms is more than three (3) months

*Delayed Onset:* Onset of symptoms is at least six (6) months after the incident

# Disorders of Extreme Stress

## (Complex PTSD)

- 1. Alterations in Regulating Affective Arousal:**
  - i. Chronic affect dysregulation
  - ii. Difficulty modulating anger
  - iii. Self-destructive and suicidal behavior
  - iv. Difficulty modulating sexual involvement
  - v. Impulsive and risk-taking behaviors
  
- 2. Alterations in Attention and Consciousness**
  - i. Amnesia
  - ii. Dissociation
  
- 3. Somatization**
  
- 4. Chronic Characterological Changes:**
  - a. Alterations in self-perception:
    - i. Chronic guilt
    - ii. Shame
    - iii. Feelings of self blame
    - iv. Ineffectiveness
    - v. Being permanently damaged
    - vi. Minimizing the importance of the traumatic experience
  
  - b. Alterations in relations with others
    - i. Inability to trust or maintain relationships with others
    - ii. A tendency to be re-victimized
    - iii. To victimize others
  
- 5. Alterations in systems of meaning**
  - i. Despair, hopelessness
  - ii. Loss of previously sustaining beliefs

## **NASMHPD Position Statement on Services and Supports to Trauma Survivors**

The National Association of State Mental Health Program Directors (NASMHPD) recognizes that the psychological effects of violence and trauma in our society are pervasive, highly disabling, yet largely ignored. Recent research indicates that interpersonal violence and trauma, including sexual and/or physical abuse over the lifespan, is widespread, has a major impact on a wide range of social problems, and are costly if not addressed. The threat of terrorism is now a constant source of stress for many Americans and the sequelae to recent terrorist events have affected untold numbers of citizens. NASMHPD believes that responding to the behavioral health care needs of women, men and children who have experienced trauma is crucial to their treatment and recovery and should be a priority of state mental health programs. In addition, the prevention of traumatic experiences is a fundamental value held by NASMHPD and its individual members; state mental health authorities. Toward this goal, it is important to support the implementation of trauma-informed systems and trauma-specific services in our mental health systems and settings.<sup>1</sup>

The experience of violence and trauma can cause neurological damage and can result in serious negative consequences for an individual's health, mental health, self-esteem, potential for misuse of substances and involvement with the criminal justice system. Indeed, trauma survivors can be among the people least well served by the mental health system as they are sometimes referred to as "difficult to treat"--they often have co-occurring mental health and substance use disorders, can be suicidal or self-injuring and are frequent users of emergency and inpatient services.

Trauma is an issue that crosses service systems and requires specialized knowledge, staff training and collaboration among policymakers, providers and survivors. Study findings<sup>2</sup> indicate that adults in psychiatric hospitals have experienced high rates of physical and/or sexual abuse, ranging from 43% to 81%. Studies have

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<sup>1</sup> For purposes of this position statement *Trauma and Traumatic Events* will be defined as the personal experience of interpersonal violence including sexual abuse, physical abuse, severe neglect, loss and/or the witnessing of violence (Jennings, 2004; NASMHPD, 2003; Moses, Reed, Mazelis & D'Ambrosio, 2003).

*Trauma Informed Care* is defined as care that is grounded in and directed by a thorough understanding of the neurological, biological, psychological and social effects of trauma and violence on humans and is informed by knowledge of the prevalence of these experiences in persons who receive mental health services. *Trauma Specific Services* are defined as promising and evidenced based best practices and services that directly address an individual's traumatic experience and sequelae and that facilitate effective recovery for trauma survivors (NASMHPD, 2004).

<sup>2</sup> All statistics cited can be found in *The Damaging Consequences of Violence and Trauma*, compiled by Ann Jennings, Ph.D. NTAC: 2004 and the NASMHPD Curriculum: *Six Core Strategies for the Reduction of Seclusion and Restraint*©, 2004

shown that up to 2/3 of men and women in substance abuse treatment suffer from posttraumatic stress disorder, acute stress disorder or symptoms; and up to 80% of women in prison and jails were victims of sexual and physical abuse. Children are particularly at risk as over 3.9 million adolescents have been victim of serious physical violence and almost 9 million have witnessed an act of serious violence. Adverse childhood experiences are related to health risk behaviors and adult diseases, including heart disease, cancer, chronic lung disease, skeletal fractures and liver disease. Especially significant for behavioral health care service systems are findings by the National Child Traumatic Stress Network and others that have linked serious behavioral problems to the biological, neurological and psychological effects of violence and trauma in childhood. Early abuse is now believed to create a particular vulnerability to hyper-arousal, explosiveness and/or de-personalization that results in ineffective coping strategies and difficult social relationships.

Confounding and complicating the prevalence of trauma in public mental health service recipients is the fact that mental health services themselves are often experienced as traumatic. The use of coercive interventions such as seclusion and restraint, forced involuntary medication practices, and philosophies of care based on control and containment vs. empowerment and choice often cause unintentional re-traumatization in already vulnerable populations.

The New Freedom Commission Report [Achieving the Promise: Transforming Mental Health Care In America](#) calls for the promise of community living for everyone and for the transformation of our mental health systems of care to meet shared goals that facilitate recovery and build resiliency. NASMHPD believes that the implementation of systems of care that are trauma informed is a cornerstone in building service systems that do not traumatize or re-traumatize service recipients or the staff that serve them. Recovery based services are sensitive to trauma issues and are never coercive. The concept of universal precautions is quite valuable when identifying and implementing the principles and characteristics of trauma informed systems of care to avoid traumatization and re-traumatization.

A set of criteria for building a trauma-informed mental health system were developed at a NASMHPD-sponsored trauma experts meeting in 2003, and a number of state mental health authorities have begun to address these issues in the public mental health system. Trauma informed prevention strategies adopted by states and service systems include reducing and eliminating the use of seclusion and restraint; the use of prevention tools such as trauma assessments, identifying risk factors for violence or self harm, safety planning, advance directives; workforce training and development; and the full inclusion of consumers and families in formal and informal roles.

Services for trauma survivors must be based on concepts, policies, and procedures that provide safety, voice and choice, and—like all good care—must be individualized/personalized. Trauma services must focus first and foremost on an

individual's physical and psychological safety. Services to trauma survivors must also be flexible, individualized, culturally competent, promote respect and dignity, and be based on best practices. Recent research indicates that the most effective approaches for supporting recovery from trauma are well-integrated behavioral health services that also reflect the centrality of trauma in the lives and experiences of consumers.<sup>3</sup>

NASMHPD is dedicated to better understanding of the effects of trauma and violence including physical and/or sexual abuse, neglect, terrorism; implementing emerging culturally competent best practices in trauma treatment within the public mental health system; and considering the role of prevention and early intervention programs in decreasing the prevalence of trauma-related behavioral health problems. State mental health authorities are committed to recognizing and responding to the needs of persons with mental illnesses and their families within a cultural and social context. Asking persons who enter mental health systems, at an appropriate time, if they are experiencing or have experienced trauma in their lives is becoming a standard of care. NASMHPD has taken the lead in recognizing that some policies and practices in public and private mental health systems and hospitals, including seclusion and restraint, may unintentionally result in the revictimization of trauma survivors, and therefore need to be changed.

NASMHPD is committed to working with states, consumers/survivors and experienced professionals in the trauma field to explore ways to improve services and supports for the public mental health service recipient inclusive of trauma survivors consistent with the recommendations of the New Freedom Commission Report. These efforts may include, but are not limited to developing and disseminating information and technical assistance on best practices; supporting research as recommended by the field; providing forums for national dialogues on trauma survivors; consistent advocacy in creating trauma informed and recovery based systems of care; including consumers and their families in the planning, design, implementation and monitoring of best and promising practices; and cooperating with other state and national organizations to develop treatment, prevention and education initiatives to address the issue of trauma.

Original Statement passed unanimously by the NASMHPD Membership on 12/7/98.

Revised Position Statement passed unanimously by the NASMHPD Membership on 1/3/2005.

Available online at:

*[www.nasmhpd.org/general\\_files/position\\_statement/NASMHPD%20TRAUMA%20Positon%20StatementFinal.pdf](http://www.nasmhpd.org/general_files/position_statement/NASMHPD%20TRAUMA%20Positon%20StatementFinal.pdf)*

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<sup>3</sup> SAMHSA citation (in press)

**The Commonwealth of Massachusetts**

**Department of Mental Health**

**Monograph Series**

**Treatment of Individuals With a History of Trauma**

*March 1999*

The National Association of State Mental Health Program Directors (NASMHPD) recently issued a unanimous position statement on services and supports to trauma survivors. NASMHPD acknowledged the psychological impact of violence and trauma and the need for state mental health authorities to be responsive to the unique needs of trauma survivors with mental illness. The NASMHPD position emphasizes that "trauma services must focus first and foremost on an individual's physical and psychological safety. Services to trauma survivors must also be flexible, individualized, culturally competent, and promote respect and dignity."

Statistics regarding the frequency of trauma are disturbing. Prevalence rates for childhood abuse among psychiatric inpatients are significantly higher than the general population. Research suggests that at least half of all women and a substantial number of men treated in psychiatric settings have a history of physical and/or sexual abuse.

In 1996, a Department of Mental Health Task Force was convened to make recommendations regarding restraint and seclusion of persons with a history of physical and sexual abuse. As a result, clinical guidelines were issued in 1996 regarding the treatment and care of trauma survivors. DMH regulations 104.CMR 27.12 also specify that staff pay special attention to needs of trauma victims when using restraint and seclusion. Both the guidelines and the regulations were intended to increase awareness, sensitivity and skills needed by clinicians to treat trauma victims. They are intended to provide basic principles and flexible tools that clinicians should integrate into their practices when treating clients with a history of abuse.

Mental health professionals cannot develop appropriate treatment plans or interventions for clients without knowing their history of trauma. For instance, restraint and seclusion can cause retraumatization because of the similarity to prior traumatic experiences. If a history exists, it is important to determine what approaches or strategies would be most helpful to the client in order to avoid the use of restraint and seclusion. If needed, the kind of restraint or seclusion and the gender of the staff who should administer it should be sensitively determined.

The clinical guidelines provide two assessment forms to determine this information--a trauma assessment form and a de-escalation form. The trauma assessment form is designed to gather information about trauma history as part of the client's intake assessment. The de-escalation form gathers information about the client with the goal of reducing agitation and distress. Other measures outlined in the guidelines are designed to be sensitive to the needs of a person in seclusion or restraint, for example, the ability to observe a clock or the ability to find out the time.

DMH is dedicated to being responsive to the needs of adult, child and adolescent clients who have experienced physical and/or sexual abuse. It should be standard practice to ask clients if they have experienced trauma in their lives so that treatment, services and supports which aid, rather than impede, their recovery can be developed. The NASMHPD position statement supports and reinforces the DMH regulations and guidelines.

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## **Nurturing Interventions**

**Tina Champagne, M.Ed., OTR/L**

**Beth Caldwell, MS**

“ Kind words can be short and  
easy to speak, but their echoes  
are truly endless. ”

Mother Theresa

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# Nurturing Interventions

**R**esearch in the mental health, child development, and education fields indicates that children need to be supported by nurturing adults in their lives (Shonkoff & Phillips, 2000; Brazelton, 1990; Shore, 1997). Experts in trauma-informed care also emphasize the importance of using nurturing interventions and practices to promote healing in residential and hospital treatment programs. Studies on resiliency found that relationships with caring people are critical in helping people to overcome obstacles (Werner, 1984). While many treatment programs have recognized the importance of nurturing interventions, they have also acknowledged that staff members may, unintentionally, have interactions with children that are not nurturing or promoting therapeutic relationships. Educating staff on the importance of creating nurturing interventions and building therapeutic relationships has been beneficial in helping children to heal and also helps many programs to significantly reduce or eliminate the use of S/R.

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Nurturing interventions that promote healing fall into four categories:

<b>1. Therapeutic Use of Self</b> (Staff interactions with children)	This includes all non-verbal and verbal interactions/interventions by staff members that send messages that they care about the child and believe in him/her.
<b>2. Development of Positive &amp; Supportive Peer Relationships, Interactions &amp; Activities</b>	This includes individual, group and community efforts to help each child respect and support their peers' efforts in recovery, healing, and learning.
<b>3. Program Practices and Interventions with Children</b>	These practices and interventions include a range of age appropriate holistic activities that are part of daily routines.
<b>4. Providing a Nurturing Physical Environment</b>	The program's physical environment is comfortable and supportive of children's sensory needs and offers helpful alternative spaces to meet these needs, such as a relaxation room or an indoor gym.

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## How programs can become more nurturing

Programs should evaluate all aspects of the daily routine to ensure that practices are nurturing, reduce stress, and facilitate each child's growth and learning throughout the day. The following are suggestions on how to achieve a nurturing environment:

- Staff should use calm voices with children at all times, actively listen, use empathetic statements that are short and specific, make eye contact, offer help and support, be fair, show concern, and make statements that reflect children's feelings. With small children, staff members should lower their bodies and physically get down to the child's level to speak with them. Staff should never talk down to or at a child.
- Staff should be given training opportunities where they can learn different ways to incorporate nurturing interventions. Programs should have systems where staff receive feedback from peers, children, and families. One program in Massachusetts, Transitions IRTP, conducts intermittent staff-resident role reversal sessions for adolescents and staff members to experience the challenges they each encounter in their respective roles.

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- Programs should use individualized empowerment systems for children in place of the point and level systems of motivation. Children should never lose all of their privileges or lose specific privileges for a long period of time (Mohr & Pumariega, 2004).
  - When staff members need to correct a child's behavior, they should use interventions that are supportive, specific, non-judgmental, and instructive and provide a clear rationale as to why the child's behavior is being corrected.
  - Staff, children and their families should work collaboratively to design creative and holistic program interventions. Examples include music therapy, art therapy, dance, drama, sports, massage therapy, meditation, Qi Gong, animal therapy, Tai-Chi, exercise, yoga, journal writing, mediation, gardening, volunteering, and aromatherapy.
  - The program should have special traditions (for holidays, birthdays, welcoming a new child to the program, etc.) that children and families can help design. Staff, children, and families can form committees and "brainstorm" ideas about how to make the program better and ways to implement these changes.
  - Children should be allowed to help create their own routines with various calming activities to slow down. Examples include drinking tea (decaf or herbal) before bed, reading, massages, listening to music, and telling stories.

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- Staff should praise children whenever they have the opportunity, especially for smooth transitions from one activity to another. They should strive for a ratio of six positive statements for every corrective statement.
  - Meals should be pleasant and include nicely set tables with flowers and napkins, taking turns, and giving thanks. Children should be encouraged to practice manners and conversation skills.
  - Programs should have routines for sharing good news, such as during community meetings.
  - Staff members **do not** use approaches that children have identified that they do not like, such as describing only problematic behaviors, showing anger, giving negative feedback, using profanity, showing lack of understanding, being bossy and demanding, displaying a negative attitude, having unpleasant physical contact, making mean or insulting remarks, shouting, not giving children the opportunity to speak, making accusations, using blame statements or being unfriendly (Willner et al., 1977).

## Do

- Recognize a child's strengths and accomplishments
- Use words to let the child know how you are feeling
- Use kind and gentle words

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- Give positively framed feedback (e.g., “That is a great loud voice for outside. I’ll bet we will hear you across the yard. Now we need to use our indoor voices.”)
  - Ask for help and cooperation
  - Use a quiet, calm voice
  - Give the child an opportunity to speak
  - Ask questions, encourage discussions
  - Use friendly touching (if the child agrees), such as a pat on the shoulder or a “high five”

## **Do Not**

- Focus on what a child is doing wrong
- Show your anger or act out your anger
- Use hurtful or profane language
- Frame feedback in a negative manner (e.g., “You really should not be so loud.”)
- Demand that a child do something
- Shout or speak harshly
- Monopolize the conversation
- Blame or accuse
- Touch the child in an aggressive manner or in any way that makes him/her uncomfortable

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## Positive outcomes of nurturing interventions

Programs can expect a number of positive outcomes as a result of incorporating nurturing interventions into all parts of the program, including:

- There is a high level of child, family, and staff satisfaction with the program.
- The use of all restrictive interventions, including S/R, is greatly reduced or eliminated.
- Children and staff laugh more.
- Children and staff members use kind words and convey a more positive, supportive attitude.
- Children, families, and staff members enjoy a variety of activities that promote health, such as sports, yoga, mindfulness, and meditation. These activities become part of children's discharge plans to help them transition successfully into the community.
- Children become more aware of what happens to their bodies and their thinking when they feel upset and learn coping skills that help them maintain self-control, such as the use of sensory diets, mindfulness exercises, and journal writing.
- Children begin to feel more confident about themselves and their abilities.

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- Families feel nurtured and supported and are able to manage their fears and become more available to participate and interact with their children and staff.
  - Staff members feel nurtured and supported and are able to more effectively and compassionately partner with children and families.
  - Staff members learn skills that help them remain calm, neutral, non-judgmental, and focused during crisis situations.

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## **Safety Tools**

**Jean MacLachlan, MS, OTR/L**

**Nan Stromberg, MSN, APRN, BC**

“ It is more fun to talk with someone who doesn't use long difficult words but rather short easy words like 'What about lunch?' ”

*Pooh's Little Instruction Book,  
inspired by A.A. Milne*

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# Safety Tools

**T**he Safety Tool was developed as a proactive intervention plan, the purpose of which is to help the client avoid or mitigate a crisis by considering strategies in advance that would be most helpful. Originally developed by consumers and clinicians as part of a DMH *Task Force on the Restraint and Seclusion of Persons who have been Physically or Sexually Abused*, Safety Tools were expected to help individuals in psychiatric hospitals avert behavioral difficulties and ultimately prevent the use of S/R, after a typically re-traumatizing and damaging experience (Carmen et al., 1996).

Central to the approach of early planning is the full inclusion of the child and family in a collaborative process with treatment providers. Young children and children with cognitive limitations may require more input from families and caregivers as well as clinical assessment and observation by staff to gather pertinent information.

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To be as useful as possible, the information obtained must be personalized and capture the child's unique history, strengths, vulnerabilities, needs, and preferences. The components of the Safety Tool should minimally include:

- **Triggers:** Antecedents or “threat cues” that could cause a child to get upset, angry, aggressive, or self-injurious. Common triggers include: loud noises, being touched, being spoken to in a harsh tone, being ignored by adults, being teased by other children, certain times of the day, or being hungry.
- **Warning Signs:** Physical precursors to escalation. Bodily changes that indicate increased agitation such as, shortness of breath, heart pounding, head throbbing, sweating, clenching fists, and pacing. People are sometimes unable to identify discrete triggering events but can describe or notice what happens in their body when they start to get upset. Developing an awareness of this state change can cue the child that he/she may be in need of immediate help.

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- **Strategies:** Individualized mechanisms used to manage stress and upset feelings that are discussed and addressed before the crisis erupts. These may be calming or alerting and should be based on the distinct emotional, behavioral, environmental, and sensory needs of the child. “One size fits all” planning should be avoided. Strategies might include reading a story, getting a back rub, bouncing on a trampoline, playing basketball, listening to music, pounding on clay, looking at pictures, writing, using a weighted blanket, talking with staff, or using a fidget tool or stress ball.

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## Implementation Guidelines:

- Conduct an interview and obtain the information necessary to complete the Safety Tool for every child. Include the family, current external caregivers, and past providers as soon as possible after the admission.
- If the child is too young or cognitively impaired, obtain information from other sources as well as clinical assessment and observation of the child in the milieu.
- Develop a Safety Tool for each child. Ensure that it meets the developmental stage of the child and is child-friendly and easy to understand.
- Decide how to best incorporate each child's Safety Tool into the day-to-day milieu (daily meetings, treatment reviews, "check sheets," etc.).
- Schedule times to regularly review each child's Safety Tool, such as treatment team, rounds, or shift report meetings, but maintain the flexibility to review it immediately, if necessary.
- Revise the tools after a "near miss" episode to capture what helped in the situation.
- Revise the Safety Tool as an outcome of the debriefing process post-incident if a S/R or other adverse event takes place.
- The child should have a copy of his/her Safety Tool.

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## The origin of the Safety Tool

In 1994 Susan Stefan, a mental health attorney, and Bill Crane, the Director of Human Rights for the Massachusetts DMH, approached Eileen Elias, the DMH Commissioner at the time, regarding concerns about the damaging effects of S/R on persons with histories of trauma treated in the psychiatric inpatient system. A request was made for DMH to formally address this issue, and Commissioner Elias authorized the formation of a task force of stakeholders representing consumers, adult and child clinicians, attorneys, administrators, and human rights personnel in 1995. The *Massachusetts DMH Task Force on the Restraint and Seclusion of Persons who have been Physically or Sexually Abused* was formed and charged with reviewing the impact of S/R on individuals with trauma histories, evaluating the extent of the problem, and making recommendations. The Task Force was co-chaired by Elaine Carmen and Bill Crane, and included Laura Prescott, Susan Stefan, Nan Stromberg, Pat Rieker, Steve Holochuck and Margaret Dunicliff.

The Task Force produced a groundbreaking report (Carmen et al., 1996) that provided a comprehensive review of the re-victimization experience of consumers in a variety of psychiatric settings in which excessive force, inappropriate treatment, and inadequately trained staff inflicted further damage on people with histories of abuse. This was one of the first documents to address the negative impact and damaging consequences of a triggering (non-trauma-informed) environment in the public mental health sector on the

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consumers served. That is, the very setting expected to be healing was, in fact, inflicting further pain and harm (Carmen et al., 1996; Prescott, 2000). In addition, task force members identified that the presence of trauma and trauma-related disorders were grossly under-estimated by psychiatric clinicians, and that this reflected a failure in appropriately assessing, diagnosing, and therefore treating consumers. To improve the experience of consumers in hospital, emergency room, and community settings, several practice improvements were recommended, including:

- The need to conduct trauma assessments with all consumers admitted to psychiatric facilities to develop effective treatment plans, provide more appropriate treatment, and collect diagnostic data to assist in planning future programs.
- The need to develop and use a De-escalation Form (later called Crisis Prevention Plans, Safety Tools, and Personal Safety Plans) as part of the hospital and community admission process to identify triggers and proactive strategies that, if identified and used in advance, could mitigate escalation and help avoid the use of S/R. The process of obtaining this information was recognized as a valuable step at the beginning of treatment to build a collaborative alliance and set the stage for further clinical work.

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Importantly, the Task Force, through its composition and process, reflected the necessary partnership between consumers, legal advocates, and clinicians in evaluating the lack of trauma sensitivity and making recommendations. In addition, there was commitment by the Task Force members to follow through with an implementation plan.

The support of key executive leaders in DMH was invaluable. Clinical guidelines reflecting the task force recommendations were developed under the direction of Commissioner Eileen Elias after the task force report was completed in 1996. The most significant outcome was the decision by DMH Commissioners to codify these recommendations into DMH regulation. The requirement that Safety Tools be performed on all patients with a history of abuse who are admitted to the hospital was instituted under the leadership of Commissioner Marylou Sudders in 1998. The expansion of this requirement that Safety Tools be performed on *all* patients who are admitted to the hospital, not just those with documented histories of abuse, was instituted under the leadership of Commissioner Elizabeth Childs in 2006. Thus, the original task force recommendations addressing specific trauma-sensitive practice expectations became a legal mandate applicable to all DMH state hospitals, licensee hospitals, and intensive residential treatment programs (DMH 104 CMR 27.12, 2006).

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Safety Tools have been implemented throughout the country in a variety of settings (Champagne & Stromberg, 2004). In fact, most treatment programs that have reduced the use of S/R made Safety Tool implementation an important part of their prevention approach (LeBel, Stromberg, Duckworth et al., 2004; Jonikas et al., 2002; Carmen et al., 1996; NETI, 2005).

In programs that use Safety Tools, individualized assessments of triggers, warning signs, and coping strategies are translated into functional plans. Staff members learn how to talk with children about their triggers, how to recognize individual warning signs for each child, and how to role-play and practice using coping strategies. During this process, staff members learn how to use the Safety Tool to help individual children calm down when they are upset, frustrated, angry, or overwhelmed at the earliest possible stage. The information is then integrated into the child's treatment plan.

Addressing each child's strategies and triggers and developing supportive interventions helps children improve their self-esteem and develop coping skills that they can use after they leave the program. Some programs have expanded the original focus on the tool itself to the incorporation of multiple components into a richer milieu.

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Group programming, sensory rooms, and available physical spaces all offer immediate support to help children calm and learn. The use of Safety Tools improves child-staff communication and provides a vehicle by which treatment can be individualized in such a way that new skills and strategies enable the child to feel more competent and more able to avoid or manage difficult emotional states.

## Sensory-based strategies

Staff in psychiatric care systems increasingly appreciate the contribution of sensory-based interventions in the treatment of children and recognize that each person has unique sensory preferences that provide self-organization and self-regulation. Please refer to the *Sensory Approaches* chapter of the *Resource Guide* for more information. Incorporating sensory strategies into the Safety Tool can offer calming, or alternatively, alerting experiences that can be immediately helpful to the individual. For example, adolescents with traumatic disorders who self-mutilate may not necessarily have the ability to verbally process their experience and may require an alternative that offers intense alerting and orienting sensation, such as holding ice or snapping a rubber band against one's wrist. (Champagne & Stromberg, 2004; Mazelis, 2003). A young child who becomes extremely agitated may find rocking or swinging soothing and calming. These and other kinds of sensory based strategies should be identified on the Safety Tool and used at key times.

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## Suggestions/guidelines for using Safety Tools

Programs should develop several versions of their Safety Tool to accommodate different developmental levels and learning needs. Programs may also want to have their Safety Tools translated into other languages so family members and children who do not read English can fully participate in the process of developing an individualized treatment and safety plan. It is helpful to include pictures on the Safety Tools to make them easy to understand.

Every program that uses Safety Tools should develop guidelines for each of the following areas (each area will be discussed in more detail in this chapter):

- Terminology
- Safety Tool intake interview and review
- Communication and evaluation
- Integration into the milieu
- Staff training

### **Terminology:**

Administrators, clinical staff, children, and family members often use different names to describe Safety Tools. Some of these include Safety Tools, crisis prevention plans, personal safety plans, de-escalation tools and “my plan.”

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The DMH regulations (104 CMR 27.12, 2006) identify these as “crisis prevention plans.” Common elements and terms associated with these tools include:

- Triggers, stressors, stimulants, “what sets you off,” threat cues, trauma reminders
- Early warning signs, body symptoms, how does your body feel, body state changes, noticeable behavior
- Strategies, coping skills, symptom relief, relaxation techniques, calming strategies, alerting strategies

It is important that staff members, children, and family members have a common understanding of the terms used. Programs should decide on the terms that they plan to use and ensure that they are used consistently in their program. Staff members should avoid using jargon that is not commonly understood.

### **Safety Tool intake interview and review:**

The Safety Tool interview should take place as soon as possible after the child’s admission. The interview is a process in which the child identifies stressors and triggers that are precursors to losing control. The child should be asked to identify those things adults have used in the past to help them calm down as well as their own successful coping and self-soothing strategies. It is important for staff members to be aware of the child’s trauma history and the possibility that just asking about triggers may, in fact, be triggering for the child. For example, if the child has been abused in a certain setting,

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such as their bedroom, he/she may be upset by seeing pictures of a bedroom on the Safety Tool. In addition, staff members should be taught to phrase questions in a gentle, non-threatening manner and to know when to stop asking questions.

During the interview, it is important to consider the least traumatizing type of S/R based on the child's history (sitting up, empty space, cushioned space, etc.). For example, if a child has a history of being locked in a closet, seclusion could be emotionally damaging and should be avoided. Staff members must also identify any current or past medical problems or recent surgeries that could adversely effect the child if a restrictive procedure were used. Knowledge of such medically-related issues should help determine the safest way for the child to be handled, including positioning, if S/R must be used. Children with short attention spans may need to meet over the course of several sessions to complete the interview.

Programs should create guidelines for Safety Tool interviews and reviews. These guidelines should determine the following:

- Which staff members will be involved in meeting with the child and family to complete the Safety Tool and help individualize it for the child.
- When and where the Safety Tool interview will take place.
- How trauma sensitive information and relevant medical history will be obtained and incorporated into the Safety Tool

- 
- How critical information obtained from the Safety Tool interview process will be shared with all staff members.

## **Communication and evaluation:**

Once a child's Safety Tool intake is complete, the information should be clearly documented and shared with the child, his/her family, and other staff members. As the tool is revised, updated, and modified, the information must be communicated to staff, clinicians, and the child's family. The child and his/her family members should have the most updated copy of the plan. There are a number of ways to ensure that staff have access to the most up-to-date information gleaned from the Safety Tool. In addition, staff and children can share a communication system. The following represents some of the most commonly used communication methods:

- The Nursing Kardex
- Staff blackboard or bulletin board or board in the nurse's station
- Safety Tools attached to checks sheets
- "Coping Tree" or other large graphic placed directly in milieu that displays each child's unique methods for calming down.
- Posting of Safety Tools on wall of bedroom or above bed
- Make laminated cards for each child/family that summarizes the child's triggers, warning signs, and strategies.

- 
- Incorporate personalized Safety Tools on the back of the child's daily schedule
  - Meet with children at the end of each day to review a coping strategy they tried that day and evaluate its effectiveness

Treatment programs should evaluate Safety Tools for individual children regularly to ensure that the tool is useful for the child. A child's Safety Tool should be reviewed and changed after serious incidents or when new strengths have been identified. When treatment providers, children, and families find coping strategies that work effectively for the child, it is important to practice them as much as possible in the program, at home, and in the community and to share the information with school personnel and community providers who will be working with the child and family after discharge.

The following are common review venues:

- weekly team meetings,
- change of shift meetings,
- treatment groups that focus on calming strategies,
- individual therapy sessions,
- family meetings,
- daily child check-ins at the beginning and end of the day,

- 
- most importantly, individual reviews with children when coping strategies do not work well and when they are successful. These individual reviews provide opportunities to clarify and pinpoint important safety strategies for staff members and children.

## **Integration of Safety Tools into the milieu**

There are many ways to integrate Safety Tools into the milieu and daily programming. When children practice their coping strategies daily, it increases their ability to use them in other settings and provides them with safe opportunities to explore new coping skills.

- Groups
  - Provide opportunities for children to learn and practice their coping skills
  - During morning goals groups each child can identify a safety strategy he/she is going to practice during the day
  - Incorporate a relaxation technique into the last five minutes of group or sports activities
  - Develop a sensory-based group that allows children to explore new coping techniques that may be added into his/her repertoire if he/she determines that they are helpful

- 
- Sensory Approaches
    - Allow children to explore the sensory options at the program (such as a sensory room, comfort room, special space, or mobile cart) to learn about the variety of coping tools that are available
    - Provide groups that explore sensory tools that are either calming or alerting
  - Individual treatment sessions
    - Review Safety Tools with the child during treatment sessions, evaluating what has been most and least helpful
    - Have the child identify how their body feels and identify the emotions they are experiencing at the start and end of their session
  - Off unit privileges
    - Remind staff and children about Safety Tools they can use to keep themselves safe outside of the program. Provide fanny or back packs with items identified in their Safety Tools that they can take with them in to self-manage
  - School
    - Use Safety Tools and coping strategies during transitions or at other times when frustration or agitation develops. Use more physically based strategies provide children a way to “blow off steam” after sitting in a classroom for several hours

- 
- Home and discharge
    - Educate the family about the Safety Tool and coping strategies that have been effective at the program
    - Provide the child, family, and community treatment providers with the most updated Safety Tools and coping strategies when the child is discharged
    - Assist the family to integrate Safety Tools and coping strategies into daily routines and difficult transition points.

## **Staff training and staff self-care**

Once programs determine how they will conduct Safety Tool interviews and implement Safety Tools for every child, staff members must be fully trained in all aspects of Safety Tool implementation. They must learn how to effectively complete the interview with the child and family and how to support each child in using his/her individual coping strategies (e.g., gentle reminders or encouragement). Staff members need to be taught to identify potential triggers for different children (e.g., loud noises, sitting for long periods of time, phone call from parent in afternoon) and help each child use his/her coping strategies before becoming emotionally overwhelmed. Training for staff may incorporate an experiential component and may include role-playing.

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Staff should be encouraged to develop their own safety plans and identify personal triggers, warning signs, and coping strategies. This enables them to develop a greater understanding of the process as well as expand their own self-care resources.

All staff members should understand how the development of a child's Safety Tool can serve as a foundation for his/her relationship with the program and involvement in treatment. The initial Safety Tool meeting should set the stage for sensitive attention to the individual child's needs, empower the child and family, and underscore the commitment by the program to a collaborative process that fully supports the child's healing.

## What do adolescents say about what helps?

DMH staff involved in the S/R Prevention Initiative realized that it was important to hear directly from the children about what they felt helped and hurt them during their hospitalizations. In January 2003, 185 adolescents in 19 Massachusetts hospitals were asked their feedback on a number of questions (DMH, 2003). The adolescents who had been involved in S/R were asked to think about the time(s) they were restrained or secluded and provide feedback on what staff members could have done differently to help them avoid these incidents.

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Some of the adolescents gave more than one response to the question. The most common responses were the following:

- 80 adolescents replied, "Talk to me."
- 75 adolescents said, "Leave me alone."
- 54 adolescents said, "Distract me."

The adolescents suggested other things that would help them when they were upset, including:

- Offering kids music or dancing
- Letting kids read or sing
- Staff members making kids laugh
- Staff members keeping negative or sarcastic comments to themselves
- Providing more activities or sports opportunities
- Permitting children to draw

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## What does this survey tell us?

Adolescents in this survey shared that there are a number of things staff members could have done (and can do in the future) to help them avoid S/R. It was evident from their responses that what might be useful for one child may be triggering for another, so interventions *must* be individualized. The adolescents also gave feedback about what would help them if they were already upset (such as talking and not being sarcastic) and what would prevent them from getting upset in the first place (such as having enough activities, going outside, or having creative opportunities like music and dance).

Safety Tools have traditionally focused on triggers (i.e. what gets them upset) and strategies to help them stay calm. The adolescents who were interviewed for the survey reported that it is just as important to find out what they like to do every day and the kinds of activities that will keep them positively engaged and less likely to become stressed and upset.

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## Additional resources

At the end of this section, there are sample Safety Tools from several Massachusetts programs. The first tool is from the Massachusetts DMH. It was created for younger children and uses simple pictures and brief descriptions to help children identify things that make them feel upset, what happens to their bodies when they feel upset, and things that make them feel better. The second tool is a “personal protection plan” from the Child Assessment Unit at Cambridge Hospital, and it is also intended for use with younger children.

The third tool is a “personal safety plan” for adolescents created by the Boston Medical Center Intensive Residential Treatment Program. The plan individualizes treatment by immediately assessing for a history of trauma, identifying possible triggers and warning signs, and requesting input from the adolescent on ways that staff members can help him/her to calm down. The fourth Safety Tool, “Safety Zone Tool,” is from the UMass Transitions Intensive Residential Treatment Program and the UMass Connections Behavioral Intensive Residential Treatment Program, and it was also designed for use with adolescents.

The Safety Tools included in the Resource Guide should not be duplicated without permission from the programs that created them. Program contact information is included in the *Additional Resources, Safety Tools* section of the *Resource Guide*.

# Suggestions/Guidelines for using Safety Tools

## Descriptions:

- **Triggers tool:** A one page document of pictures and words to help the child recognize triggers or situations that create fear, sadness, anger, etc. The triggers tool is divided into sensory categories to help staff and children identify circumstances that create upset more easily.
- **Warning sign tool:** A one page document of pictures and words to help the child make the “cause and effect” connection between triggers, their reaction to triggers and how the situation physically effects their body.
- **Safety Tool:** A two page document of pictures and words to help the child identify sensory-based calming (coping) tools. Blank spaces are included to add personalized tools not included on the list.

## Initial Safety Tool Use:

- Tools should be filled out within the first 24-48 hours of admission
- Information for the tools should be obtained from the child and their family/people who know the child best; though not necessarily at the same time.
- Safety Tools can be completed in more than one session.

## Important History:

- Understand the child’s trauma history to be sure Safety Tool interventions are not re-traumatizing. For example, has the child been locked in bedrooms or closets; has he/she been abused by specific objects that may invoke re-traumatization.

- Have the child identify the least traumatizing style of containment based on their history. (Face-down, face-up, empty space, cushioned space, etc.)
- Does the child have a history of asthma, a recent fracture or pre-existing medical condition that may be further impacted by the use of restraint or seclusion?

**Staff Training:**

- Protocols should be in place to train staff on the implementation, integration and communication of the information obtained from the Safety Tools.
- Consistency of terminology must be used for safety/calming tools, treatment plans, coping strategies, etc. so that staff, family and consumers have a similar understanding of what different tools and strategies are and how they are being utilized.

**Integration on the unit:**

- Provide copies of the Safety Tools to each child
  - Hang copies on the child's room door (with consent of the family and child)
  - Post calming strategies on bulletin boards and highlight skills that are utilized during the day
  - Create laminated pocket size Safety Tool cards for children to carry with them
  - Incorporate personalized Safety Tools on the back of the child's daily schedule
- Revise and update Safety Tools on a frequent basis
  - At the end of the day, have children identify to their "check in person" a Safety Tool strategy that they tried that either worked or did not work

- Provide time for the Safety Tool information to be reviewed from shift to shift
- During individual treatment sessions, assist children with the integration of triggers, warning signs and sensory-based coping skills (MA DMH Safety Tool, August 2006)
- Groups and program integration
  - Offer groups that incorporate a variety of sensory-based Safety Tools to help calm and organize the child during transitions
  - Incorporate sensory-based activities after sports or active groups to calm and ground children prior to their next group
  - Provide role-play situations for children to practice using identified Safety Tool strategies
  - Provide environments (quiet room, unit, corners, etc.) with sensory-based activities to foster exploration and incorporation of Safety Tool strategies into daily experiences
- Education
  - Educate children about the importance of Safety Tools and the use of the Safety Tool information to assist with calming, grounding and organizing themselves on a day to day basis
  - Educate child's family members about the Safety Tool information and how it has been useful to the child
  - Educate the treatment team and staff at potential discharge settings about Safety Tool strategies that were useful (and not useful) in helping the child feel safe

- Discharge
  - Promote carry over of the skills the child has learned and used by providing a copy of the Safety Tool to appropriate community-based clinicians working with the child and family
  - Every child should receive a copy of their up to date Safety Tool to take with them upon discharge
  - Parents/guardians should receive an updated copy of the child's Safety Tool
  - If a child is being transferred to another treatment program, a copy of the Safety Tool should be clearly identified and attached to the transfer paperwork.

# What helps you feel better?

(Circle all that help you)

## Touch



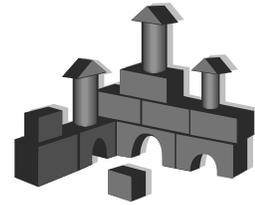
Writing



Fidget tools



Games



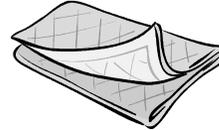
Toys or Blocks



Bath or Shower



Stress ball or clay



Special blanket or cloth

Any other objects you touch or hold that help you feel better? \_\_\_\_\_

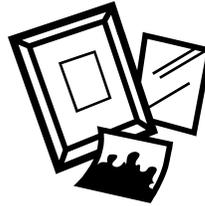
## See



Reading



Watching TV



Looking at pictures



Using a computer

Any other objects you like to look at that help you feel better? \_\_\_\_\_

## Movement



Using a rocking chair



Swinging



Dancing



Sports  
(kickball, basketball, soccer, etc)

Any other movements you like that help you feel better? \_\_\_\_\_

## Hear



Talking on the telephone



Listening to music



Singing or humming



Quiet place



Counting to ten

Do you prefer music that is:  Loud or  Soft

What type of music do you prefer: \_\_\_\_\_

Any other sounds or noises that help you feel better? \_\_\_\_\_

**Pressure touch**



Hugging a stuffed animal



Sitting in a bean bag chair



Using a weighted blanket



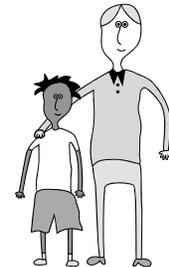
Climbing on a jungle gym



Exercise



Sitting on a therapy ball



Getting a hug

Any other activities that help you feel better? \_\_\_\_\_  
(Examples: blowing bubbles, deep breathing, etc.)

**Smell**

Any smells that help you feel better? \_\_\_\_\_  
(Examples: peppermint, popcorn, cookies, flowers, etc.)

**Taste**

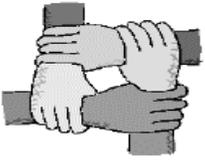
Any certain tastes that help you feel better? \_\_\_\_\_  
(Examples: chewy, crunchy, salty, sour, spicy, etc.)

Are there times that it is important or helpful for you to eat? \_\_\_\_\_

# What makes you feel upset?

(Circle all that make you feel sad, mad, scared or other feelings)

## Touch

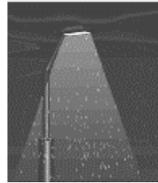


Being touched



Too many people

## See



Darkness

## Hear



Loud noises



Yelling



Thunderstorms

## Other



Missing someone



Being left alone



Being surprised



Having a fight with a friend



Not having visitors



Being hungry



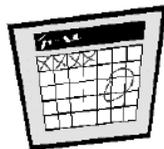
Being tired



Someone being mean



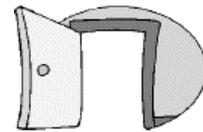
Being sick



Certain time of year



Certain time of day/night



Having my bedroom door open

Anything else that makes you feel upset? \_\_\_\_\_

NOTE: The following are general triggers for people

Being told what to do rather than asked;

Being told no rather than being given choices.

# What happens to my body when I am angry, scared or upset?

(Circle all that apply)



Cry



Clench teeth



Loud voice



Red/hot face



Laughing/giggling



Being mean or rude



Swearing



Racing heart



Breathing hard



Wringing hands



Clenched fists



Upset stomach



shaking or tapping



Jumping up and down  
or stamping feet



Rocking



Hyper



Running or pacing



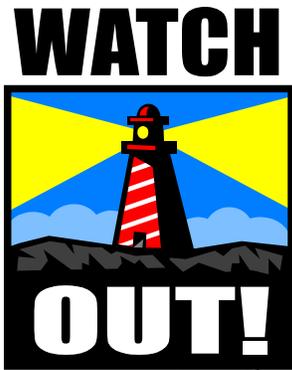
# My Personal Protection Plan

---

Date: -----



Sign Name:



Things that really upset me!

1)

2)

3)



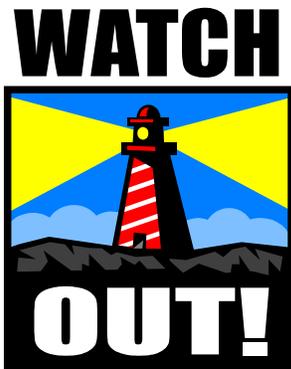
**COOL**

Things that help me to calm down when I am upset:

1)

2)

3)



When I am having a  
meltdown:

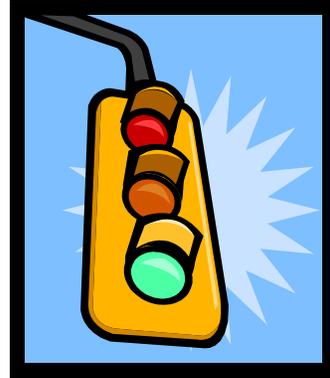
Please don't do this:



1)

2)

3)



Please do this:

1)

2)

3)

# Boston Medical Center IRTP SAFETY PLAN

Patient Name: \_\_\_\_\_

Date: \_\_\_\_\_

## PROBLEM BEHAVIORS: What type of behaviors are problems for you?

- Losing control
- Feeling suicidal
- Other: \_\_\_\_\_
- Assaultive behavior
- Injuring yourself
- Restraints/Seclusion
- Suicide attempts
- Feeling unsafe
- Drug or alcohol abuse
- Running away

## TRIGGERS: What type of things (triggers) make you feel unsafe or upset?

- Not being listened to
- Loud noises
- Being isolated
- Particular time of year: \_\_\_\_\_
- Other: \_\_\_\_\_
- Feeling pressured
- Feeling lonely
- Darkness
- Being touched
- Arguments
- Being teased or picked on
- Contact with family \_\_\_\_\_
- Lack of privacy
- Not having control
- Particular time of day/ night: \_\_\_\_\_
- People yelling
- Being stared at

## WARNING SIGNS: Please describe your warning signs, for example what other people may notice when you begin to lose control?

- Sweating
- Red faced
- Hyper
- Being rude
- Eating more
- Isolating/ avoiding people
- Other: \_\_\_\_\_
- Breathing hard
- Wringing hands
- Swearing
- Pacing
- Hurting others or things
- Laughing loudly/ giddy
- Racing heart
- Loud voice
- Bouncing legs
- Crying
- Hurting myself
- Singing inappropriately
- Clenching teeth
- Sleeping a lot
- Rocking
- Squatting
- Not taking care of self
- Clenching fists
- Sleeping less
- Cant sit still
- Eating less

## INTERVENTIONS: What are some things that help to calm you down or keep you safe?

- Time out in your room
- Pacing
- Exercising
- Taking a hot shower
- Being around other people
- Lying down
- Using cold face cloth
- Deep breathing exercises
- Other: \_\_\_\_\_
- Time out in the Quiet room
- Talking with peers
- Calling family (who?)
- Taking a cold shower
- Using ice
- Ripping paper
- Bounce a beach ball in QR
- Speaking with therapist
- Listening to music
- Talking with staff
- Writing in a journal
- Playing cards
- Doing chores/ special jobs
- Screaming into pillow
- Male staff support
- Drawing
- Reading a book
- Coloring
- Punching a pillow
- Snapping bubble wrap
- Running cold water on hands
- Crying
- Female staff support
- Being read a story
- Sitting with staff
- Molding clay
- Hugging a stuffed animal
- Making a collage
- Humor

What are some things that **do not** help you calm down or stay safe?

- Being alone                       Loud tone of voice                       Humor                       Not being listened to                       Peers teasing
- Being disrespected                       Being ignored                       Having many people around me
- Other: \_\_\_\_\_

**STRENGTHS:** What are your strengths when feeling out of control?

\_\_\_\_\_

**SKILLS:** What skills do you have/ what are you good at?

\_\_\_\_\_

**OTHER:**

Are you able to communicate your safety to staff? For example can you tell staff when you are struggling? If no, what can staff do to help you communicate this?

\_\_\_\_\_

What kind of incentives work for you?

\_\_\_\_\_

**SPECIAL PLANS:** List any special plans that help you (things you have used in the past or would like to try).

\_\_\_\_\_

**Patient Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Staff Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Updated Date & Staff Signature:** \_\_\_\_\_

**The Adolescent Safety Zone Tool**  
**UMass Medical School**  
**Transitions IRTP & Connections BIRT Adolescent Services**

Name: \_\_\_\_\_ Date: \_\_\_\_\_

We would like to make your stay with us a safe and therapeutic one. Please read the following questions and answer all that apply to you. This will assist us in making this a more positive experience for you. Please let us know if there is anything else we can help you with. Thank you!

**Do you have a history of:**

- |  |   |   |   |
|--|---|---|---|
| <input type="checkbox"/> Losing control                                | <input type="checkbox"/> Feeling unsafe   | <input type="checkbox"/> Restraint or seclusion | <input type="checkbox"/> Running away     |
| <input type="checkbox"/> Assaultive behavior                           | <input type="checkbox"/> Feeling suicidal | <input type="checkbox"/> Injuring your self     | <input type="checkbox"/> Suicide attempts |
| <input type="checkbox"/> Physical abuse                                | <input type="checkbox"/> Sexual abuse     | <input type="checkbox"/> Drug or alcohol abuse  |   |
| <input type="checkbox"/> Other behaviors (Please describe these below) |   |   |   |

**What type of facility are you in now?**     Hospital     Residential     Group Home     Home

**Have you ever been restrained before?**     Yes     No:  
 (If yes, please check those that apply)     Physical     Mechanical     Chemical

**What worries you about being here?** \_\_\_\_\_

**How long have you been restraint free?**  
 0-1 week     2 weeks – 2 months     3-5 months     6 months or more

**When was the last time you were restrained?** \_\_\_\_\_

**Do you remember why you needed to be restrained?** \_\_\_\_\_

**When do most of your restraints occur?**     Day     Evening     Night     Anytime

**How often do you get restrained?**     Daily     Weekly     Monthly     Occasionally     Never

**Do you have any medical conditions that place you at greater risk during a restraint?**     Yes     No  
 If yes, please describe: \_\_\_\_\_

**If you are in danger of hurting yourself or others, we may need to use a mechanical (safety coat) or a chemical (medication to calm you down) restraint or seclusion. We may not be able to offer you all of these but we would like to know what you prefer or have used before?** (Please check all that apply)

- |   |   |   |
|---|---|---|
| <b>Prefer <input type="checkbox"/> / <input type="checkbox"/> Used Before</b> | <b>Prefer <input type="checkbox"/> <input type="checkbox"/> Used Before</b> | <b>Prefer <input type="checkbox"/> <input type="checkbox"/> Used Before</b> |
| <input type="checkbox"/> <input type="checkbox"/> Quiet room or area          | <input type="checkbox"/> <input type="checkbox"/> Open door seclusion       | <input type="checkbox"/> <input type="checkbox"/> Closed door seclusion     |
| <input type="checkbox"/> <input type="checkbox"/> Chemical restraint          | <input type="checkbox"/> <input type="checkbox"/> 4 point restraint         | <input type="checkbox"/> <input type="checkbox"/> Safety Coat               |
| <input type="checkbox"/> <input type="checkbox"/> Physical holds              | <input type="checkbox"/> <input type="checkbox"/> Mitts                     | <input type="checkbox"/> <input type="checkbox"/> Blanket wrap              |

**What helps you to stay safe? Please check all that apply:**

- |   |   |   |                                  |
|---|---|---|----------------------------------|
| <input type="checkbox"/> Yelling            | <input type="checkbox"/> Writing              | <input type="checkbox"/> TV/Movie           | <input type="checkbox"/> Music   |
| <input type="checkbox"/> Male staff support | <input type="checkbox"/> Female staff support | <input type="checkbox"/> Support from Peers | <input type="checkbox"/> Walking |
| <input type="checkbox"/> Reading            | <input type="checkbox"/> Ice                  | <input type="checkbox"/> Video Games        | <input type="checkbox"/> Talking |
| <input type="checkbox"/> Exercise/Sports    | <input type="checkbox"/> Drawing/Coloring     | <input type="checkbox"/> Other _____        |                                  |

Are you able to communicate about your safety level? For example, can you tell staff when you are struggling?  Yes  No  Sometimes

What kind of space is most comfortable when you need it?

Quiet area  Your room  Safety room  In bed  Other: \_\_\_\_\_

Do you see a safe place you can use here?  Yes  No

If no, please describe where you believe you would feel safe: \_\_\_\_\_

Please describe your warning signs, for example, what your body feels when you are losing control and what other people can see changing?

Sweating  Breathing hard  Racing heart  Clenching teeth  Clenching fists  
 Red-faced  Wringing hands  Loud voice  Sleeping a lot  Bouncing legs  
 Rocking  Pacing  Squatting  Can't sit still  Swearing  
 Crying  Isolating  Hyper  Sleeping less  Eating less  
 Eating more  Being rude  Singing inappropriate songs  
 Other: \_\_\_\_\_

What are your triggers?

Being touched  Being isolated  Bedroom door open  People in uniform  
 Yelling  Particular time of day  Loud noise  Not having input  
 Being forced to talk  Being around men  Being around women  Anniversaries  
 Seeing others out of control  Specific people (Who): \_\_\_\_\_  
 Time of year? (When): \_\_\_\_\_  
 Other: \_\_\_\_\_

What helps you stay in control? \_\_\_\_\_

What has helped you to stay in control in the past? \_\_\_\_\_

What positive alternative behaviors can you use? \_\_\_\_\_

What kind of incentives work for you? \_\_\_\_\_

Is there anything else you can tell us that you think would be helpful? \_\_\_\_\_

Family notification plan complete?  Yes  No

Thank you for completing this form. We will update it with you in three months.

Please sign: Adolescent: \_\_\_\_\_

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# Sensory Approaches

**Tina Champagne, M.Ed., OTR/L**

“ When late morning rolls around and you’re feeling a bit out of sorts, don’t worry; you’re probably just a little eleven o’clockish. ”

*Pooh’s Little Instruction Book,  
inspired by A.A. Milne*

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# Sensory Approaches

## Early pioneers

**D**r. A. Jean Ayres pioneered the sensory integration (SI) framework in the field of occupational therapy in the 1960s. Her ideas brought forth a new way of viewing behavioral, emotional and developmental problems that arise in childhood. Ayres (1979) believed that sensory input is necessary for human development and optimal neurological functioning. Research supports the hypothesis that sensory deprivation, particularly during critical periods of early development may cause perceptual distortions and disruptions in development, problems in forming healthy attachments, and difficulties with the ability to regulate emotions and behaviors (Castler, 1968; Cermak, 2001; Cermak & Daunhauer, 1998; O'Connor & Rutter, 2000).

According to Dunn (2001), the essence of being human is embedded in the sensory events of daily life. When a person is diagnosed with a mental illness, the symptoms of their illness influence every part of them, including their sensory and motor systems. All children with mental health problems have unique sensory experiences and needs that contribute to or detract from their ability to participate in daily activities and cope with stressful situations. SI is a theoretical frame of reference that helps treatment providers better understand how children perceive their sensory experiences and how these perceptions influence their every day and therapeutic activities. If treatment

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providers understand each child's sensory needs, they can help them develop strategies to experience more success in school, in treatment, at home, and in the community.

Sensory processing refers to the neurobiological process that organizes sensory and motor information from the body and the physical environment. Effective sensory processing makes it possible to choose and focus on relevant stimuli and for the spirit-mind-body to regulate itself (adapt) when engaging in various activities (play, school work, self-care) in different contexts (playground, classroom, home) over time. When staff members understand the importance of sensory processing and the difficulties that impaired sensory processing creates, they can create sensory supportive prevention and crisis intervention strategies that are specific to each child's individual needs.

Sensory processing disorders (SPDs) include sensory modulation, sensory discrimination, and sensory-based motor disorders that can co-exist and range in level of severity. Sensory modulation refers to a person's regulatory ability, which allows him or her to switch from being attentive to inattentive, alert to falling asleep, or from being depressed to being more cheerful. Sensory modulation takes into account the fact that the spirit-body-mind (the child) is not separate from the physical environment (school or therapeutic environment). In addition, it recognizes the influence of different kinds of sensory and motor stimulation (various activities, milieu influences, therapy exchanges) on the child, particularly when he/she has mental health problems. A more technical definition

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of sensory modulation states, “sensory modulation is the ability to regulate and organize responses to sensory input in a graded and adaptive manner.” (Bundy, Lane & Murray, 2002)

Sensory modulation disorders or dysfunctions often appear behavioral in nature in the form of regulatory problems, such as over responsiveness (too much) or under responsiveness (too little). One example of a sensory modulation disorder is sensory defensiveness, which refers to strong aversive or noxious responses to experiences most people find typical (Wilbarger & Wilbarger, 1991). Generally, when a person is overly sensitive to something, such as a certain smell or touch, they tend to avoid it by walking away from it or quickly getting rid of the source of the noxious smell. Therefore, it is not surprising that sensory defensiveness often results in sensory avoidant behaviors.

Children who have been traumatized may experience a number of developmental interruptions as a result of their experiences. Trauma often results in sensory defensiveness, which may emerge within a particular sensory system (tactile or smell). All of these factors affect a child’s ability to regulate or modulate his/her emotions and behaviors. The child may develop problematic patterns of behavior, he/she may have difficulty identifying his/her sensory perceptions, or he/she may struggle with understanding and managing his/her sensory experiences and needs, commonly referred to as sensory modulation problems.

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In contrast to sensory defensiveness, some children may be more sensory seeking than most of their peers. Sensory seeking is normal child behavior; and, children who are strong sensory-seekers may also be risk-takers, thrill seekers, and constantly “on the go.” Sensory seeking and sensory avoidant behaviors that are outside of normal ranges are often categorized as sensory modulation disorders. When a person has difficulty modulating, regulating, or adapting their responses to stimulation, it interferes to some degree, largely based on the perceived level of severity, with the ability to function and the development of self-esteem and positive self-image.

There are other sensory processing disorders, including sensory discrimination disorders and sensory-based motor disorders. Sensory discrimination refers to the ability to differentiate one type of stimulus from another, such as knowing which direction a sound is coming from, and the ability to perceive the temporal (time) and spatial (space) aspects of stimulations, activities, and the environment, all of which are used in the act of catching a ball. For example, knowing where one’s body begins and ends is part of the discriminatory process at work. Brushing teeth and drinking from a cup both require sensory discrimination and coordinated neurological processes. Children who are clumsy, awkward, or too forceful in their movements often have problems integrating the neurological processes involved in the ability to engage in activities in a planned, smooth, and coordinated way. This type of problem is indicative of sensory-based motor disorders.

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Sensory processing disorders often co-exist, and a person may have any combination of sensory modulation, sensory discrimination, and sensory-based motor disorders.

It is important to emphasize that behaviors are not always reflective of the underlying problems. Someone who is sensory defensive may not appear to be anxious or triggered, and someone who is sensory seeking may not always appear to be constantly “on the go” or hyperactive. Behaviors can be similar to or in contrast to the underlying problem, and they may be specific to certain stimuli. It is difficult to assess sensory processing problems through the use observational assessments (Dunn, 2001), and it is best to refer the child to an occupational therapist for a more specialized evaluation.

## Sensory assessments

Assessments of sensory processing disorders are most often conducted by occupational therapists specializing in this area. There are a number of standardized and non-standardized sensory-related assessment tools that are used with both children and caregivers to obtain a comprehensive view of sensory processing issues that may be influencing the child’s development, behaviors, and performance in various settings. The results of these assessments give treatment providers information that is necessary to set priorities and integrate sensory-related problems into the child’s treatment.

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The Safety Tool is an essential element in this process, which is typically completed with the child (and caregivers when available) with nursing and other treatment staff in most settings (Carmen et al., 1996). This provides initial information about the child's triggers, early warning signs, trauma history, and his/her sensory preferences in terms for activities that the child considers to be soothing and comforting when in crisis. This is a critical element in the assessment process that must be incorporated into the child's daily activities, treatment plan, and daily programming. It is essential to create Safety Tools that are appropriate for all age groups and developmental levels to help children identify the things that they find comforting and helpful. Please see the Safety Tool section of the *Resource Guide* for more information.

## Treatment planning process

Sensory processing problems may be a primary focus in treatment or they may be secondary or tertiary depending upon the level of severity and the child's other treatment priorities. Treatment programs that support children in learning healthy self-regulation (sensory modulation) and coping strategies should use language and methods that are age-appropriate and integrated across all levels of the program. One example of a sensory modulation program for children ages eight through early adolescence is *How Does Your Engine Run*, also known as the *Alert Program* (Williams & Shellenberger, 1992). This program was designed to be used in a variety of settings, such as schools, residential programs, inpatient hospital units,

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and outpatient treatment programs. The materials that are required to implement the program are inexpensive and practical. The *Sensory Modulation Program* was developed for older adolescents and adults, and was organized to serve as a guide when beginning to employ sensory modulation concepts and strategies (Champagne, 2006).

Sensory approaches enhance traditional psychiatric treatment methods. They are person-centered and supportive to the individual, and they promote self-organization, development, and recovery. By incorporating sensory supportive approaches into the treatment environment, staff members can use a variety of unique strategies to help the children in their care. Programs that have incorporated a collaborative approach into the assessment of sensory processing patterns, treatment planning, and the use of individualized interventions have found that these strategies play an important role in reducing the use of S/R (Champagne & Stromberg, 2004).

## The senses

Most clinicians are well aware of the five basic sensory systems: visual, tactile (touch), auditory, olfactory (smell), and gustatory (taste). However, there are two others that are not as well-known: Proprioceptive and vestibular systems. All of the sensory areas contribute to our continuous sensory experiences and to the ongoing development of the self; however, the Proprioceptive and vestibular sensory systems are considered essential for movement, balance, and body

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awareness and for feeling oriented and grounded in the world. Children who have moderate to severe problems with the proprioceptive and/or vestibular sensory systems may appear avoidant and/or fearful when involved in the following activities:

- Stair climbing
- Walking on different surfaces
- Riding in a car
- Riding a bicycle
- Catching a ball
- Kicking a ball
- Playing on a jungle gym
- Jumping and/or hopping activities

Children who are avoidant or fearful of these activities should be referred for an occupational therapy evaluation to determine whether they have sensory-related disorders that need treatment.

## Where to begin?

There are a variety of activities that stimulate the senses, such as listening to classical music (auditory) or using scented lotions (olfactory and touch pressure). The following list provides activity ideas that can be used when treatment providers want to emphasize different sensory areas.

There is a great deal of overlap between the lists and they are not all-inclusive.

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## Proprioception (Pressure/body awareness/movement sense)-Engagement in active movement against resistance

- Wrapping up in a blanket
- Wearing a weighted vest
- Doing thera-band rowing or playing tug-of-war
- Exercise activities or isometrics
- Using a jungle gym or climbing equipment
- Swimming
- Hiking
- Doing push-ups and sit-ups
- Playing hopscotch
- Playing wheel-barrow races
- Walking on beach sand or digging in the sand
- Sitting in a big bean bag chair
- Squeezing a stress ball
- Chewing gum
- Kneading clay or bread
- Wrestling

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## Vestibular (movement/balance/directionality sense)

- Riding a bike
- Sitting & spinning
- Swinging
- Rocking in a rocking chair or glider
- Dancing
- Jumping on a mini-trampoline
- Sliding
- Skating or roller-blading
- Running or using a treadmill
- Riding on a see-saw
- Crawling through a crawling tunnel
- Going on amusement park rides

## Visual (seeing/looking)

- Playing Simon Says games
- Using glitter wands
- Reading *Where's Waldo* or *I Spy* type posters/books
- Looking at mobiles
- Reading books
- Playing tag
- Playing pinball

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- Coloring/writing
  - Painting
  - Sweeping the floor
  - Carrying things
  - Moving gym mats, chairs, equipment

## **Tactile (touch)**

- Playing with *Koosh* balls or stress balls
- Playing with *Silly Putty*,/thera-putty, or *Play Dough*
- Using stuffed animals
- Using *Wikki Sticks* (plastic wax strings)
- Playing with sand and water (special tables are made for this activity)
- Reading books with different touch options
- Playing with *Slime/Smud*
- Sewing/doing craft activities
- Using clay/making pottery/making ceramics
- Gardening/planting activities
- Petting or holding a cat or dog
- Doodling
- Knitting or crocheting
- Doing puzzles

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## **Auditory (listening and hearing - also contributes to balance)**

- Listening to music
- Listening to a sound machine
- Listening to waterfall sounds
- Listening to birds chirping
- Playing musical chairs
- Listening to books on tape
- Listening to a story

## **Olfactory (smell)**

- Using scented candles
- Using scented lotions
- Using essential oils
- Using scratch n' sniff books, stickers, or scented magic markers
- Using scented soaps
- Using flowers and plants
- Cooking or baking

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## Gustatory (taste/oral motor)

- Eating foods with different qualities:
  - Crunchy: popcorn, chips, cereals, pretzels, carrot sticks
  - Sour: sour apples, sour pickles, lemons, sour candy
  - Sweet: tangerines, fruit snacks, roll-ups, apple sauce
  - Chewy: granola bars, dried fruits, sugar-free gum, string cheese, bagels
  - Spicy: salsa, seasoned foods
  - Hot: hot balls, a warm drink, oatmeal, red hots
  - Cold: ice, popsicles, frozen yogurt, cold drink
- Singing
- Talking
- Sucking: sucking a thick milkshake through a straw
- Blowing: blowing bubbles, whistling, playing a harmonica

## Everyone is different

What is calming for one person may not be calming for another. There are many times when calming activities are not necessary, and alerting or orienting kinds of activities are more beneficial. In a study by Tschacher (1995), people who were depressed (without anxiety) responded poorly to calming techniques. The use of calming strategies may be counter-productive for some children, while others may need assistance

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with calming before being able to talk or concentrate. The challenge of helping children determine what is most beneficial for them at different times is part of the art and science of using sensory approaches.

<b>Calming</b>	<b>Alerting</b>
Familiar stimulation or activities with positive associations	Novel stimulation or activities
Slow pace	Fast pace
Slow, rhythmic, linear motions	Fast, rhythmic motions going in different directions
Mild stimuli (smells, tastes, etc.)	Strong stimuli
Quiet Environment	Loud environment
Low lighting	Bright lighting
Things that one likes (stimulation, people, or activities)	Things that one dislikes (aversive stimulation, people, or activities)
Repetition	Unexpectedness
Consistency	Irregularity
Low complexity	High complexity
Warm temperatures	Cold or cooler temperatures

Although what is calming for one person may be alerting for another, the following chart shows some general forms of stimulation/activities that are generally considered calming or alerting:

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<b>Calming/Relaxing</b> (Familiar or low demands)	<b>Alerting/Orienting</b> (Novelty or high demands)
Decaf herbal teas Chewing gum Rocking in a rocking chair Swinging on a swing Wrapping in a heavy quilt Hot shower or bath Focusing on calming scenes Soft lighting Soft or slow music Slow and evenly paced rhythms Calming sounds of nature (ocean) Soothing or mild scents: (oils, lotions, or candles) Deep pressure touch or hugs Massage: deep pressure touch Beanbag tapping Humming or singing quietly Yoga Leisure walks Soft materials or textures	Holding ice Popsicle Sour or fireball candies Sucking a lemon Frozen fruit treats Rapid or jerky movements Cold water or washcloth to face A cool room Unexpected visual stimuli Changing patterns of light and brightness Quick paced or offbeat music Alerting sounds of nature (birds) Strong or aversive scents: (oils, lotions, or candles) Light touch Yawning Loud forceful handclap Aerobic exercise Power walks Rough or prickly materials or textures

It is often beneficial to help children identify the things that help them feel calm and the things that help them feel alert. They can then begin to think about when they might want to use calming strategies rather than activities that make them feel more alert.

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## Sensory diet: prevention and crisis interventions for the daily schedule

All people use strategies throughout the day, either consciously or unconsciously, that help them remain at an optimal level of alertness to perform the tasks at hand. We continuously modulate or change how alert we feel, which is an important self-regulation skill that we develop over time. Children learn how to wake themselves up enough to be able to get ready to go to school each day, to stay attentive to teachers and school work, to play with peers, and then to slow down in preparation for bed time. Children who have difficulty with self-regulation (sensory modulation) require extra assistance to master this skill, particularly during transition periods or in times of crisis.

Wilbarger (1984), coined the term “sensory diet” in an attempt to reinforce what Ayres thought about the ongoing need for sensory nourishment. The development of a sensory diet is a sensory modulation strategy that takes this concept a step further by focusing on creating an organized daily plan or schedule that included specific kinds of stimulation and activities to support a child’s ability self-regulate (Wilbarger, 1984; Nackley, 2001). Sensory diets should include both prevention and crisis intervention strategies (Champagne, 2003, 2005). Sensory diets help people feel more organized and better able to handle transitions and stressful activities more flexibly and with less distress.

Sensory diets are often created for individuals, but it is also useful to think of sensory diets in relation to the treatment

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programming within the milieu. The use of a daily schedule often helps to organize sensory diet elements for different times of the day, including transition times, and it supports the different tasks each person needs to do to prepare themselves throughout each day. The following is an example of a morning routine sensory diet that may be used by an inpatient pediatric unit.

- 7:00 Wake up time & ADLs

(Use of sing-a-long throughout the transitions from one morning ADL activity to the next, use of favorite soaps, lotions, toothpastes, shower brushes, or sponges; offer sensory supportive clothing choices)

- 7:45 Breakfast

(Have the children sign up to help with each of the morning routine needs. Have each child help set up the room and move furniture as needed. Each child should gather his/her own tray and dishes. Use music that is centering to the whole group when preparing for mealtime and eating. Each child should put his/her own tray away when finished, and help clean up.)

- 8:00-8:30 Stretch, exercise, or yoga break

(Active stretching and isometric activities)

- 8:30-9:00 Recess

(Jungle gym equipment, sports games, use of an obstacle course to get to and from different program rooms, or another movement related activity to prepare for school or group work)

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- 9-10:00 First group or class

(Use of therapy balls to sit on, incorporating brief group movement, isometric exercise breaks at start and/or throughout the session, sitting on own carpet square with texture of choice)

- 10-10:15 Transition to next class or group

(Move to a new room, go through an obstacle course to get to the next room)

- 10:15-11:00 Second group or class

(Isometric grounding activity for the first few minutes, use of learning activities that provide active movement learning opportunities that help to sustain attention and foster sensorimotor development [use of activities that use objects to hold, draw with, toss, hop, etc.]).

- 11:00-11:30 Recess (similar to above)
- 11:30-11:45 Clean up for lunch

(Offer a choice of scented soaps or lotions, hand or nail scrub brushes)

- 12:00 Lunch (similar to breakfast)

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## Incorporating sensory supportive approaches into treatment

Staff members should be trained in the use of sensory-based strategies and in the integration of these strategies into individual prevention and crisis de-escalation plans. This knowledge and skill set provides staff members with tools for reducing the use of S/R. In addition, the following steps can help programs incorporate sensory supportive approaches into treatment in a safe and responsible manner:

- Conduct comprehensive individual assessments, including the evaluation of the child's sensory processing patterns by an occupational therapist or another professional qualified to offer sensory processing-related assessments (neuropsychologist)
- Provide individual and/or group treatment sessions with an occupational therapist
- Integrate the use of appropriate sensory supportive activities into everyday living, such as stress balls, climbing equipment, weighted blankets, and rocking chairs
- Provide a range of activities focusing on the sensory diet needs of the children at different times of the day and evening, such as music, yoga, visiting with animals, story-telling
- Familiarize staff members and children with a variety of activities that address needs for calming and/or active movement at different times of the day and evening

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- Address individual child sensory needs as well as sensory needs of the group of children throughout the day and evening
  - Create a population specific sensory diet for the entire therapeutic milieu or program
  - Consider a variety of environmental modifications or enhancements

## Therapeutic modalities

When considering sensory diet elements to add into each child's daily schedule and into the overall program, there are a number of therapeutic modalities that may be used. It is important to recognize the need for proper training, certifications when necessary and for developing policies and procedures for their use. Some general examples of integrative therapies include:

- Pet therapy
- Biofeedback
- Aromatherapy
- Light therapy
- Music therapy

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## Music therapy

Music is a powerful sensory modulation tool that is commonly used for many different therapeutic purposes. Different types of music help people in different ways, and playing soothing music in hospital and residential treatment programs may help children feel more calm.

- Baroque Era music is generally predictable & consistent. It may help children pay attention. *Bach and Pachelbel* are good for facilitating concentration.
- Mozart's or Hayden's compositions may be stimulating to some children and can be used to stimulate the imagination. Romantic music, such as the works of *Tchaikovsky or Beethoven*, uses strong rhythms, unique sound textures, and changes in context and may stimulate (activate) the imagination.
- Ambient music generally facilitates a state of calm-alertness. It is good to use for cool down purposes after exercise, to promote a relaxing atmosphere, or for use during breath work or mindfulness activities.
- Drumming is a form of directive body music because of the strong beat and potentially upbeat rhythmical patterns. These patterns facilitate movement and body awareness.
- Upbeat and fast-paced music, movie themes (such as *Rocky*), 50's tunes, and other popular music are often stimulating and motivate children to get up and move.

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For more information, literature on music therapy contains valuable information about how different qualities of music influence the nervous system. It is important to recognize the impact of the music selected for use and how it can be utilized for different treatment purposes. The American Music Therapy Association promotes research on the effects of music and music therapy.

Other sensory tools and activities that can be used to help children include:

- Engaging in physical movement five to six times daily at regular intervals
- Sitting on a therapy ball or a textured seat cushion to help stay attentive during school or groups
- Carrying stress balls to hold or squeeze when feeling fidgety or frustrated
- Wearing colored or tinted sunglasses for distraction or self-soothing
- Using a rocking chair during therapy or group meetings
- Listening to music, drinking warm tea and holding a soft stuffed animal to become sleepy at night
- Carrying stress balls around in their pockets at all times so that they can use them whenever they want. Staff members can also keep these balls handy and offer them to children when the child becomes frustrated.

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There are a number of resources for developing sensory diets for specific program populations and needs. Please refer to the information at the end of this section for additional resources.

## The creation and use of sensory kits

When a child chooses the sensory activities and tools that are helpful for him/her, it often helps to create a sensory kit for the child that is specific to his/her treatment goals. It may be helpful to include the kit in the child's Safety Tool and sensory diet, which includes prevention and crisis intervention strategies based upon the child's needs, transition times, and daily activities. Sensory kits should be customized to meet the child's individual needs. Examples of kits that have been used in some treatment programs include mindfulness kits, grounding kits, relaxation kits, distress tolerance kits, spirituality kits, sobriety kits, and kits to assess how a child's "engine" is running (Alert Program).

## Deep pressure modalities in occupational therapy

### **Brushing and joint compression**

The therapeutic use of deep pressure touch modalities often provides a sense of being grounded within one's body and within the world. Deep pressure touch modalities that are frequently used by trained occupational therapists include

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brushing, joint compression, beanbag tapping, and the therapeutic use of weighted items (vests, blankets, ankle weights). Brushing involves applying firm pressure touch using a specifically chosen therapy brush and rapid brushing strokes to the arms, hands, back, legs and feet. There are different schools of thought regarding what types of brushes are most effective for varied therapeutic purposes and protocols used (Burpee, 2002; Wilbarger & Wilbarger, 1995).

Brushing followed by the use of joint compression has been found to be effective with people experiencing sensory defensiveness, mania, depression, and anxiety. Joint compression (deep pressure stimulation to the large joints and muscles) is typically used after brushing techniques but can be used by itself as a therapeutic activity. Exercises, playing sports, wall or chair push-ups, wheel-barrel races and isometric exercises are examples of different activities that provide joint compression (deep pressure).

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## Beanbag tapping

Beanbag tapping entails using beanbags to apply moderate pressure in the form of tapping to the arms, legs, hands and feet. Tapping is not recommended over the stomach area due to the possibility of triggering lightheadedness or nausea after eating. Staff members can help children make personalized beanbags for tapping using assorted fabrics (fleece, cotton), non-toxic fabric paints, dried beans and other items for stuffing (lavender buds, aromatic spray, uncooked popcorn, pillow stuffing).

## Weighted modalities

Studies conducted on the skilled use of weighted vests in a variety of child populations demonstrated that their use appeared to improve the children's ability to focus and remain on task while completing school work. Studies on the use of weighted vests with older people found that it helped people increase their physical endurance.

It is important to recognize that children may benefit from the use of weighted vests for different reasons and the use of the vests should be specifically related to the treatment goals for the individual child (Fertel-Daly, Bedell & Hinojosa, 2001; Olson & Moulton, 2004 a; Olson & Moulton, 2004 b; Vandenberg, 2001). There are national guidelines for using the vests and their use should be supervised by a licensed OT.

Pressure garments provide a similar sensation to weighted vests but the pressure is often more evenly distributed.

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Pressure garments include special pressure vests and/or garments that may be worn under clothing, such as tight fitting lycra body suits.

The therapeutic use of weighted blankets is becoming more popular across mental healthcare settings. Weighted blankets offer a means for children to nurture themselves during times of distress and may even be used to aid sleep at night or for comforting at times when the child is not upset. Although some children like to use weighted blankets every night, other children may simply need to use a weighted blanket during a stressful time, such as after a disappointing phone call or meeting or when they are trying to go to sleep and stay asleep throughout a difficult night.

Research studies are currently being conducted on the safety and effectiveness of the use of weighted blankets. Until the outcome of the studies is known, it is advisable to follow the weighted blanket guidelines for carrying weighted blankets from one location to another (not to carry more than 10% your body weight, use a cart for blankets that are heavier) and to have the weight evenly distributed (Walker & McCormack, 2002). Weighted blankets should never be placed over a person's head or used involuntarily. The child must be a part of the process of determining how much weight is most helpful and must be able to put the blanket on and take it off at will (Champagne, 2006). Anyone with circulatory, pulmonary (breathing), orthopedic problems (fractures, broken bones, misalignments) or open wounds should not use a weighted

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blanket without a doctor's assessment and recommendations (Champagne, 2006).

Weighted blankets can also be used for more sedentary purposes (in sitting or lying down positions), while weighted vests are often useful when the child is active (up and moving about). Some children may benefit from using both weighted blankets and weighted vests at different times of the day.

## **Environmental considerations**

The physical environment of a program is an important consideration in any program's goal of becoming more sensory supportive (Champagne & Stromberg, 2004). Sensory carts and multi-sensory treatment rooms are examples of environmental enhancements or modifications that may be used to create a more sensory-supportive, nurturing and healing treatment environment (NETI, 2006). Multi-sensory rooms or "Snoezelen" rooms were originally created for use with people of all ages who had profound cognitive limitations. Today they are being used in treatment programs for children with mental health issues.

Multi-sensory rooms provide a therapeutic and meaningful space to keep sensory tools organized and readily available (Champagne, 2003). Staff and children appreciate having space when using multi-sensory rooms for individual and group therapy sessions. There is no exact formula for creating a sensory room, and no two program's sensory rooms should be exactly alike. The rooms are generally filled with sensory tools

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and décor specific to the purpose of the room, themes of the program and the population served. These environments need to be generally appealing to the age group using it.

Some common examples of items that may be included in sensory rooms are listed below:

Weighted blankets	Colored sunglasses
A rocking chair	Bubble gum
Rain sticks and glitter wands	Skate board
A mini-trampoline	Stress balls, squeeze balls, <i>koosh</i> balls
Scented lotions and powders	Stuffed animals and bean bags
A sound machine	Slide rocker
A bold colored body sock or tunnel	A rock climbing wall
Music selections and instruments	Bubble lamp or fish tank

Please refer to the section entitled *The Importance of Physical Environment* in the *Resource Guide* for more information on developing multi-sensory rooms and carts.

## Consulting with experts

Although programs may incorporate some sensory modulation elements into daily programming on their own, it is recommended that all programs utilize a licensed occupational therapist with sensory integration expertise for assistance. The occupational therapist should conduct individual assessments

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to determine the specific needs of each child in the program. He/she should also plan individual and group treatment interventions based on the results of these assessments and work with staff to plan sessions that inter-disciplinary staff can provide to help work toward therapy goals. Consulting with an occupational therapist when creating policies and procedures specific to the safe use of all sensory-related interventions and equipment is also important. This investment will ensure that, at a minimum:

- Staff members and children will acquire a better understanding of SI
- Staff members and children will begin to understand the specific SI needs of individual children
- Staff members and children will become familiar with different sensory interventions, how to use them safely and effectively, and how to use different types of activities to address individual needs for calming or active movement at different times of the day and evening and group needs
- Staff members will begin to understand their own learning styles and sensory preferences

If a program does not have the financial resources to contract or hire an expert, staff may begin learning more about how to incorporate sensory strategies into the program by reading some of the following books:

- *How Does Your Engine Run* (Williams & Shellenberger, 1996)

- 
- *The Sensory-Sensitive Child* (Smith & Gouze, 2004)
  - *The Out-of-Sync Child* (Kranowitz, 2001)
  - *The Out-of-Sync Child Has Fun* (Kranowitz, 2003)
  - *Too Loud, Too Bright, Too Fast, Too Tight* (Heller, 2003)
  - *Thinking In Pictures* (Grandin, 1995)

Please refer to the *Additional Resources* section at the end of the *Resource Guide* for more reading suggestions.

## Implementation ideas

The following are ideas for programs that want to incorporate SI into their treatment:

- Contract with or hire a licensed occupational therapist with expertise in sensory integration to provide individual child assessments, staff training, and program consultation.
- Send staff members to workshops on sensory integration, integrative therapies, and sensory supportive program offerings that promote sensory integration and bring back ideas to the program.

- 
- Appoint a work group of children and staff members to review the activity schedule, taking into account that children need both gross motor and calming activities during the day. Review the sensory and rhythmical needs of individual and groups of children and adjust the schedule as appropriate. For example, the children may need gross motor activities after school, outdoor walks before school, yoga in the evening, meditation in the morning, etc.
  - Appoint a workgroup of children, staff and family members to work with a licensed occupational therapist consultant with expertise in sensory integration. Develop a plan to include some aspects of sensory integration into the program. Design a training program for all staff members, children, and families and purchase necessary materials.

## A classification system

There are a number of different terms that are used to describe some of the sensory related problems children may struggle with and strategies that may be helpful. Occupational therapists are currently working with the American Psychiatric Association to include sensory processing disorders in the next edition of the *Diagnostic Statistical Manual of Mental Disorders*. This ongoing work toward the inclusion of sensory processing disorders within the current classification systems used in mental health will help integrate sensory processing evaluation

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and treatment approaches across levels of care in psychiatric services.

## Additional resources

The following sample sensory tools are included as attachments at the end of this chapter. Feel free to photocopy them to use them in your program:

- *Exploring the Senses, What is Soothing to you?*
- *Grounding Techniques*
- *Sensory Diet Checklist*
- *Self Rating Tool - Using Sensory Interventions*

# Exploring the Senses!

## What is Soothing to You?



**Tastes:**



**Sights:**



**Sounds:**



**Touch:**



**Smells:**

## ***Grounding Techniques***

***What are grounding techniques?*** Grounding techniques are simple active strategies to help with orienting and focusing on the present and/or to distract or self-soothe when feeling distressed.

***Why do grounding techniques?*** Grounding techniques can be used in times of crisis and for prevention purposes within a "sensory diet". When feeling dysregulated, grounding techniques can assist emotionally, physically, cognitively and spiritually.

### ***Grounding Techniques:***

- ❑ Stomping your feet
- ❑ Yoga
- ❑ Bean bag tapping/brushing
- ❑ Sitting on a balance ball/textured cushion
- ❑ Moving furniture
- ❑ Cleaning
- ❑ Yard work
- ❑ Rocking in glider or rocker
- ❑ Blanket wrap
- ❑ Holding/chewing ice
- ❑ Eating sour balls, hot balls, lemon
- ❑ Aromatherapy
- ❑ Pottery/clay work
- ❑ Breathing exercises
- ❑ Yawning
- ❑ Music: \_\_\_\_\_
- ❑ Clapping your hands
- ❑ Using a koosh or stress ball
- ❑ Walking/ Running
- ❑ Lifting weights
- ❑ Using thera-bands
- ❑ Wearing weighted item: i.e.: vest, backpack, ankle or wrist weights
- ❑ Weighted blanket
- ❑ Jumping rope/jacks
- ❑ Stretching
- ❑ Tossing medicine ball
- ❑ Petting dog/cat/pet
- ❑ Push-ups/ wall push-ups
- ❑ Clenching fists/jaw
- ❑ Cold/warm cloth to face/neck
- ❑ Hot/cold shower
- ❑ Playing earth drums/instrument(s)
- ❑ Isometric exercises
- ❑ Cold/hot drink

Others: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## *Sensory Diet Checklist*

The following is a checklist of things people may use or do in order to help decrease &/or to prevent distress. Please take a moment to check off those things that seem to be helpful for you! Each of these activities employs all or most of the sensory areas. However, they are categorized to help you identify some of the specific sensorimotor qualities you may want to focus on.

### *Movement*

- Riding a bicycle
- Running or jogging
- Walking/hiking
- Aerobics
- Dancing
- Stretching or isometrics
- Lifting weights
- Yoga or Tai Chi
- Swimming
- Jumping on a trampoline
- Rocking in a rocker/glider
- Rocking yourself
- Bean bag tapping
- Shaking out your feet/hands
- Playing an instrument
- Doodling
- Re-arranging furniture
- Gardening
- Yard work
- Shopping
- Taking a shower
- Cleaning
- Driving
- Going on amusement park rides
- Chopping wood
- Washing/waxing the car
- Skiing/skating
- Building things

Others: \_\_\_\_\_

### *Different Types of Touch & Temperature*

- Blanket wraps
- Getting a massage
- Holding/chewing ice
- Soaking in a hot bath
- Using arts/crafts supplies
- The feel of the sunlight
- Pottery/clay work
- Petting a dog, cat, or other pet
- Holding a dog, cat or other pet
- Planting or weeding
- Warm/cold cloth to head/face
- Hot/cold shower
- Hand washing
- Washing the dishes
- Using a stress ball
- Fidgeting with something
- Twirling your own hair
- Going barefoot
- Getting a manicure/pedicure
- Washing or styling your hair
- Bean bag tapping/brushing
- Cooking or baking
- The feel of certain fabrics
- Being hugged or held
- Knitting/crocheting
- Sewing
- Using powders/lotions
- Playing a musical instrument

Others: \_\_\_\_\_

## ***♫Auditory/Listening***

- Enjoying the quiet
- The sound of a water fountain
- The sound of a fan
- People talking
- White noise
- Music box
- Wind chimes
- Singing
- Humming
- Whistling
- Plays/Theater
- Live concerts
- Radio shows
- Ocean sounds
- Rain
- Birds chirping
- Ticking of a clock
- A cat purring
- Using the telephone
- Use of a walkman/MP3 Player
- Listening to musical instruments
- Relaxation or meditation CDs

Others: \_\_\_\_\_

## ***👁️Vision/Looking***

Looking at:

- Photos
- The sunset or sunrise
- Snow falling
- Rain showers
- Fish in a tank
- Autumn foliage
- Art work
- A bubble lamp
- A mobile
- Waterfalls
- Cloud formations
- Stars in the sky
- Ocean waves
- Watching sports
- Movies
- Animal watching
- Window shopping
- Photography
- Reading
- Looking through different colored sunglasses
- A flower
- Water or fish swimming in a lake

Others: \_\_\_\_\_

## ***👃Olfactory/Smelling***

- Scented Candles
- Essential oils
- Cologne/perfume
- Baking/cooking
- Coffee
- Aftershave
- Freshly cut grass
- Flowers
- Tangerines/citrus fruits
- Herbs/Spices
- Chopped wood
- Smell of your pet
- Linens after being hung outside to dry
- Scented lotions
- Incense
- Herbal tea

Others: \_\_\_\_\_

***☛Gustatory/Tasting/Chewing***

- Chewing gum
- Crunchy foods
- Sour foods
- Chewing ice
- Sucking a thick milkshake through a straw
- Chewing on your straw
- Yawning
- Deep breathing
- Biting into a lemon
- Eating a lollipop
- Drinking coffee/cocoa
- Drinking herbal or regular tea
- Drinking something carbonated
- Listerine strips
- Mints
- Hot balls
- Chewing carrot sticks
- Spicy foods
- Eating a popsicle
- Blowing bubbles
- Chocolate
- Strong mints

Others: \_\_\_\_\_

***Additional Questions:***

What kind of music is calming to you? \_\_\_\_\_

What kind of music is alerting to you? \_\_\_\_\_

Do you prefer bright or dim lighting when feeling distressed? \_\_\_\_\_

***Are there other things that are not listed that you think might help? If so, what?***

\_\_\_\_\_

\_\_\_\_\_

***After reviewing all of the activities you have checked off and listed, what are the top five things that are the most helpful when you are feeling distressed?***

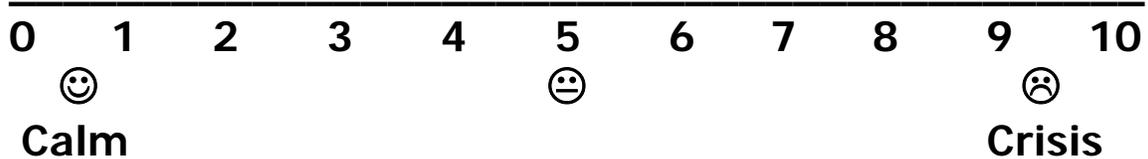
1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

# Self-rating Tool: Using Sensory Interventions

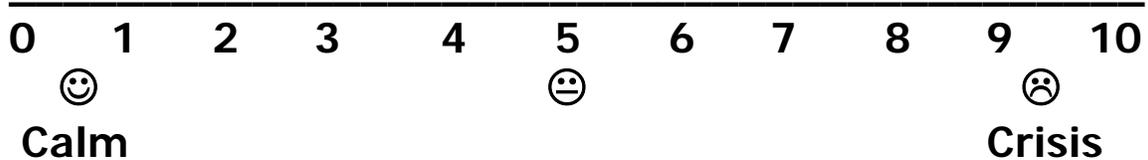
Name: \_\_\_\_\_

Date, Time & Location: \_\_\_\_\_

Before use how did I feel?:



After use how did I feel:



What was used: \_\_\_\_\_

How it was used:

\_\_\_\_\_  
\_\_\_\_\_

Reflections:

\_\_\_\_\_  
\_\_\_\_\_

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# Touch

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**Beth Caldwell, MS**

“ I have learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel. ”

Maya Angelou

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# Touch

## A confusing history of touch in hospital and residential programs

**T**ouching and hugging children is a natural instinct for human beings that has both a psychological and a physiological basis. Studies point to the importance of touch for healthy child development and demonstrate that touch deprivation stunts growth and contributes to the decreased development of the hippocampus, a structure of the brain that is important for emotional processing and creating meaning and context to situations (Meaney, Aitken, Bhatnagar, Bodnoff, Mitchell, & Sarrieau, 1990; Schanberg, Kuhn, Field, & Bartolome, 1990). In cases where touch deprivation is severe and prolonged, children may have “lifelong vulnerability to psychiatric disorders” (Carlson & Earls, 1997).

For many years, residential and hospital programs for children encouraged different types of touch and agreed that regular touch was important for normal child development. More recently, programs have developed “No Touch” policies in response to concerns about protecting children from possible abuse by staff, protecting staff from false allegations by children, and protecting children with sexual abuse histories from being re-traumatized. However, the “No Touch” policies and practices sometimes inadvertently reinforce control-based practices by promoting the use of consequence-based systems in programs.

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Although there are ongoing debates about whether it is appropriate to use touch in inpatient and residential treatment programs, the growing body of evidence on the value of touch emphasizes the importance of touch in normal child development. These findings combined with a national interest in strength-based treatment led many programs to revise their “No Touch” policies. These programs found that they can allow and encourage healthy touch opportunities and still be sensitive to issues of child abuse, allegations of abuse, and re-traumatization. For example, therapeutic touch techniques and massage have been found to be effective in reducing pain and anxiety, symptoms commonly seen in children who have experienced trauma (Field et al., 1992; Hughes, Meize-Grochowski, Duncan Harris, 1996).

Because the use of touch has been well researched and identified as a critical component of healthy child development (Shonkoff & Phillips, 2000), DMH has encouraged hospital units and intensive treatment programs to thoughtfully consider the issue and find reasonable ways to incorporate the appropriate use of touch into care and treatment. The topic of touch has been raised at DMH Grand Rounds, the Annual Provider Forum, and provider-organized Roundtables. The ongoing dialogue is helping all members of the Massachusetts mental health inpatient and intensive treatment community consider and implement this important element of compassionate care.

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## Families and children must define the types of touch that are helpful

Before embarking on any touch intervention, children need to be asked about their touch preferences when they are admitted to a hospital or residential treatment program, and these preferences should be honored. Sometimes children may not have the language to describe their preferences or circumstances in which touch was helpful or harmful. In that case, this information should be elicited from the parent or legal guardian who knows the child best. This information should be updated regularly, because children's preferences may change. Use of touch should be individualized based on the histories, preferences, and emotional needs of each child. For example, some children who have been sexually abused may prefer receiving "high five" hand claps rather than hugs. Other children may like the physical contact of a hug, but prefer a side hug, where a staff member stands beside them and puts his/her arm around the child's shoulders, rather than a hug that involves full body contact. Some children may not want to engage in any sort of physical contact with staff.

Useful questions to assess touch preferences include:

- Do you like (or mind) being touched?
- What types of touch do you prefer?
- Are there times when you would prefer not to be touched?
- Do you tend to like heavy blankets when you sleep?

- 
- Do you like to play partner-games with touch like tag or wheel barrel races?

Touch is only positive when children and families and staff members provide the parameters for how touching will occur. Some staff members may not feel comfortable touching the children in their care, even after education about the potential value of touch for children, and it is important to respect their preferences and wishes. There are different cultural preferences around touching as well, which should be considered in treatment planning.

When children are admitted to hospital or residential treatment, programs should:

- Provide children and families with specific examples of the types of touching used by staff
- Ask children to identify preferred therapeutic touch strategies
- Ask families and children for permission to use therapeutic touch (if indicated)
- Gather comprehensive information about the child's trauma history (if any)

## The human tactile system

As human beings, we are always touching things or being touched by elements in the environment. Standing with feet firmly on the ground, sitting in a beanbag chair, playing catch,

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and wrapping in a blanket are all different ways people can experience touch. The sense of touch, also known as the tactile sense, helps people recognize whether something is cold, hot, soft, rough, smooth, dull, or sharp.

The skin contains the tactile sensory receptors that detect sensations of temperature, pressure, vibration, movement, and pain. The tactile system includes both the discriminative systems, which help with body awareness and sensory perception, and protective systems, the body's defensive survival mechanism. The tactile system cannot work in isolation, and it functions in concert with the other sensory systems to help people make sense out of the world and to discriminate between touch sensations that are pleasurable and those that are not.

Please refer to the *Sensory Approaches* chapter of the *Resource Guide* for more information on sensory integration.

## Problems with the tactile system

Dysfunctional tactile processing can be caused by many things, such as trauma, physical torture, prolonged stress, touch or sensory deprivation, injury, and immobility. These are just some of the possible reasons problems may arise in the tactile system. Children with problems with tactile dysfunction may display some of the following behaviors:

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1. May have difficulty with **tactile discrimination**, which is difficulty in differentiating between different types of tactile stimulation (e.g., types of fabrics, hot/cold, pain perception). They may have difficulty recognizing the physical characteristics of objects (e.g., temperature, shape, texture, density, size). These children may demonstrate the following:

- May get burned easily and/or often
- May not be sensitive to cold temperatures
- May have difficulty distinguishing between different types of fabrics
- May appear indifferent to pain
- May appear to be a sloppy eater or have difficulty with self-feeding
- May have trouble learning to hold a writing instrument correctly
- May have decreased body awareness

2. May be **tactile defensive** (hyper-sensitive) to certain or many kinds of touch (e.g., may scream or strike out when touched; may crave the deep pressure of a hug but then appear to be trying to ward it off). These children avoid the kinds of tactile stimulation they are aversive to and proceed cautiously, and sometimes fearfully, when they have new tactile experiences. These children may demonstrate the following:

- May not like to have hair brushed, face washed or teeth brushed
- May only be comfortable wearing soft cotton clothing

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- May not be able to tolerate seams in socks or tags in clothing
  - May not be able to tolerate hugs, even from family members
  - May not like to stand in lines out of fear of being touched or bumped
  - May dissociate or self-injure in order to escape discomfort or when feeling overwhelmed by the stimulation within in the physical environment

3. May be **under-responsive** to tactile stimulation (lack of responsiveness)

These children may demonstrate the following:

- May not appear to notice when they get injured
- May constantly touch things (seeking more touch stimulation)
- May be unaware of tactile cues
- May seek deep pressure to increase their ability to feel (e.g, seem hyperactive, engage in risky behaviors, self-injure)
- May appear unkempt (messy dressers)
- May require visual cues to button or zip up clothing

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These tactile processing problems, which can vary from mild to severe, often contribute to difficulty with body awareness, self-image, motor planning, the ability to form relationships, and the ability to engage productively in school, work and play activities.

## Assessment of the tactile system

The following is a list of some of the questions that may be asked of children and caregivers to assess a child's tactile system:

Does the child:

- Like to be touched or held
- Become silly when touched
- Always seem to be touching things
- Always seem to try to avoid touch
- Pinch, bite, scratch, cut or punch self
- Head bang
- Seem overly sensitive to certain foods
- Avoid playing in dirt, mud or with clay
- Avoid silky fabrics
- Only like cotton materials
- Demonstrate indifference to pain or extreme temperatures

- 
- Seek deep pressure activities (e.g., jump, run, climb, hug, push/pull, chew)
  - Seem excessively ticklish
  - Dislike being physically close to people
  - Have strong reactions to getting hair brushed
  - Have strong reactions to having nails clipped
  - Have strong reactions to having face washed
  - Seem unaware of bruises or cuts obtained
  - Like to bite on objects (gum, pencils, straws)

## Some therapeutic touch methods used in Massachusetts

Some programs in Massachusetts recognize that touch can play an important role in treating children who have been traumatized. The Child Assessment Unit (CAU) at Cambridge Hospital developed a parent assessment form that invites parents to comment on their child's sensitivity to sensorial stimuli, including touch. .

For example, the parent may write that, while their child does not usually like to be touched, he/she may tolerate/enjoy a small squeeze or rubbing lotion onto their skin helps to calm him/her down. This assessment is included as a resource at the end of this section. Cooley-Dickinson Hospital in Western Massachusetts teaches adolescents how to perform therapeutic brushing, beanbag tapping, and blanket wrapping

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techniques so that they learn how to engage in using them independently.

Brushing techniques vary, but one formal brushing protocol, called the Wilbarger Deep Pressure and Proprioceptive Technique (DPPT), requires specific training before use (Champagne, 2006). Some programs use soft and careful touch methods, such as pats on the back, specific types of hugs, light touches to the arm, and hand hugs, as described in each child's treatment plan. Many programs offer different kinds of tactile manipulatives (stress balls, tangle toys, wikki sticks, different kinds of putty), lotions, blankets, sand/water tables, gardening activities, and art supplies.

Please refer to the Sensory Diet Checklist at the end of the *Sensory Approaches* chapter in the *Resource Guide* for more information on ideas for sensory strategies to help children decrease and/or prevent distress.

## Types of touch

There are many types of touch that children can experience in residential or hospital programs. Each program should incorporate both formal and informal healthy touch opportunities. It is helpful for programs to use pictures to show children and families the different types of touch used in the program and types of touch that are not allowed.

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Examples of touches that are used in some treatment programs include:

- Child to child touch, such as hugs, holding hands, and sitting close
- Staff to child informal touch, such as hugs, pats on the back, holding hands, sitting side-by-side
- Staff to staff touch, such as hugs, pats on the back
- Staff to child formalized touch, such as massage, playing a game that involves touching, like tag, wheel barrel races and certain types of dancing (e.g., square dancing)

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## **The Cutchins Program for Children & Families – Therapeutic Touch Policy**

The Cutchins Programs for Children and Families in Western Massachusetts created a therapeutic touch policy for their residential treatment programs for children with guidelines for staff members around the use of touch in the programs.

Their policy states:

“One of the goals of treatment is to teach clients to use words to express affection, anger, and complex combinations of emotions. Touch is not a substitute for this learning process. Therapeutic use of touch is an educational piece of work that concerns appropriate vs. inappropriate boundaries. Touch can be a corrective emotional experience, but must be introduced in a mindful way that takes into account the individual and their unique history. Clients who have experienced violations should also be taught to use their voices to set boundaries. Clients should also be taught that warmth and affection could be communicated without touch.”

The policy specifically states that staff members may never use the following touches:

- Touch that is sexual, aggressive, or intrusive
- Touch that is startling or hurtful
- Touch that is part of pretend fighting
- Touch that is part of competitive physical interactions

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- Touch that includes stroking or kissing
  - Touch that includes sitting in laps
  - Touch that includes surprise embraces
  - Touch that includes massages unless it is part of a group activity with permission, such as the program Spa Day.

Staff members are permitted to engage in the following touching (with the child and family's permission):

- Staff members may jostle children awake.
- Staff members may place a hand on a child's arm or shoulders or back.
- Staff members may engage in incidental contact (e.g., high five) that is appropriate as a greeting.
- Staff members may help children with special hygiene programs that are approved by the treatment team.

Experienced staff members who have been at the program for over a year and have received specific training may use the following forms of touch with the children:

- Playful touch (throwing kids in the water).
- Hugs with verbal or non-verbal permission.
- Picking children up off the ground.
- Putting sunscreen on a child's back.

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## Massage therapy

The Touch Research Institute (TRI) at the University of Miami School of Medicine was the first center in the world dedicated to the study of touch and its application to science and medicine (TRI, undated). In over ninety studies conducted on the positive effects of massage therapy, researchers found that touch therapy had a soothing effect on adolescents and on victims of sexual abuse of all ages. One study found that after a month of two chair massages a week, adolescents were less aggressive (Diego et al., 2002). Findings from other studies conducted at TRI suggested that physically neglected adolescents often behave aggressively, and massage therapy can be effective in helping them decrease their level of violence (Field, 2002).

Massage therapy and other forms of touch therapy are thought to decrease anxiety, reduce dopamine levels, and increase serotonin levels. Programs may want explore offering massages as part of the treatment that they provide, either through licensed massage therapists (LMT), certification programs, or by staff members trained in simple massage techniques by a LMT. The adolescent inpatient unit at Providence Hospital in Holyoke, Massachusetts offers hand and arm massages to children who find it helpful. The adolescent inpatient units run by the University of Massachusetts at Westborough State Hospital offer back massages with a weighted medicine ball and also have massage therapy interns working with the adolescents.

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Please refer to the resource list at the end of the *Sensory Approaches* Chapter of the *Resource Guide* for samples of tools and additional resources that may be helpful in learning more about the therapeutic use of touch.

## Pet therapy

The therapeutic use of animals is another way to integrate touch into hospital and residential programming. Several programs in Massachusetts offer pet therapy. For example, Taunton and Tewksbury State Hospitals have integrated the therapeutic use of horses (hippotherapy) into their treatment. Transitions and Centerpoint IRTP's, Metro-West Medical Center, and Cooley-Dickinson Hospital offer regularly scheduled dog therapy sessions as part of both individual and group treatment.

## Self-injury and dissociation

Children who engage in self-injury and dissociate often report that they do so either to escape feeling overwhelmed, upset, or scared; when they feel as though they have no control over their lives; or in an attempt to experience feelings at times when they are “numb.” Some of these children benefit from using “grounding” techniques, such as a child’s preferred tactile and deep pressure techniques, to help them re-establish their mind-brain-body-world connection.

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These techniques are often taught and used as alternative coping techniques, but it is important to understand that changing behavior patterns and learning to consistently use new coping skills usually takes patience, practice, and trained professionals. Treatment programs should make use of staff training and consultation with occupational therapists skilled in using these assessment and treatment techniques to help integrate them into program practices.

## Additional resources

The Cambridge Hospital Child Assessment Unit's *Parent Assessment Sheet* is included as a resource at the end of this section. The assessment may be photocopied with permission from the CAU, and the program contact information is included in the *Additional Resources, Touch* section of the *Resource Guide*.

## CAU Parent Assessment Sheet

Child's Name

### Date:

Our job on the CAU is to better understand what makes your child upset and to help him or her with this. Often kids get upset when they become frustrated. Some kids have figured out ways to deal with frustration and for other kids this is harder.

We would like to help your child when he or she is beginning to get "frustrated" before it becomes a big deal and ends in a "meltdown". "Meltdowns" are times when someone is so upset and frustrated or angry that they "can't even see straight". At these times, it is very difficult to figure out what to do to make things better. The feelings of being upset, frustrated and angry may make it difficult to think clearly and make decisions to solve the problem. At times such as these it is very hard to feel in control and to problem solve.

Many of the children who come to this unit have problems managing frustration and stress. When they become very upset and lose control, it creates problems for parents/caretakers in knowing how to manage the situation.

We want to get to know enough about your child so that we can help when he or she is first beginning to become frustrated.

And we want to work on a plan with you and your child to help with this.

Here are some questions that will help us find the answers we need to help you and your child:

For the following, please answer as if you were answering this for your child.

### **Which of the following do you think is true for your child?**

Put a Y for yes or an N for No.

It is very hard for me to sit still

It is very hard for me to be quiet and not talk out loud.

It is very hard for me to switch what I am doing in a hurry, especially if I am having a good time.

I can't think straight if I am given more than 1 direction at once.

I have a hard time listening if people talk too long.

I need help trying to decide what I should do next and how to do it.

I have trouble remembering things especially when I am upset.

I have a really hard time thinking clearly when I am upset.

I have a hard time making and keeping friends.

I need people to tell me exactly what they want; I can't figure it out by myself by looking at them.

I am not good at taking hints or body gestures and knowing what they mean.

I know that I want friends but I do not know how to play with them.

I have a hard time trying to imagine ahead of time what will happen if I do something to someone.

I have a hard time figuring out what someone means or wants just by looking at their face, or listening to their tone of voice.

I have a hard time finding the right words to say when I want to tell someone something important.

I often have a hard time figuring out what someone is saying to me.

It is very hard for me to describe my emotions in words.

I feel cranky, grouchy, irritable most of the time.

The littlest thing can make me very grouchy.

I have a hard time getting out of a grouchy mood.

I always imagine the worst.

I don't expect good things to happen to me.

I think that I am stupid, or fat, or ugly.

I do think that people like me.

I don't like my life.

I feel I need to look out for myself or people will hurt me.

I worry about a lot of things.

I expect bad things to happen. I wait for bad things to happen to me.

I feel scared a lot of the time.

I am afraid of people.

I want the same things to happen over and over again.

I do not like changes in my routine. I want each day to be the same.

I am sensitive to:

Temperature I don't like it too hot or too cold.

Clothing I only like certain types of clothes and it depends on the way they feel.

Food I only like certain foods. The way food feels in my mouth is important.

Motion. I like to sit, stand, jump, move a certain way.

Sound I do not like certain noises. I don't like loud noises.

Touch I do not like people to touch me. I like it when people squeeze me a little.

**Tell us what really “bugs” your child.**

For example: I can't stand it when someone interrupts me when I am speaking.

I don't like it when people get too close to me.

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**When your child becomes really upset what helps him/her calm down?**

Being left alone

Being given some time to go to my room

I like to throw things when I am upset

I like to yell when I am upset

I like someone to stay with me until I am a little calmer

I need to feel that grown-ups understand why I am upset

I need someone to help me understand what I did but to tell me in a soft voice.

I need to wait until I am calmer to talk about what happened

I don't like to talk about what made me upset.

I can write down why I am upset.

It helps me to calm down if I can talk to my mother, father, grandmother, aunt, foster mom, etc.

I like to read in my room.

I like to take a bath or shower

I like to rub lotion on my skin

I like to comb my hair

I like to take pace up and down the hall

I like play with my toys (Gameboy, stuffed animals, cars)

I like to shoot hoops

I like to rollerblade

**What else would help your child to calm down?**

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**What should we watch for as a sign that your child is beginning to have a “meltdown”?**

I clench my fists

I mutter to myself

I curse

I yell

I argue with people

I try to start a fight

I try to throw things

I start to sweat

I turn red in the face

I run as fast as I can

I refuse to move

I repeat what someone says

I start to talk loud

I talk faster

I make faces

I cry

**What other things would tell us your child is very upset?**

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**What things would make it worse for your child when he/she was very upset?**

Closing the door to the room I am in

Male staff coming close to me

Female staff coming close to me

Being in the dark

Being in a room with bright lights

Being held down by staff (all staff, male staff, female staff)

Warning me about the consequences

Trying to talk to me

Not letting me make a phone call to my mom, dad, etc.

Making me sit still

**What time of the day is harder for your child?**

No time

I have a hard time getting going in the morning.

I have a hard time at night.

I have a hard time in the afternoon, before dinner.

**Are there times or places that make him/her afraid or scared?**

I am afraid to fall asleep

I am afraid to be in a room alone at night

I am afraid to be in a room with other people

I can't fall asleep without music being on.

I need the light on to fall asleep.

I am afraid of the bathroom

I don't like having to go into a closet.

I get scared when someone yells

I am afraid of strangers

I am afraid of certain types of people ( big men, big women, etc)

**What else is important for us to know about your child?**

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Additional information that is very important for us to know about has to do with experiences your child may have had or witnessed. Please share with us this personal information so that we can not only help your child but also insure that we do not make things any worse for him or her.

Has your child experienced any physical, sexual or emotional abuse? (If you are not sure what this would be, please ask the staff person who asked you to fill out this form.)

No

Yes, (Please explain)

Was this experiencing a one-time occurrence or did this occur repeatedly?

No

Yes, (Please explain)

Has your child or family experienced other upsetting or traumatic events? (fire, flood, witnessed a death of relative or friend, etc.)

No

Yes, (Please explain)

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# The Importance of Physical Environment

**Tina Champagne, M.Ed., OTR/L**

“ Your outlook upon life, your estimate of yourself, your estimate of your value are largely colored by your environment... ”

Orison Swett Marden  
(founder of *Success* magazine)

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# The Importance of Physical Environment

## Physical space

**P**hysical environments in inpatient and residential programs are central to the experience in these programs. There are many key environmental elements, including the shape of the physical space, the amount of space available, the variety of spaces available, furnishings, cleanliness, state of repair, cultural décor, colors, decorative objects, smells, sounds, and availability of outside space.

Physical environments can influence feelings of safety, security, and comfort, or conversely contribute to feelings of irritation, anxiety, sadness, and insecurity, depending on the environment.

Experts in the field of child development emphasize the need to ensure that the physical environments in treatment programs are safe, functional, and meet the developmental and treatment needs of the children (Bundy, Lane & Murray, 2002; Thelen & Smith, 2000; Ayres, 1979). The use of greenery, soft colors, presence of animals, and integrative therapies may also be beneficial to a child's sense of well-being and comfort.

Programs that have successfully implemented a strength-based approach and significantly reduced or eliminated the use of S/R

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have assessed and improved the physical environment. These programs have attended to the basic physical environment (e.g., repairs, organization, space for large motor activities) and ensured that the environment is nurturing (e.g., colors, music, plants) and affirming (e.g., cultural competence, displays of child works).

## Creating a positive physical environment: ideas for helping programs promote nurturing and affirming physical environments

### **The program environment should be:**

- In good repair; maintenance should be done promptly;
- Welcoming and visually attractive;
- Painted in soothing colors;
- Decorated to reflect the different ethnic heritages of the children and families served;
- “Normalizing” (for example, signs should say “Family Members are Welcome,” rather than Visiting Hours are Restricted to...)
- Replete with awards, art work, and school work of children proudly displayed;
- Decorated with murals the children have created;
- Furnished with solid and comfortable furniture.

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**The program environment should be able to provide:**

- Indoor spaces for large motor activities and the items to encourage these activities (e.g., big balls to roll around on, climbing apparatus, punching balls);
  - A well-kept outdoor area for different types of play (if this is not available, the program should have access to parks, swimming, gyms near to the program that can be used frequently);
  - Cozy and quiet areas;
  - A private space for children to meet with their families;
  - Toys and activities for young children visiting with their families;
  - A Calming or Comfort Room or distinct Comfort Areas and many sensory integration tools, as described in the following section on sensory rooms;
  - A quiet place for staff members to meet;
  - Places for staff members to keep their belongings;
  - An abundance of green plants;
  - Live animals (e.g., fish tanks, gerbils);
  - Many games and activities for different age groups that are kept in good repair, easily accessible and organized;
- and

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- Visible references to promoting self-esteem of children and adolescents of all sizes, shapes, colors, and religious preferences through pictures, reading materials, and magazines.

**Program staff members should:**

- Clean up after themselves, both outside (i.e. in the staff parking lot) and inside (all areas of the program);
- Pick up debris or sweep up messes they find on the property and in the program;
- Take care of the environment at the program (e.g., water and repot plants, update bulletin boards with child work, help children decorate their rooms, rearrange furniture to change the mood on the unit);
- Teach, model, and help children pick up after activities and in everyday cleaning of the unit;
- Teach, model and help children learn to respect the physical environment (e.g., pushing chairs in gently after eating, straightening up a room before leaving) and to properly use different living areas (e.g., reading areas, Comfort Room).

## Use of the environment to promote self-regulation

Experts support the creation of specialized multi-sensory treatment rooms dedicated to providing nurturing and healing therapeutic options (Long & Haig, 1992; Pinkney, 2000; Ashby

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et al., 1995; Baker et al., 2001; Champagne, 2003a) in treatment programs for children. .

Increasingly, treatment programs are recognizing how the environment can be used as a tool to help children learn self-regulation (or sensory modulation) and self-control strategies (NETI, 2003). Creating sensory rooms has also allowed some programs to significantly reduce or eliminate the use of S/R (Champagne, 2003b; Champagne & Stromberg, 2004).

Please see the chapter on *Sensory Approaches* for more information.

## History of the sensory room

Sensory rooms, first introduced in the 1970's, are recognized by a variety of names including: Snoezelen rooms, sensory integration rooms, dark rooms, white rooms, multi-sensory environments, multi-sensory rooms, sensory modulation rooms, creativity rooms, water rooms, Comfort Rooms, and sensory gardens. They are being utilized internationally, among a variety of populations, with a host of different purposes and approaches. It is important to understand the purpose of the different types of sensory-focused treatment rooms.

Sensory rooms provide: (1) a space that supports therapeutic treatment goals; (2) offer interventions for staff to implement; and, (3) create new learning opportunities for skill development for children. Creating a nurturing, healing, and recovery-focused multi-disciplinary treatment environment is now

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considered an essential element within a variety of mental healthcare settings (Champagne, 2006).

At the De Hartenburg Institute in Holland, a range of sensory items were developed within a specialized therapeutic treatment environment called “Snoezelen.” Snoezelen rooms were named using a combination of terms from the Dutch language, “snuffelen” (to explore or to seek out) and “doezelen” (to relax). The use of a non-directive treatment approach was the treatment philosophy attached to snoezelen, and these environments were made available primarily for people with profound developmental and cognitive disabilities (Hulsegge & Verheul, 1987; Hutchinson & Haggard, 1991).

## Promoting peace: creating nurturing and healing environments

Many child and adolescent programs that have significantly reduced the use of S/R attribute some of their success to the use of rooms or spaces painted in soft colors and filled with furnishings and objects that promote feelings of safety, relaxation, and healing (NETI, 2003). Objects include soft stuffed animals, calming musical selections, materials for writing and painting, stress or squeeze balls, weighted blankets, portable rocking chairs, and sound machines. These programs provide ongoing training for staff members and children on how to use the space and how make changes in the rooms as needed based on the changing needs of the clients they serve (Champagne & Stromberg, 2004).

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Gayle Bluebird, R.N., created a Comfort Room at Atlantic Shores/South Florida Hospital in 2001 for the purpose of providing a calming space. She conceptualized it as a room to “provide sanctuary from stress... and/or... a place for persons to experience feelings within acceptable boundaries.”

Ms. Bluebird found that Comfort Rooms are a “preventive tool that may help to reduce the need for seclusion and restraint” (NETI, 2003).

Quality improvement studies on the use of the sensory modulation room in one acute care setting and found that it had positive effects on 89% of the clients in 2003 and 85% in 2004. Staff received comprehensive training on the use of sensory approaches and the sensory room. During the year that the first quality improvement study was conducted, this facility’s restraint rates decreased by 54% (Champagne & Stromberg, 2004). Programs that implement sensory rooms find them to be effective in helping children to learn self-soothing, distraction, and relaxation strategies. Children and family members have also provided similar positive feedback to programs about the utility of Comfort Rooms.

## Getting started with creating a sensory space: equipment and setup (Champagne, 2006)

**How to Begin:** It is important to consider the ages of the children in the program, their diagnoses and symptoms, their current and past experiences, their cultural backgrounds,

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and their cognitive, emotional, psychosocial, sensory, and physical abilities as well as any limitations when developing the room. Keep in mind the philosophy of the program and also safety regulations.

**Room Size:** Although it is optimal to have a large room, it is reasonable to begin with a small space or even a sensory corner, if necessary, due to space or financial limitations. Large rooms can be divided into different areas, themes and stations, but smaller rooms may afford a cozy space.

**Themes:** Programs should create clear and distinct rooms for specific treatment purposes. For example one space may be used for relaxation and calming purposes (glider rocker, bean bag chairs, calming music, reading, or writing), while another space may be more active (rock wall climbing or gross motor activities). There are a variety of themes that can be implemented, such as exploration (art supplies, therapeutic books and magazines, tactile objects, instruments), or seasonal (use of seasonal themes, orientation boards, seasonal objects). Be creative with themes, but, if possible, remember to be consistent with one distinct theme for each room.

**Availability:** The sensory room should be readily available and easily accessible for all staff members to use with the children.

**A Work in Progress:** Most sensory rooms are works in progress and develop in stages. Programs do not have to start off with an elaborate room or state-of-the-art equipment. The most important factor is to develop a plan, acquire the space

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and begin. The room may take some time to evolve, but the process will give staff and children a chance to participate.

**A Group Effort:** Whenever possible, programs should solicit input from staff members and children at all phases of the sensory room development. There are a variety of ways to get this input, such as surveys, group planning and decorating sessions, team meetings, sensory room committees, sign-up sheets, development of wish lists, or “brainstorming” sessions with clients and staff members.

**Considerations for all clients:** As staff and administrators begin to recognize the effect of having a sensory friendly environment, they often begin to consider the potential for changes throughout the entire environment.

**Caution and Safety Considerations:** Many facilities require items to be fire resistant, latex-free, generally safe and washable. Research the requirements specific to your program before purchasing equipment.

**Policies and Procedures:** It is important to develop policies and procedures for the use, cleaning, and maintenance of the room and equipment.

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**Purchasing Equipment and Supplies:** There are numerous vendors listed in the resource section, although the following suggestions may help to decrease costs. If staff members think creatively, there are a number of options!

- Dollar stores
- Novelty catalogs
- Toy stores
- Hand-made items
- Donations of supplies/wish lists
- Department stores
- Science and learning stores
- Rehabilitation and sensory equipment vendors
- Garage sales

**Funding:** Grants, fundraisers, donations and organizational funding are examples of financial sources for program that want to develop a sensory room.

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## Developing a sensory room

To develop these spaces, treatment programs require training and methods for evaluation. Guidelines for development include the following (Champagne, 2003; 2006):

- **Lighting** – There are various types of lighting that can be used to create a soothing atmosphere in a room, including full-spectrum lighting, bubble lamps, colored light bulbs, projectors, and fish tanks. If there are windows in the room, blinds help modulate the amount of sunlight or outdoor distractions. Dimmer switches are helpful so that children and staff can vary the amount of light in the room.
- **Noise** – A quiet environment is best unless recorded music, musical instruments or other types of sounds (sound machine) are preferred or are part of the theme of a particular room.

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- **Distractions** – Distractions must be kept to a minimum when a room is being used for relaxation purposes. A visually rich environment that is not over stimulating or complex is optimal in the general layout of the room, and other lighting options may be added as desired. However, when distraction or stimulation is assessed to be therapeutically appropriate, there are a number of options to create a more active environment, such as mobiles, projectors, bubbles, music, instruments, bubble lamps, rock wall climbing, and the exploration of tactile objects to name a few. Many of these stimulating and distracting items will need to be put away when the room is going to be used for calming purposes, and the program must ensure that staff members continually assess the individual needs of the children in the program.
  - **Temperature** – It is important to be sure the room is a comfortable temperature at all times.
  - **Room Arrangement** – The room arrangement will vary depending upon the theme of the room. It should appear balanced and reflect the chosen theme. Furniture and equipment should be arranged based on comfort and safety and distributed evenly throughout the treatment space. Some rooms may be large enough to accommodate different stations making a variety of themes available within one room.

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- **Seating** – A variety of seating options should be available. Rocking chairs, glider rockers, a small couch, large bean bag chairs, a swivel chair, large therapy balls, and, if possible, a swing, are great seating ideas. Various seat cushions and different types of foams, such as egg crate foam, are useful items that provide different kinds of sensory input.
  - **Ventilation** – It is imperative that the room has adequate ventilation and air purifiers are always beneficial.
  - **Color** – Color has a powerful impact on mood and emotions and is an important consideration when creating environments to promote health and healing. The color choice for the room is dependent upon the theme of the room. Light to moderate color choices rather than bright and intense shades are generally more organizing for most people. Sponge or rag painting techniques are inexpensive ways to add texture to the color scheme. The use of posters and wall murals are also cost effective ways to add color and theme intensity. The following is a list of common descriptions of colors and general recommendations and precautions (Howard, 2000; Champagne, 2003b; 2006).
    - **Green** is often referred to as the universal healing color because it symbolizes nature, harmony, balance, and tranquility. It is the best choice to use in many situations and promotes healing and compassionate insight.

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- **Yellow** symbolizes wisdom, clarity, and self-esteem. It is often used to promote a healthy nervous system, to clear heads, and encourage personal power and confidence. It should be used cautiously because it may be over-stimulating for some people.
  - **Blue** symbolizes truth, serenity, harmony, peace, calm, and spirituality. It is considered to have a soothing effect, but it may also elicit feelings of depression or sorrow in some individuals.
  - **Red** symbolizes love, power, reaching goals, courage, self-confidence, and energy. It is considered to be energizing and may facilitate the activation of the adrenal glands, which can elicit feelings of anxiety, aggression, or agitation in some individuals.
  - **White** symbolizes truth, spirit, purity, faith, and perfection. It may be alerting and very unsettling to some individuals, because it often carries a sterile, institutional or authoritative association.
  - The use of projectors, lighting equipment, murals, and sunglasses with different colored lenses, bubble lamps, fish tanks, posters, colored scarves, glitter wands and colored furniture are general examples of ways to add/modify color in a sensory room.

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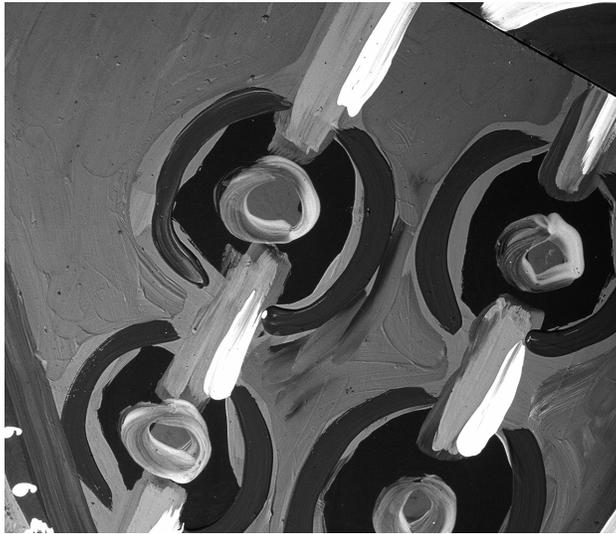
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## Promising Practices

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“ Do not follow where the path may lead, go instead where there is no path and leave a trail. ”

Ralph Waldo Emerson

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# Promising Practices

**M**any programs that have significantly reduced or eliminated the use of coercive interventions, including S/R, have embraced specific models of care that are trauma-focused, strength-based, and have an emphasis on building skills and competencies. The Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Child Traumatic Stress Network (NCTSN) have categorized treatment approaches based on rigorous standards of research and evaluation. There are also numerous treatment approaches that are being used successfully around the country and showing positive results that are not listed with SAMHSA or NCTSN. For the purpose of this *Resource Guide*, the term “promising practices” refers to treatment practices where at least some components of the practice have been shown to be effective, either through research involving control groups, or through less stringent evaluation protocols. Most of the practices listed in this chapter of the *Resource Guide* are being used by residential and hospital programs in Massachusetts, New York, and other areas.

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## SAMHSA model programs

SAMHSA defines model programs as well-implemented and well-evaluated programs that have been reviewed from National Registry of Evidenced-based Programs and Practices (NREPP) according to rigorous standards of research.

SAMHSA also recognizes Promising Programs, which are those programs that have been implemented and evaluated sufficiently and are considered scientifically feasible and have produced some positive outcomes. Below are two examples of model programs.

### Trauma-Focused Cognitive Behavioral Therapy (TF-CBT)

Cognitive-behavioral therapy emphasizes the idea that our thinking causes us to feel and to behave the way we do (NACBT, 2006). According to the model, if we are experiencing unwanted feelings and behaviors, then we need to change our way of thinking. CBT involves several essential features: identifying and correcting inaccurate thoughts associated with the problem (cognitive restructuring), helping children engage more often in enjoyable activities (behavioral activation), and enhancing their problem-solving skills.

Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) is a short-term individual treatment for children ages 4 to 18, and combines trauma sensitive interventions with CBT (NCTSN, undated). Children and parents are provided with knowledge

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and skills related to processing trauma; managing distressing thoughts, feelings, and behaviors; and enhancing safety, parenting skills, and family communication.

TF-CBT has been proven to be effective in improving PTSD, depression, anxiety, externalizing behaviors, sexualized behaviors, feelings of shame, and mistrust.

The specific approaches considered to be model and effective programs by SAMHSA are TF-CBT and CBT for Child Sexual Abuse (CBT- CSA).

## Multisystemic Therapy (MST)

MST is an evidenced-based practice for children ages 12 to 17 who have a history of violence or substance abuse (SAMHSA, undated). At the core of MST is the belief that family strengthening is key in promoting positive social behavior and helping children make better connections to other environmental supports (e.g., peers, neighborhoods, schools). MST aims to address risk factors in an individualized, comprehensive, and integrated manner. Its primary goals are to reduce antisocial behavior, to improve functioning, to decrease the number of out-of-home placements, and to empower families. It has been proven to have positive results on serious, violent, and chronic juvenile offenders (MST Services, 1998).

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## National Child Traumatic Stress Network (NCTSN) promising practices

The NCTSN incorporates trauma-informed approaches in their treatment programs to reduce the impact of exposure to traumatic events on children and adolescents. NCTSN assigns a level of evidence for each service approach that ranges from “novel and experimental” to “supported and acceptable,” but these levels are subject to change as the approaches are further refined and implemented. Below are NCTSN examples of promising practices.

### Attachment, Self Regulation, and Competency (ARC)

The goal of ARC is to provide a guiding clinical framework to address symptoms of complex trauma in children and adolescents (please refer to the *Trauma-Informed Care* section of the *Resource Guide* for more information on complex trauma). The ARC approach is built around three core domains affected by trauma: attachment, self-regulation, and competency (Kinniburgh & Blaustein, 2005; NCTSN, undated). Treatment goals are identified for each of these domains and the framework includes a menu of suggested interventions. The ARC framework also recognizes that each child brings unique attributes, exposure history, context, and presentation to their treatment, and it encourages clinicians to modify the suggested interventions as necessary to meet the needs of their clients.

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## Sanctuary Model

Sandra Bloom, M.D., created the Sanctuary Model. It was originally developed for adult treatment programs, but has been adapted for use with children. It is a trauma-informed method, where the goal of the treatment is to restore hope, meaning, and purpose in the lives of people who have experienced trauma (Bloom, 2005). It reaches the treatment goal by focusing on creating a democratic, non-violent community environment for the client with an emphasis on affect management, safety, positive social connections, and skill building.

## Trauma Systems Therapy (TST)

Glenn Saxe, M.D., and his team at Boston Medical Center developed TST based on the child development concepts of attachment, identity, and emotional and cognitive development. TST is a community-based program that includes the child's family, school, and neighborhood to help children and adolescents who have difficulty regulating their emotions (NCTSN, undated).

The program has up to five phases, including surviving, stabilizing, enduring, understanding, and transcending (Saxe, Ellis & Kaplow, 2006). The child's treatment phase depends on the degree to which he/she can regulate his/her emotional responses and the stability of his/her social

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environment. There are prescribed treatment modules within each phase, many of which have their own demonstrated efficacy, such as Dialectical Behavioral Therapy (DBT).

For a complete list of SAMHSA and NCTSN of model programs/promising practices, please go to:

[www.modelprograms.samhsa.gov](http://www.modelprograms.samhsa.gov)

and

[http://www.nctsn.org/nccts/nav.do?pid=ctr\\_top\\_trmnt\\_prom](http://www.nctsn.org/nccts/nav.do?pid=ctr_top_trmnt_prom)

## Other promising treatment approaches

### **Applied Behavioral Analysis (ABA)**

Behavioral analysis techniques used by the famous psychologist B.F. Skinner were expanded upon to create ABA. The goal of ABA is to create a structured environment where children and adolescents with developmental disorders acquire the same skills that other children learn naturally (Saffran, 2006). Ivor Lovaas, Ph.D. developed discrete trial training (DT), which is an intervention based on a series of table-top drills focusing on a particular skill-set that is repeated until the child masters it and can apply it in a variety of settings (Lovaas, 1987). In this technique, the child is given a stimulus as well as hints at what the responses should be.

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The following is a child's interaction with a teacher who is being as helpful as possible **without** ABA training:

Teacher: Are you excited about Thanksgiving?  
*Sam:* [no response]  
Teacher: Are you going to eat turkey?  
*Sam:* Yes.  
Teacher: What else are you going to eat?  
*Sam:* I don't know.  
Teacher: Will you eat pumpkin pie?  
*Sam:* Yes.  
Teacher: Thanks, Sam!

Here is how an **ABA-trained person** might make this an opportunity for practicing conversation skills:

Teacher: Hi, Sam, are you excited about Thanksgiving?  
*Sam:* [no response]  
Teacher: Are you excited about Thanksgiving? Say, "Yeah, I can't wait to eat..."  
*Sam:* Yeah, I can't wait to eat turkey!  
Teacher: What else will you do on that day?  
*Sam:* I don't know.  
Teacher: What else will you do on that day? Say, "On Thanksgiving I'm going to watch..."  
*Sam:* I'm going to watch the parade. On Thanksgiving.

## Boys Town Psychoeducation Treatment Model

The Boys Town psychoeducation treatment model (PEM<sup>®</sup>) is a nationally recognized model of care to treat youths with

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psychiatric and related behavioral disorders. It is a systems-based approach where adults teach social skills and give positive discipline. The curriculum includes training in the following areas: accepting and giving compliments, greeting others, making introductions, engaging in conversation, accepting criticism, resisting peer pressure, and following instructions. The PEM curriculum also provides a framework for the treatment environment to teach children to better manage their behavior and to cope calmly and consistently with crises (Furst et al., 1994).

## **Collaborative Problem-Solving (CPS)**

Ross Greene, Ph.D., a Boston-based child psychologist, developed a specific collaborative approach, called CPS, to teach problem-solving skills to children and adolescents (Greene & Ablon, 2005). It emphasizes the need for a comprehensive assessment and understanding of the specific factors underlying each child's oppositional behavior. CPS articulates common pathways to oppositional behaviors including:

- executive skill deficits,
- emotion regulation difficulties,
- language processing deficits,
- social skill deficits,
- cognitive rigidity,
- and sensory and motor difficulties.

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Using the pathways as a guide, in the CPS model, families and staff members learn to view oppositional behavior as the byproduct of difficulties in the areas of frustration tolerance, problem-solving, and flexibility. This helps staff respond to oppositional behavior in a more empathic manner, and recognize the necessity for a specialized approach to intervention.

Many parents and treatment programs have adapted components of Dr. Greene's CPS. A popular adaptation guides parents and staff in how to respond to behaviors before the incidents occur and suggests that they categorize the behavior into one of three plans before responding:

- Plan A:** A safety situation that requires imposing adult will
- Plan B:** An opportunity to use a CPS approach
- Plan C:** A situation where it is best to ignore the behavior, because it is not worth getting into a power struggle

Plan B is the preferred response approach in many situations, because it allows a parent or staff member to gain an understanding of what is driving a particular child's oppositional behavior, and work with that child to solve the problem at hand. By repeating these interactions over time, children develop their own tolerance for difficult situations and enhance their ability to solve problems by themselves. Parents and programs have found that when adults use this collaborative and respectful

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approach, they are often able to diffuse potential power struggles and help children practice thinking skills.

## **Dialectical Behavioral Therapy (DBT)**

DBT is a cognitive-behavioral therapy that was developed by Marsha Linehan, Ph.D. (1993) to treat individuals with Borderline Personality Disorder. DBT is based on the proposition that the core problem for the individuals with “borderline personality patterns” is that they lack coping skills to manage feelings, thoughts, and behaviors effectively.

Without such emotional regulation skills, these individuals are particularly vulnerable to what are described as “invalidating environment.” Invalidating environment are those that:

- do not value the individual’s behavior,
- inconsistently punish and ignore emotional expression,
- oversimplify how difficult it is for the person to cope and change, and
- treat the person as a threat to the system and teach the individual not to disclose his/her needs.

Families and residential support environments may be unintentionally invalidating and further perpetuating the individual’s problems, thus making it very difficult for the individual to learn new skills using a DBT framework. It is important for programs to assess how their practices may be invalidating and strive to make necessary changes.

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Some DBT concepts that are particularly important for support providers to integrate into a program include:

- Individuals accept themselves as they are to move towards changing.
- DBT is based on the idea that individuals are doing the best they can, given their experiences and skill deficits in each situation. This mindset is critical, because it creates a non-judgmental and accepting environment for the individual.
- Teams need to continually improve their abilities and increase motivation to effectively support individuals.

## Grotberg Resiliency Model

Edith Grotberg, Ph.D., a national leader in the field of developmental psychology and child resilience, examined the factors that enable children to overcome adversities. In her publication, *A Guide to Promoting Resilience in Children: Strengthening the Human Spirit*, resilience is a basic human capacity present in all children, but adults must teach them how to communicate with others, solve problems, and successfully handle negative thoughts, feelings, and behaviors (Grotberg, 1995). Dr. Grotberg grouped the factors into a paradigm of resilience consisting of three components:

1. **I have:** Names the source of support around each child. For example “I have people around me I trust and who love me, no matter what.”

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2. **I am:** Encourages self esteem and responsibility. For example, “I am respectful of myself and others.”
  3. **I can:** Fosters the acquisition of interpersonal and problem-solving skills. For example, “ I can control myself when I feel like doing something not right or dangerous.”

By encouraging children to think of and act on their competencies, parents and staff members create an environment where the children can build on their natural strengths and promote resilience through their words and actions.

## **Positive Behavioral Support (PBS)**

PBS, sometimes called Positive Behavioral Interventions and Support (PBIS), is an empirically validated, function-based approach to decrease challenging behaviors in children and adolescents and replace them with prosocial skills (Cohn, 2001). It is often used in school settings, and it was developed because traditional methods for addressing serious behavior problems were often focused on consequences and were ineffective in helping children change their behavior. It is an approach that blends values about the rights of children with disabilities with a practical science about how learning and behavior change occur (RRTC, undated).

The most important part of devising PBS plans is conducting a Functional Behavioral Assessment (FBA), which gives

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information about the antecedents, consequences, and frequency of problematic behavior. PBS plans are individualized and data-based, and they include procedures for monitoring, evaluating, and reassessing the process. A PBS strategy may be as simple as changing where a child is sitting in a classroom to help him/her pay attention in class and complete more written work. PBS is most effective when it is a collaborative effort among parents, school psychologists, teachers, counselors, administrators, and peers.

## **Risking Connections**

*Risking Connections* is a training curriculum along with specific interventions for working with survivors of childhood abuse, which was created as a joint venture from the Sidran Traumatic Stress Institute, the Trauma, Research, Education and Training Institute (TREATI), and the Departments of Mental Health in Maine and New York (Saakvitne, Gamble, Pearlman and Lev, 2000). It is designed for staff members of all disciplines, and it may be used in a variety of treatment settings.

The curriculum helps staff members understand that most survivors of abuse need the support of interpersonal connections to resume meaning and wholeness to their lives. It recognizes that taking steps to form these connections can be very challenging for survivors who have been betrayed in relationships.

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The curriculum consists of five parts, including:

- Understanding Trauma
- Learning to use connections to develop treatment goals with clients
- Learning to keep a trauma framework when responding to crises and life-threatening behaviors
- Learning to help clients with dissociation and flashbacks
- Learning to understand and manage symptoms of vicarious traumatization

## Seeking Safety

Seeking Safety is a present-focused therapy developed by Lisa Najavits, Ph.D. (Seeking Safety, undated). It is a treatment approach for adults and adolescents with co-occurring substance abuse disorders and trauma. The treatment is designed for flexible use in a variety of inpatient and outpatient settings. Seeking Safety encourages the development of coping skills focused on behavior, thinking, and relationships and encompasses twenty five skill areas including: compassion, asking for help, boundary-setting in relationships, grounding, and self care.

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## Sensorimotor Psychotherapy

Sensorimotor Psychotherapy, developed by Pat Ogden, MA, is a method that integrates sensorimotor processing with cognitive and emotional processing in the treatment of trauma. Unassimilated somatic responses evoked in trauma involving both arousal and defensive responses are shown to contribute to many PTSD symptoms, and these symptoms can be directly addressed in Sensorimotor Psychotherapy.

By using the body (rather than cognition or emotion) as a primary entry point in processing trauma, this treatment directly treats the effects of trauma on the body, which in turn facilitates emotional and cognitive processing. This method is especially beneficial for individuals who suffer from dissociation, emotional reactivity or flat affect, frozen states, hyperarousal and other PTSD symptoms (Ogden & Minton, 2000). Although this method has been primarily used in outpatient programs, it would naturally “fit” with the sensory approaches currently being used in inpatient and intensive residential treatment settings across Massachusetts and should be considered a promising practice.

## Teaching Family

The Teaching Family approach was one of the first researched models in the country for use in residential programs that promoted a positive focus and attention to skill building (Bedlington et al., 1988). It has also been successfully adapted to hospital programs (Furst et al., 1994). It ensures that every

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aspect of the organization is focused on supporting the child for who he/she is as a whole and individual person and not focused primarily or solely on his/her problem areas. Any focus on problem or areas of need within a strength-based approach is based on helping the child and family build new skills and learn new approaches to experience more success, based on the individual histories and physiological make-up of each child.

Please see the *Strength-Based Treatment* chapter of the *Resource Guide* for more information on strength-based treatment approaches.

## Future vision

For any model to be successful, it is important that key administrative supports accompany the implementation process through training, supervision, and evaluation. These supports should continue beyond implementation to ensure model fidelity.

The treatment models and approaches described in this chapter all focus on resilience, strengths, and increasing competencies, but are not intended to be a comprehensive review. The *Resource Guide* will be updated in the future to include additional and evolving promising practices.

It is important to remember that specific treatment models may work very well for some children and not at all for others. When programs embrace specific models of care, they may have to

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make exceptions and modifications for children whose needs are different.

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## **Experts Share**

**The Children of Everett House**

**The Adolescents of the UMass  
Adolescent Continuing Care Units**

**Julie Heuberger, LICSW**

**Annabelle Lim, MPH**

**Colleen Reed**

**Hannah Williams**

“ Listen, listen, and listen some more and when I feel heard, I will begin to heal. ”

A thoughtful adolescent  
at the UMass Adolescent  
Continuing Care Units

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# Experts Share

In 2001, DMH undertook an initiative to promote strength-based care and reduce the use of S/R in licensed and contracted child and adolescent hospitals, Clinically Intensive Residential Treatment programs (CIRT's), Behavioral Intensive Residential Treatment programs (BIRT's), and Intensive Residential Treatment programs (IRTP's), as described in more detail in the *Overview* section of the *Resource Guide*.

As part of the process of creating the first edition of the *Resource Guide*, children and adolescents shared their thoughts about S/R and their ideas about how programs can further reduce their use of S/R in the future. In the second edition, the focus was expanded to people of all ages and families who were asked about their experiences in treatment programs and recovery.

Information included in this chapter came from direct interviews and materials that were provided for this project. Several adult experiences were taken from publicized accounts of people who have been involved in the mental health system.

A number of narratives are from people who participated in interviews or provided written accounts and explicitly gave permission to print their work for this *Resource Guide*. We are very grateful for all of these important contributions.

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Former Residents of a  
Clinically Intensive Residential  
Treatment Program (CIRT)  
Children ages 5-13

Thoughts offered during interviews

**Andrew, age 11: “I used to beat up staff. Maybe they wanted to cry inside, too.”**

Andrew reported that staff members often restrained him when he was first admitted to the program. He stated, “I used to beat up staff. Maybe they wanted to cry inside, too.” Andrew said that restraints were not helpful for him, but he was able to identify a number of calming strategies that he now uses to avoid using aggressive behavior. He listed calling his mother on the telephone, using the quiet room, listening to music, and using the swing in the sensory room as important settling strategies.

**Robbie, age 12: “I’m the one that goes to the hospital.”**

Robbie said that he had been in treatment at the CIRT program for over two years. He stated, “I’m the one that goes to the hospital.” Robbie said that he used to be restrained “a lot” by staff, but now it does not happen as often. He said that restraints are not helpful for him, and he listed a number of things that he tries to do when he is feeling upset, including

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playing with toys, playing basketball, using the swings in the sensory room or outside, and playing catch with staff.

Robbie said that staff members remind him to use those settling strategies that are helpful for him. He made a number of suggestions of things he thinks the program needs to do to help kids, such as building a track and a swimming pool, because he enjoys physical activities.

University of Massachusetts,  
Adolescent Continuing Care Units  
Westborough State Hospital,  
Westborough, MA  
Adolescents ages 13-18

The adolescents at the UMass Adolescent Continuing Care Units shared their thoughts in several different ways. Two adolescents wrote down their ideas; a number of adolescents talked with program staff, who wrote down their comments; and, finally, several adolescents agreed to participate in interviews about their experiences with S/R.

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## Written thoughts

**Jeff, age 19: “As time goes by, the stronger I am.”**

“As time passes by I see all the pain  
As time passes by I see all the rain  
As time passes by I wish I was home  
As time passes by I grow older  
As time goes by time kills  
As time goes by the more I sing  
As time goes by the stronger I am.”

**Kim, age 18: “... all we need to do is work as a team and think outside the box.”**

“Restraint prevention is a very important thing that needs to happen in all hospitals. Restraints are painful and degrading. By putting a kid that has already been traumatized into a restraint is mortifying. There is a way around restraints; you have to think outside the box. Some things work well for one kid, but can be more damaging for another. To avoid restraints everyone needs to feel safe. For example: a sensory room, that is sound proofed, has sensory things, and relaxation equipment. I know in my times of suffering, being in the coat was a way to punish myself, but once that placement got a sensory room, that everyone took part in making, I found that I was restrained less. I also think that instead of giving treats after a certain amount of time restraint free, we should take all the kids that have been safe for one month or more and pick a

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place to go and enjoy the road to recovery. Most kids who have a hard time will see those who get the reward and will try harder. We should, as kids, start a group around restraint prevention. Like I said before, all we need to do is work as a team and think outside the box.”

## Thoughts offered to staff

Adolescents at UMass said the following to staff members on their units:

"Talk to me about my strengths"

"Ask us about our assets"

"We are ramping up our resilience"

"We are positive problem-solvers"

"Get to know all about me, not just my mental illness"

"I am so much more than a patient, I am a son/daughter, friend, relative and a youth in your community"

"We are restraint -free youth"

"Trauma can happen to anyone"

"The relationship I had with the staff person was what helped me the most"

"I have a positive future vision, please don't let stigma get in my way"

"Listen, listen, and listen some more, and when I feel heard, I will begin to heal"

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## Thoughts offered during interviews

Eight adolescents agreed to participate in interviews for the *Resource Guide*. They were all excited by the idea of having their thoughts printed in a book to help staff members reduce the use of S/R in treatment programs serving children and adolescents.

**Tristan, age 15: “Restraints are no fun. You have to be held down on your hands and legs. You can’t even move. It’s very frustrating.”**

Tristan reported that staff members usually restrain him for hitting people and throwing things at people. He stated, “I get frustrated when things don’t go my way and I flip out.” Tristan said that staff members do not restrain him nearly as often as they did in the past. He cited several coping skills he uses, including talking, playing basketball, doing physical exercises in his bedroom, talking to his mother on the telephone, and listening to music.

Tristan said that he thought some staff members use the safety coat too quickly, without waiting to see if he was starting to calm down. He stated, “Staff should look for safe behavior.” Tristan went on to say, “Restraints are no fun. You have to be held down on your hands and legs. You can’t even move. It’s very frustrating.”

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Tristan likes some of the items in the program sensory cart, and he said that he uses *Game Boys*, jump ropes, and stress balls. He also uses outdoor time with staff members “to shoot hoops.” He said that physical activity helps him calm down, and there are usually staff members available to take him outside to engage in an activity when he feels he needs it.

**Brianna, age 13: “They think the chart knows everything. No one knows everything unless you tell them.”**

Brianna said that she has been in the program for over a year. She stated, “I was restrained all the time when I came.” Her suggestions for staff members to help prevent the use of restraints were: “Don’t argue with us like we are little kids;” and “Don’t talk to us like we are little kids.” She added, “Some staff want to get the last word in.” Brianna said kids often say “*forget it*” to staff members and walk away. She pointed out that means they do not want to talk anymore, and staff members should respect what they say or when they don’t want to talk.

Brianna believes that when staff members do not speak English well, it contributes to misunderstandings. She stated, “They get offended.” She also said that there are staff members who assume that they know kids because they have read their clinical records. She stated, “They think the chart knows everything. No one knows everything unless you tell them.”

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Brianna said, “Everyone here has their own problems. Some kids hit people and staff intervene quicker. They were worried about that when I first got here, but I haven’t hit anyone here.” Brianna said that she was physically assaultive at other hospitals and at DYS when she was there. She said she was restrained with handcuffs at DYS and locked in her bedroom until she calmed down. Brianna believes that the incentives in her current program, such as going home on overnights, help motivate kids to do well. She also said that trips to the hospital vending machines, the social center, and recreational trips every Sunday are good motivators, too.

**Tiesha, age 16: “In the past, I never thought about the future.”**

Tiesha reported that she was being discharged to a less restrictive program the following day, although she had been restrained by staff the previous day. She indicated that a peer was teasing and threatening her, and she “went after her.” Tiesha was able to calm down with staff assistance and this ended the physical restraint quickly. She said that a staff member asked her if her favorite stuffed animal, a large tiger, would help her calm during the restraint. Tiesha said yes, and the staff member put the tiger on her back at her request. Tiesha felt that, with the comfort of her stuffed animal, she was able to allow staff members to help her calm. They asked her to take slow, deep breaths, which she did.

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Tiesha said that staff members also helped her by reminding her that she was leaving the next day, and they told her that they knew she did not want to hurt anyone and say goodbye in a sad or negative way.

Tiesha said that she was able to think about her future during the restraint and to remember that she always feels bad after she hurts someone. She stated, "In the past, I never thought about the future."

**Liz, age 16: "A few staff like to have the last word. That doesn't help things."**

Liz said that she had been in the program for three years. She immediately stated, "This no restraint thing... it's chaotic. Kids are flipping out and getting away with so much, like punching walls and swinging at staff. Three years ago you would go into the safety coat for anything or be in the quiet room permanently." Liz went on to say, "If I had keys, I would not put up with punching walls and threatening. Kids would go to the quiet room." She said that she believes the correct approach is a balance between the old way and the new way.

I asked Liz if she had suggestions for staff members to decrease their use of restraints. She stated, "Some staff do not know when to back off. It pisses me off. A few staff like to have the last word. That doesn't help things."

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Liz's coping skills include listening to music, playing with a hackey sack, and being outside and "just walking." She also said she has an incentive plan that helps her stay in control. She earns CDs and other items that she enjoys if she maintains safety for a period of time. She stated, "That's cool. It is something to look forward to."

Liz said she believes the program should make changes to their level system. She said that kids are penalized for not attending groups and that it is impossible to move up the level system if you don't go to almost all of your groups. She stated, "They should base levels more on safety than on groups. Sometimes isolating helps." Liz was in favor of being permitted to skip a group every day as a privilege for higher levels. She also suggested that staff members should provide kids with more activities to do in their rooms during quiet time. She stated, "Lots of kids can't stand being in their rooms during quiet time," and she said that she believes that kids get into more trouble during quiet time.

**Julisa, age 17: "Kids get into trouble when they're bored. You start thinking about stuff and get anxious."**

Julisa believes that staff would not use restraints if there were more activities at the program. She stated, "Kids get into trouble when they're bored. You start thinking about stuff and get anxious." Julisa wishes for more outdoor time, even in the winter. She stated, "It helps me calm down." She also said that she believes there are not enough activities during the evening

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shift or on the weekends. She stated, “We need more structure on the weekends.”

Julisa complained that when peers “flip out,” they get “too much attention” from staff members. She stated, “They don’t need seven staff members with them. It’s hard for the other kids with all of the staff gone.” Julisa went on to say, “When other kids are getting restrained, we need staff the most and they are not available.”

Julisa talked about her last restraint. She stated, “I lost my level and flipped out.” She added that kids typically lose their levels for unsafe behavior. She stated, “Staff got close and I kicked them.” She acknowledged that staff members probably needed to put hands on her to help her stop kicking. Julisa said that staff members helped her settle down by talking to her and encouraging her to take deep breaths.

**Andrea, age 16: “Mostly staff do not know what it’s like to be in and out of hospitals since you were nine. If you want to help, just listen.”**

Andrea stated, “I’ve been in a lot of restraints since I was ten.” She said that staff used the safety coat several times when she first arrived at the program because she was hitting people. Andrea said she has been restrained the least at her current program. She stated, “The older I get, the worse it is for my chart.” She proudly reported that she had not been restrained by staff for almost four months. Andrea said that she has an

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individualized incentive plan that is helpful for her. She earns points for safe behavior and school attendance and cashes in the points for special prizes. She stated, “My main goal was to not be restrained by staff, but I started small by not assaulting people.” Andrea stated, “Now my goal is about gaining hope. I am hopeful that I can do better than I used to.”

Andrea said she still feels “aggravated” and swears at people, but she emphasized, “no restraints.” She stated, “People in restraints need hope that they can do better.”

Andrea believes that staff members can make changes to decrease their use of restraints. She stated, “They should not get agitated as fast as they do. They should LISTEN. They should see things from our point of view.” She added, “Mostly staff do not know what it’s like to be in and out of hospitals since you were nine. If you want to help, just listen.”

Andrea said that she believes staff members should use some of the techniques themselves that they encourage adolescents to use, such as deep breathing and meditation. She stated, “They should listen and understand.” She added, “They should be strict but helpful. If they are too strict, kids get frustrated.”

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**Kelly, age 16: “Usually if they (kids) get restrained, staff have tried everything first.”**

**Alison, age 14: “Staff members say helpful things to kids to help them remain in control.”**

Kelly and Alison are friends and asked to be interviewed together.

Kelly said that staff restrained her frequently during her first few months at the program. She proudly reported that she had not been restrained in “one month and one day.” She said that she has been restrained less by staff because, “I got sick and tired of it.” She did not have suggestions for staff members to help reduce restraints. She stated, “I would have kept hurting myself if staff did not stop me.” She went on to say, “Usually if [kids] get restrained, staff have tried everything first.”

Kelly said that she has an incentive plan to help her, and she explained that incentive plans are special plans for kids who are having a hard time. She stated, “You earn prizes like food, CDs, magazines. It keeps you motivated.”

Alison said that she has an incentive plan too, which she thought was helpful. She and Kelly said that they worked with staff at the program to develop the plans and the rewards.

Alison reported, “Staff members say helpful things to kids to help them remain in control.” She said that they frame these statements positively, such as saying, “Don’t forget about the pass you have with your mother tomorrow. You are going to

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have so much fun together,” instead of something negative and threatening, like, “you better behave or you’ll lose your pass.”

Kelly and Alison said that staff members play lots of games with kids in the program, which they believe is good. Alison stated, “It distracts us and gives us other things to focus on.” They talked about a program contest, where the entire unit earns a special prize, such as a pizza party or an ice cream party, when everyone is safe. Kelly and Alison also talked about a special weekend activity that all kids are permitted to participate in, no matter what level they are on. Staff members purchase a special snack for everyone, and all kids and staff members watch a movie together.

Kelly and Alison gave their ideas about important questions to ask staff members who are being interviewed to work at the program, such as:

“How will you take it when kids get restrained?”

“Will you get offended?”

“Are you good with kids?”

“Can you handle anything?”

“Can you handle the stress?”

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Transition Age Youth & Young Adults  
(TAY)  
Ages 16-25

The TAY Initiative at the Massachusetts Department of Mental Health was established to help young persons embark on a positive life path into adulthood toward the goals of obtaining personal stability, community housing, employment, and positive family/social relationships. One young adult involved with the TAY initiative shared her thoughts and recovery experiences in an essay included below.

**Hannah, age 23:**

“To write this essay on my experience with restraint and seclusion is an honor. What I am about to tell you is a true story on what I went through with restraints and seclusion.

When I used to be in the hospital, I had out-of-control behavior that usually led to restraints. During my restraints, I did a lot of struggling when they were holding me down to get me into the restraint bed and to give me a shot so I could calm down, but being in restraints at the same time did not help.

I was in my teenage years when I was first restrained. I was angry at the time but being put in restraints made it worse. I felt bad when my peers were restrained or secluded.

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Things that would help me avoid restraint and seclusion:  
When I was having a difficult time I would rock, listen to music, write in my journal, talk to staff or I would go to the sensory room. Those were the coping skills that helped me at that point and still help me today. I also used to calm down using a blanket wrap. When I used the sensory room, the main tools I used were the sound machine and the rocking chair. For me, rocking helped a lot. My social worker introduced rocking to me. She had me sit on the edge of the bed or on a mattress on the floor, I crossed my arms and just rocked. For awhile when I used to see people rocking, it scared me. But when I did it myself, it helped. I would rock until I calmed down.

The advice I give to children and transition-age clients is to use your coping strategies and if you are in the hospital, do what staff tells you to do. It keeps you out of trouble (restraint/seclusion-wise). It helps you with your goals to get discharged sooner than you think. Stay safe - hurting yourself only keeps you in the hospital longer.

Thank you for letting me share my experience with restraints and seclusion.”

## Adults

### **A Story of Survival, Courage, and Transformation— Anonymous**

“I am a survivor, and I would like to share my story. At the age of 30 years, I had a major schizoaffective breakdown.

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Unfortunately, I was hospitalized, and given a long series of electroconvulsive shock treatments. The odds were against my survival. I had no home and no job. I had a four-year-old son to care for, a husband who had left me, and I was still very ill. I don't know to this day why I didn't just go on welfare, or move in with my parents, but the thought just didn't occur to me. I got a job a thousand miles away, moved, and I supported myself and my son with no assistance. Most of the time I felt terrible, but slowly, very slowly, I started to get better. It took me about ten years before I actually felt well again, but I did improve.

I am 55 years old now. My son has grown into a successful man, I have remarried, and I continue to teach school. I still take some medication, but I stay far away from psychiatrists.

I have survived! And not only have I survived, I have grown and developed strengths as a person throughout the ordeal. In fact, I never returned to the person I was prior to the breakdown. Instead I became a stronger, mentally healthier person. I have reached a level of development that I never would have attained without the experience of the illness. I feel blessed!

I believe that there are many factors that have enabled me to successfully survive my illness:

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1. The love I had for my young son kept me going. His father had little interest in him, and I was all that he had. I had the choice of either killing both of us (which I considered), or to keep on going no matter what. I couldn't justify killing my little boy, so I had to keep trying to get better.
  2. I read a book about a survivor of a Nazi concentration camp. In the book, the author explained why he had survived whereas others had not. He explained that a person can not always control the circumstances of life, but a person can control the attitude with which the circumstances are met. Because of what I learned from this author, I chose to regard my condition as a challenge rather than a disability. That made a big difference.
  3. I had a lot of personal resources. Because of the late onset of my illness, I had a personality that was already formed; I had a good education and the means of supporting myself. Also, I was blessed with above average intelligence and insight.
  4. I learned early not to believe everything that a psychiatrist said, and instead, to keep myself informed, and to make my own decisions." (Successful Schizophrenia, 2003)

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## **Laura Prescott**

Laura Prescott is the Executive Director and Founder of Sister Witness International. She described herself as a recovering addict, psychiatric ex-patient, and survivor of childhood abuse. Her comments were taken from her keynote address given at the International Society of Psychiatric Mental Health Nurses convention in April 2000 (Prescott, 2000).

Ms. Prescott speaks and writes about her own experiences in psychiatric hospitals. On the topic of restraint, she stated:

“Rather than deterring anything, these episodes perpetuated a vicious cycle. The more I was restrained, the more humiliation I felt. The more shame and humiliation I felt, the more I dissociated, self-injured, and was restrained. This level of containment is not only traumatizing, but it is also a costly proposition. Research shows a correlation between the use of restraints and increased length of stay in a facility (Philips & Nasr, 1983). This disruption to the milieu could have been avoided had people been willing to take some risks well in advance, assisting expression and witnessing pain.”

Ms. Prescott went on to say: “Violence only teaches violence and indifference; it never teaches kindness and compassion. It is the antithesis of healing and true recovery. I believe that recovery is only possible in the absence of attack, force, and coercion, that health happens when the greatest dignity and respect is afforded to each human life.” (Prescott, 1998)

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## An Elder recounts her experiences in treatment

Dorothea Buck is a ninety year old woman who has written and spoken about her experiences in five different psychiatric hospitals in Germany between 1936 and 1959. Her experiences, and those of other patients who were considered to have psychoses, included having buckets of cold water poured over her head, sitting in long-duration baths in a tub covered in canvas with her neck fixed in a high, stiff collar, and being wrapped tightly in cold wet sheet packs where she could not move at all. Ms. Buck was one of many psychiatric patients who was sterilized during a time period when many treatment providers believed that hereditary carriers of “social inferiority” should be excluded from procreating. At the time, patients were told that the sterilization surgery was an appendectomy. Ms. Buck learned that she had been sterilized from another patient, after the operation had already occurred.

In her key-note speech at the World Psychiatric Congress in Dresden, Germany (June, 2007, Ms. Buck reported that what she calls “decades of backwardness of this kind of psychiatry” still influences practices today. She stated, “It remains devoid of conversation and uses medication also under coercion and restraints, only fighting the symptoms, instead of understanding.”

Ms. Buck also stated: “Many people are afraid of psychiatric institutions with their forced medication and complete lack of help to understand either the psychosis or the self. From their

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very first contact with a patient onwards, psychiatrists should prove themselves to be helpers and not opponents. My wish would be that the patients could, right from the start, present their disturbing experiences in group sessions, that they could talk about them, write about them, paint and draw them. That they would be taken seriously with their experiences, without needing to fear unwanted psychiatric interventions. During this process it would be very valuable to have the aid of those who have experienced psychoses and have overcome them and have understood their meaning for their lives and have been able to integrate them into their normal lives.” (Buck, 2007)

## Families

Ms. Colleen Reed, a parent of a child diagnosed with a mental illness, presented at the Massachusetts Department of Mental Health's 6th annual Provider Forum on Restraint/Seclusion Prevention. The theme of the forum was on "Consumer & Family Partnerships," and Ms. Reed spoke about the importance of collaborating and including families with all aspects of a child/youth's/young adult's mental health treatment and care. The following are excerpts from her presentation at the May 3, 2007 Provider Forum.

“For the most part, I think providers grossly underestimate the shock, strain, and apprehension parents experience when first immersed into a psychiatric setting for their child. Moreover, I think they are also less than mindful of the of the internal conflict parents experience about relinquishing control and

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entrusting the care of their ill child to what—at the time—are essentially ‘professional strangers.’ Given that, establishing trust with the parents at the outset of treatment should be a priority for providers. I see it as paramount. Ultimately, it sets a solid foundation for treatment to begin. From my experience, it cannot move forward without it.”

“Today we live in an “on-demand” society. When we want something, we want it NOW. Moreover, we have come to expect concrete solutions to problems. If something is broken, we want it fixed. Completely. In short, our expectations are high. Given that mindset, it’s natural for parents to expect their child to recover from mental illness. Quickly. And completely. But unfortunately, mental health is not available on-demand, and it appears to have total disregard for parental expectations. As painful as it was, I had to learn that my child’s recovery was not going to be six weeks long. I had to understand that it was not going to be over in four months. I had to accept that my child’s recovery time would not end in one year. Rather, I had to come to terms with the fact that my child’s recovery would be a process, not an end result. A continually evolving process. This was a turning point for me during my child’s treatment. Considering that, I think one of the most important things providers can do during the course of treatment is to help parents adjust their expectations. Help them to understand that mental illness is different than other medical conditions.”

“I think parents have a tendency to put off living during treatment when their child is struggling so. Instead, they wait for the difficulty to pass, and for that elusive guest named

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“Better” to arrive. Providers should strive to help parents accept that the situation “is what it is,” so they can learn to incorporate it into their lives, and learn to manage living with it, rather than waiting for the opportunity to live without it.”

“Parents are hard-wired to respond to a child’s needs. When they are hungry, we feed them. When they are sad, we want to make them happy. And when they are in pain, we want to comfort them and make it go away. Naturally, when they are struggling with a mental illness, we want to make it all better. But sadly, we can’t. As providers, one of the greatest things you can do is to help parents understand that they cannot make their child well. That instead, the child needs to do the work, not the parent. Quite simply, a shift needs to take place, and providers can help make it happen. To start, help them come to terms with the fact that it is not their battle. Help them understand that they can support their child, advocate for them, comfort them, and be there for them, but that they can’t do the work. But achieving this shift requires delicate balance. It is not about shutting the parent out, or abandoning the child, instead it’s about changing their role. More than anything else, this was by far the most significant turning point in our course of treatment, and as my child continues to recover and mature, it continues to be so today.”

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## The International Consumer Perspective: The Declaration of Dresden Against Coerced Psychiatric Treatment

June 7, 2007

“... The World Health Organization and European Commission have [also] stated the need for the development of new non-stigmatizing and self-help approaches for people in emotional distress. Organizations of people who have experienced psychiatric treatment have taken the lead in developing self-help programs that are based on quality and choice, rather than on coercion, and have been successful in helping people lead integrated lives in the community. We know that healing can only occur when people are respected as humans with free will and when there are alternatives beyond psychiatry which are based on ethical approaches, which see the whole person, and which support recovery, while force makes recovery impossible...”

*Signed by:*

European Network of (ex-)Users and Survivors of Psychiatry  
(ENUSP)

World Network of Users and Survivors of Psychiatry (WNUSP)

MindFreedom International (MFI)

Bundesverband Psychiatrie-Erfahrener (BPE)

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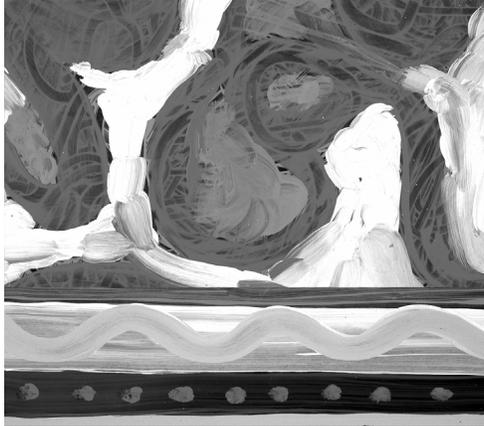
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# The Legal Perspective

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“ The welfare of the people is the  
ultimate law. ”

Cicero

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# **LEGAL LIMITATIONS ON THE USE OF RESTRAINT AND SECLUSION ON CHILDREN AND ADOLESCENTS IN TREATMENT SETTINGS AND RESOURCES TO SUPPORT THEIR CARE**

Robert Fleischner, Kathryn  
Rucker, and Susan Stefan

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## OVERVIEW OF FEDERAL AND STATE REGULATORY LIMITATIONS ON THE USE OF RESTRAINT AND SECLUSION

**S**ince different kinds of children's facilities and programs are subject to different requirements, it is important to know which rules apply. In fact, some programs may be subject to more than one set of rules (or to both rules and accreditation requirements) and the requirements of each may differ.

### CONSTITUTIONAL RIGHT

**Involuntarily committed children, adolescents, and adults have a federal constitutional right to be free from unreasonable bodily restraint and from the use of excessive force in state facilities.** They also have a right to safety, which may be implicated by dangerous restraint procedures, including airway obstruction, basket-holds, or prolonged pressure on the torso during takedowns. In addition, involuntarily committed individuals have a right to minimally adequate treatment that will help them be free from unreasonable bodily restraint.

The constitutional standard used in determining whether a particular practice or omission violates the Constitution is whether the practice or omission constitutes a substantial departure from professional judgment or standards, *Youngberg v. Romeo*, 457 U.S. 307, 323-24 (1982).

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While the constitutional standards may not apply to private facilities, patients in private facilities have a right to be free from negligent treatment, i.e., treatment that violates the standards of care.

## FEDERAL REQUIREMENTS

***Federal regulatory requirements are new and continually being updated. Massachusetts rules have been updated to conform with federal requirements and professional judgment about the use of restraint.***

Until recently, the regulation of restraint and seclusion was mostly a matter of state law and, to a limited extent, accreditation standards. Most federal requirements are new since 1999, when the Centers for Medicare and Medicaid Services (CMS) issued its rules. Professional and accreditation standards followed suit. For example, the Joint Commission on Accreditation of Health Care Organization's (JCAHO) accreditation requirements were revised to substantially increase oversight of restraint and seclusion. These new standards took effect in 2001 (JCAHO, 2001). In 2006, the Massachusetts Department of Mental Health (DMH) promulgated first-in-the-nation regulations applying restraint reduction principles to both state and private licensed psychiatric facilities. These regulations bring Massachusetts facilities fully into conformity with the federal rules, JCAHO standards, and the consensus of professional judgment

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concerning the use of restraint and seclusion (DMH, 2006).  
DMH's regulations took effect on April 3, 2006.

More regulations are expected from both the federal government and JCAHO. The United States Department of Health and Human Services (HHS) is in the process of developing the regulations relating to restraint and seclusion that are required by the Children's Health Act of 2000. P.L. 106-310 (2000), codified at 42 U.S.C. §§ 290ii and jj. The Children's Health Act was established by Congress and restricts the use of restraint and seclusion with children and adolescents in psychiatric facilities receiving federal funds, including inpatient programs. In Massachusetts these rules apply to inpatient facilities, Intensive Residential Treatment programs (IRTP's), Behavioral Intensive Residential Treatment programs (BIRT's), and Clinically Intensive Residential Treatment programs (CIRT's) (Children's Health Act, 2000).

In early 2006, JCAHO added measurement of hours in restraint and seclusion as "core indicators" for psychiatric inpatient facilities. This means that by the time these measures are implemented in 2008, all JCAHO-accredited inpatient psychiatric facilities will have to provide JCAHO with quarterly data on the number of hours patients spend in restraint and seclusion, and the public will be able to compare hospitals' performance on this core quality indicator.

Therefore, while the information in this chapter is up to date as of April 2006, the reader should be aware of which regulations apply to his or her facility or program and keep up to date on

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any new regulations. Agencies which provide legal assistance to individuals with psychiatric disabilities are listed at the end of this chapter, and may be able to provide up-to-date information on restraint and seclusion regulations. In addition, web sites with this information are listed.

*Different kinds of facilities are also subject to different federal regulations:*

Different federal regulations and statutes apply to different kinds of facilities that serve children.

#### Inpatient Facilities

- *Hospital.* If the facility is a hospital, and it receives payments from Medicare or Medicaid, it is subject to Conditions of Participation relating to patients' rights, which include limitations on the use of restraint and seclusion. 42 C.F.R. 482.13(f). Any hospital, nursing facility, intermediate care facility, or other health care facility is also subject to the requirements of the Children's Health Act of 2000, 42 U.S.C. § 290ii., if it receives federal funding, whether directly or indirectly.

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- *Psychiatric Residential Treatment Center.* If a facility meets the definition of a “psychiatric residential treatment center” (PRTC) under federal law, it must comply with certain specific regulations promulgated by the Center for Medicare and Medicaid Services (CMS) of the Department of Health and Human Services. A PRTC is “a facility other than a hospital, that provides psychiatric services to individuals under the age of 21 in an inpatient setting.” 42 C.F.R. 483.352. Many states are confused about just which, if any, programs in their states are PRTCs. In Massachusetts, IRTPs, BIRTs and CIRTs meet the definition. The forthcoming HHS regulations may help define the programs and set the limitations on the use of restraint and seclusion at PRTCs.

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### Community Facilities

- *Non-medical, community-based facility for children and youth.* If a facility is a “non-medical, community-based facility for children and youth” it is subject to a part of the Children’s Health Act which prohibits the use of mechanical restraints, 42 U.S.C. § 290jj (b)(3)(B), and permits seclusion and physical restraint only in “emergency circumstances and only to ensure the immediate physical safety of the resident, a staff member or others, and only when less restrictive interventions have been determined to be ineffective.” 42 U.S.C. § 290jj(b)(1)(A). Most such facilities in Massachusetts would be licensed by the Department of Early Education and Care, whose regulations would apply.

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## STATE REQUIREMENTS

***Massachusetts programs and facilities that serve youth may be subject to one or more of several state agency restraint rules.***

Children and adolescents in Massachusetts may receive services from a variety of programs funded or regulated by any one of several state agencies. Although this chapter will consider the federal requirements and the DMH regulations applicable to inpatient facilities, with only occasional reference for comparison purposes to Department of Early Education and Care (DEEC), Department of Youth Services (DYS), and Department of Education (DOE) standards, it is obviously important for service providers, consumers, family members, and advocates to know just which rules apply.

The following agencies that may be involved in a young person's life operate, contract for, or license programs in which the use of restraint is regulated:

**DMH:** A child or adolescent may receive mental health services from a program or facility operated, under contract with, or funded by the Department of Mental Health. DMH has very specific regulations on the use of restraint and seclusion. However, these regulations apply only to programs or facilities operated, licensed, or contracted for by DMH, except for those children's programs that although contracted for by DMH, are licensed by DEEC.

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- DMH operates (sometimes under contract with private or public providers) inpatient facilities for children and adolescents, such as those at Westborough, Worcester, and Taunton State Hospitals. The DMH regulations apply to those units, which are considered part of the state psychiatric hospitals, which in turn are certified by JCAHO.
  - DMH licenses all inpatient mental health units, including child and adolescent mental health units, in private and public (for example, city or county) hospitals. Although the Department of Public Health (DPH) may also license the hospital as a whole, the DMH regulations apply to the mental health units (but not, for example to the emergency room, where restraint may also be used). However, DPH and DMH are increasingly working cooperatively when a DMH client is restrained in the emergency department.
  - DMH licenses Intensive Residential Treatment Programs (IRTPs), which vendors operate under contracts with the Department that provide residential diagnosis and treatment to adolescents. IRTPs can admit youth on an involuntary basis. 104 CMR 27.04(1). The DMH restraint regulations apply in the IRTPs, and IRTPs (such as the one on the grounds of Westborough State Hospital) are separately accredited by JCAHO.

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- DMH licenses Behaviorally Intensive Residential Treatment programs or (BIRT) units. These BIRT Units tend to serve younger children who are referred for behavioral health services by the Department of Social Services. BIRTs are secure treatment settings, often located on the campuses of state DMH facilities, such as those programs at Tewksbury and Westborough State Hospitals. BIRTs are licensed as IRTPs, adhere to DMH regulations pertaining to IRTPs as described above, and are separately accredited by JCAHO.
  - Even though it “contracts” with some community programs for children and adolescents, DMH does not license those programs. 104 CMR 28.01(2). Therefore, the restraint standards in the DMH community licensing regulations do not apply. Since most of these programs are licensed by the Department of Early Education and Care (DEEC), the DEEC restraint regulations apply. (DMH does license *adult* mental health community residential programs and does not allow the use of chemical or mechanical restraint or seclusion in those adult community programs. Physical restraint is allowed. 104 CMR 28.05. This is one area in which the rules applying to adults in community mental health programs are more stringent than those applying to children.)

**Department of Early Education and Care:** In 2005, the new Department of Early Education and Care (DEEC) assumed the licensing responsibilities of the former Office of Child Care Services (OCCS). In addition to its many other functions,

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DEEC licenses most non-hospital based programs for adolescents and children, including residential programs and Department of Youth Services facilities. DEEC has regulations and policies on the use of restraint, 102 CMR 3.07(7)(j), and a detailed policy statement. DEEC Policy Statement, Chemical and Mechanical Restraint, P-EEC-R&P-02. DEEC has multiple regulations that apply to different types of child residential programs. The standards particularly for Group Care can be found at

[http://www.eec.state.ma.us/kr\\_regulations\\_main\\_gcc.aspx](http://www.eec.state.ma.us/kr_regulations_main_gcc.aspx)  
(CIRTs fall under these standards).

**Department of Youth Services:** DYS' programs, both community and facility based, regardless of the degree of security, are licensed by DEEC. Although DEEC has some regulations concerning use of restraint in locked secure detention or treatment programs, the DYS regulations on restraint and seclusion are the main source of rules for DYS operated or contracted programs (109 CMR 5.05, 6.01- 6.04).

**Department of Social Services:** DSS provides a variety of residential services for youth. Although DSS licenses foster homes and pre-adoptive placements, the licensing of group care settings is the responsibility of DEEC. DSS and DMH jointly operate some hospital based and community programs. The restraint regulations that will apply to a child in a program will depend on which agency (e.g., DMH, DEEC) is the licensing authority. Most programs have their licenses posted in a conspicuous place.

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**Department of Education:** DOE certifies special education schools, but DEEC, licenses the residential portion of schools. DOE has restraint rules that apply to public schools, including charter schools and educational cooperatives. These are found at 603 CMR 46.01.

**Department of Mental Retardation:** Although DMR has extensive restraint regulations, very few children and adolescents with mental retardation are served in DMR licensed programs.

Children with developmental disabilities are likely to be in educational programs, either in their neighborhood schools or in day or residential schools.

**Department of Public Health:** DPH regulates and licenses general hospitals. Except for psychiatric units, which are also licensed by DMH and to which the DMH regulations apply, DPH rules apply elsewhere in the hospitals, including emergency rooms. (If the hospital receives Medicaid funds, as almost all do, the hospital is bound by the CMS “Conditions of Participation,” which include rules on restraint.)

***Seclusion and restraint are among the highest priorities of certification and standard-setting agencies as well, such as JCAHO, which is the nation’s oldest and largest accrediting body in health care.***

JCAHO’s accreditation standards are important because it accredits many inpatient facilities and some community programs. JCAHO accredited facilities and programs are

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considered by CMS to meet its certification requirements, as long as JCAHO ensures the facility meets CMS restraint and seclusion certification requirements where they are more stringent than those of the JCAHO. Although the Massachusetts DMH also “deems” JCAHO-accredited facilities and programs to meet most of the DMH licensing requirements, DMH requires facilities that it licenses to follow DMH’s restraint and seclusion regulations.

JCAHO’s revised restraint standards took effect in 2001. For the most part, they conformed to new CMS conditions of participation involving patient rights (including restraint and seclusion) and rules relating to psychiatric residential treatment centers for individuals under the age of twenty-one.

While JCAHO receives many complaints about patient care and cannot respond to all of them, it has emphasized on its web site that complaints regarding restraint and seclusion will receive the highest investigative priority. This is also true at CMS, the federal Medicaid agency, which has suspended certification at a number of facilities due to violations of conditions of participation relating to restraint and seclusion.

## **LIABILITY**

Because restraint is inherently dangerous, especially when used on children and adolescents, it is strictly limited and heavily regulated by federal and state law and regulations and by national licensing and accreditation standards.

With a few exceptions, the limitations on the use of restraints

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with children and adolescents are considerably more exacting than those for adults. There are, for example, greater restrictions on the use and duration of restraint, and more stringent reporting requirements. Some types of community residential programs may not use mechanical restraint at all. Other programs are forbidden from using certain other forms of restraint and seclusion.

These are important matters. Not only does restraint have critical physical and clinical implications, but the improper use of restraint and seclusion, even in the absence of injury or death may result in legal liability. There have been a number of lawsuits in Massachusetts related to restraint or seclusion events that resulted in injuries or death. Some have resulted in jury awards or settlements; still others have resulted in criminal or licensing investigations.

## FEDERAL AND LEGAL RESOURCES

***Where can I get further information on current federal requirements and efforts regarding restraint and seclusion of children and adolescents?***

The Center for Medicare and Medicaid Services, [www.cms.hhs.gov](http://www.cms.hhs.gov). This website contains information about the Conditions of Participation for hospitals receiving Medicare and Medicaid funds, including question asked by surveyors to determine whether the hospital's attention to patient's rights meets the certification standards in the area of restraint and seclusion,

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[http://www.cms.hhs.gov/CertificationandCompliance/13\\_PRTFs.asp#TopOfPage](http://www.cms.hhs.gov/CertificationandCompliance/13_PRTFs.asp#TopOfPage).

The Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services has declared that reduction of restraint and seclusion is a major national priority, and has funded a number of grants in mental health programs serving both children and adults aimed at reducing the use of restraint and seclusion.

Further information can be found at [www.samhsa.gov/Matrix/matrix\\_seclusion.aspx](http://www.samhsa.gov/Matrix/matrix_seclusion.aspx).

The National Association of State Mental Health Program Directors has been a leader in developing techniques to reduce restraint and seclusion. The National Technical Assistance Center of the National Association of State Mental Health Program Directors has provided technical assistance to forty-eight states, including programs aimed specifically at reducing restraint and seclusion use in children's programs. For further information, see: [www.nasmhpd.org](http://www.nasmhpd.org).

*Which agencies provide legal services to children with severe emotional disabilities and mental illness?*

**Legal services:** For a complete list of free legal services programs in Massachusetts, go to [www.masslegalservices.org](http://www.masslegalservices.org).

**The Center for Public Representation,** The Center for Public Representation has a Children's Law Project which assists children and adolescents in obtaining home and community

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based services and avoiding unnecessary residential placement. CPR has offices in Newton (617-965-0776) and Northampton (413-586-6024).

**The Disability Law Center**, 11 Beacon Street, Suite 925, Boston, MA 02108, (617) 723-8455 or (800) 872-9992. DLC is the protection and advocacy agency for the Commonwealth of Massachusetts. If this agency receives a complaint from a child's parent about abuse, neglect, or violation of the laws or regulations in a children's facility, it has federal authority to investigate the complaint, including access to the facility, staff, and records (with the parent's consent in most, but not all, cases).

**The Mental Health Legal Advisor's Committee**, 399 Washington Street, 4<sup>th</sup> Floor, Boston, MA 02108, (617) 338-2345, [www.mass.gov/mhlac](http://www.mass.gov/mhlac). MHLAC is an arm of the Supreme Judicial Court of Massachusetts which provides advice on legal matters and represents clients who are having difficulties receiving needed mental health services.

**Children's Law Center of Massachusetts**, 298 Union St., 2d Floor, PO Box 710, Lynn, MA 01903. (781) 581-1977. CLC represents children and youth in legal and administrative proceedings, including child abuse and neglect, runaways, custody and adoption disputes, school matters including suspension/expulsion cases, special education cases, SSI matters, access to adequate and appropriate services for children in the custody of DSS or DYS and the cases of

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severely handicapped children who are denied services due to bureaucratic red tape.

**Massachusetts Advocates for Children**, 100 Boylston St., Suite 200, Boston, MA 02116, (617) 357-843. MAC provides legislative, policy, administrative and case advocacy on behalf of children from low-income families in areas of education, special ed, child welfare and health. Bi-lingual intake (Spanish, English) is available.

**Health Law Advocates** 30 Winter Street, Suite 1004, Boston, MA 02108; (617) 338-5241, [www.hla-inc.org](http://www.hla-inc.org). Health Law Advocates, Inc. (HLA) is a public interest law firm affiliated with Health Care for All. HLA provides education, outreach and free legal representation to eligible consumers who live or work in Massachusetts and seek improved access to health care. HLA has a Children's Mental Health Project.

**The Committee on Public Counsel Services**, 44 Bromfield Street, Boston, MA (and twelve other regional locations) (617) 285-4666, [www.mass.gov/cpcs](http://www.mass.gov/cpcs). CPCS provides representation to individuals in Section 7&8 (involuntary commitment) and Rogers (involuntary medication) hearings. It coordinates and oversees the work of attorneys who represent children in delinquency, care and protection (abuse and neglect) and CHINS (children in need of services) cases.

## References

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Children's Health Act. (2000). *Public Law 106-310* (codified at 42 USC 2010). Retrieved on August 11, 2006 from:  
[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106\\_cong\\_public\\_laws&docid=f:publ310.106.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106_cong_public_laws&docid=f:publ310.106.pdf)

Joint Commission on Accreditation of Healthcare Organizations. (2001). *Restraint and Seclusion Standards for Behavioral Health*. Oakbrook Terrace, IL: JCAHO.

Massachusetts Department of Early Education and Care. (1997, rev. 2004). Policy Statement: Chemical and Mechanical Restraint. Retrieved September 22, 2006 from  
<http://www.eec.state.ma.us/docs/RPChemicalMechanicalRestraint.pdf>

Massachusetts Department of Early Education and Care. (2001). Standards for the Licensure or Approval of Residential Programs serving Children and Teen Parents (102 CMR 3.00). Retrieved September 22, 2006 from [http://www.eec.state.ma.us/docs/residential\\_regs.pdf](http://www.eec.state.ma.us/docs/residential_regs.pdf)

Massachusetts Department of Education. (2001). Education Laws and Regulations: Physical Restraint. Retrieved September 22, 2006 from <http://www.doe.mass.edu/lawsregs/603cmr46.html>.

Massachusetts Department of Mental Health. (2006). Licensing and Operational Standards for Mental Health Facilities. 104 CMR 27.00. Retrieved August 11, 2006 from:  
[http://www.mass.gov/Eeohhs2/docs/dmh/regs/reg\\_104cmr27.pdf](http://www.mass.gov/Eeohhs2/docs/dmh/regs/reg_104cmr27.pdf)

## ADDITIONAL RESOURCES

### OVERVIEW

#### Articles (Overview)

Bluebird, G. (2004). *Redefining consumer roles: Changing culture and practice in mental health care settings*. *Journal of Psychosocial Nursing*, 42, 46-53.

Bullard, L., Fulmore, D., & Johnson, K. (2003). *Reducing the use of restraint and seclusion: Promising practices and successful strategies*. Washington, DC: CWLA Press.

Child Welfare League of America (2004). *Achieving Better Outcomes for children and families: Reducing Restraint and Seclusion*. Washington, DC: CWLA Press. Retrieved July 17, 2006 from [www.cwla.org/programs/behavior/pubs.htm](http://www.cwla.org/programs/behavior/pubs.htm).

Child Welfare League of America (2004). *CWLA Best Practice Guidelines for Behavior Support and Intervention Training*. Washington, DC: CWLA Press.

Donovan, A., Plant, R., Peller, A., Siegel, M., & Martin, A. (2003). *Two-year trends in the use of seclusion & restraint among psychiatrically hospitalized youths*, *Psychiatric Services*; 54(7), 987-993.

Donovan A, Siegel L, Zera G, Plant R, & Martin A. (2003). *Seclusion and restraint reform: An initiative by a child and adolescent psychiatric hospital*. *Psychiatric Services*. 54(7), 958-959.

Huckshorn, K.A. (2004). *Reducing seclusion restraint in mental health use settings: Core strategies for prevention*. *Journal of Psychosocial Nursing Mental Health Services*. 42(9):22-33. Review.

Mohr, W.K., & Anderson, J.A. (2001). *Faulty assumptions associated with the use of restraints with children*. Journal of Child & Adolescent Psychiatric Nursing, 14(3), 141-151.

Mohr, W.K., Petti, T.A., & Mohr, B.D. (2003). *Adverse effects associated with physical restraint*. Canadian Journal of Psychiatry, 48(5), 330-7.

Plant, R. (2003). *Courageous patience: Implementing continuous quality improvement to reduce the use of restraint and seclusion*. Residential Group Care Quarterly, 3(3), 10-14.

*Practice Parameter for the Prevention & Management of Aggressive Behavior in Child and Adolescent Psychiatric Institutions, with special reference to Seclusion/Restraint*. (February 2002, supplement). Journal of the American Academy of Child & Adolescent Psychiatry, 41(2).

Weiss, E.M. et al. (1998). *Deadly Restraint: A Hartford Courant Investigative Report*. Hartford Courant 1998; October 11-15.

### **Websites (Overview)**

American Academy of Child & Adolescent Psychiatry (AACAP):

[www.aacap.org](http://www.aacap.org)

Center for Mental Health Service:

[www.samhsa.gov/centers/cmhs/cmhs.html](http://www.samhsa.gov/centers/cmhs/cmhs.html)

Child Welfare League of America:

[www.cwla.org](http://www.cwla.org)

National Association of State Mental Health Program Directors, NTAC:

[www.nasmhpd.org/ntac.cfm](http://www.nasmhpd.org/ntac.cfm)

Presidents New Freedom Commission on Mental Health:

[www.mentalhealthcommission.gov](http://www.mentalhealthcommission.gov)

Substance Abuse and Mental Health Services Administration (SAMHSA):  
[www.samhsa.gov](http://www.samhsa.gov)

Children & Families:  
[www.samhsa.gov/Matrix/matrix\\_families.aspx](http://www.samhsa.gov/Matrix/matrix_families.aspx)

Restraint & Seclusion:  
[www.samhsa.gov/Matrix/matrix\\_seclusion.aspx](http://www.samhsa.gov/Matrix/matrix_seclusion.aspx)

The Hartford Courant. Deadly Restraint: A Hartford Courant Investigative Report.:  
[www.pcma.com/crisis\\_intervention\\_news/deadly\\_restraint/index.st](http://www.pcma.com/crisis_intervention_news/deadly_restraint/index.st)

## **LEADERSHIP**

### **Books (Leadership)**

Gladwell, M. (2000). *The Tipping Point*. Boston: Little, Brown & Company.

Kotter, J. (1996). *Leading Change*. Boston: Harvard Business School Press.

Schein, E. (1985). *Organizational Culture and Leadership*. Washington: Jossey-Bass Publishers.

### **Videos (Leadership)**

Commonwealth of Pennsylvania. (2001). *Leading the Way: Toward a Seclusion and Restraint Free Environment* [Motion picture]. United States: Commonwealth of Pennsylvania, Pennsylvania Office of Mental Health and Substance Abuse, Department of Public Welfare.

Available from:

Department of Public Welfare, Commonwealth of Pennsylvania

506 Health and Welfare Building

Harrisburg, PA 17105

Robert Davis, MD

[robedavis@state.pa.us](mailto:robedavis@state.pa.us)

## **STRENGTH-BASED TREATMENT**

### **Articles (Strength-Based Treatment)**

Adams, N., & Grieder, D. (2005). *Treatment Planning for Person-Centered Care: The Road to Mental Health and Addiction Recovery: Mapping the Journey for Individuals, Families, and Providers*. London: Elsevier.

Brendtro L.K. (2004). *From Coercive to Strength-Based Intervention: Responding to the Needs of Children in Pain*. 2004. Retrieved from [www.nospank.net/brendtro.pdf](http://www.nospank.net/brendtro.pdf) on July 22, 2006.

Catalano, R.F., Berglund, M.L., Ryan, J.A., Lonczak, H.S., & Hawkins J.D. (2002). *Positive youth development in the United States: Research findings on evaluations of positive youth development programs*. *American Academy of Political & Social Science*, 591(1), 98-124.

Horner R.H., Dunlap G., Koegel R.L., Carr E.G., Sailor W., Anderson J.A., Albin R.W., & O'Neill R.E. (1990). *Toward a technology of "nonaversive" behavioral support*. *Journal of the Association for Persons with Severe Handicaps*, 15, 125-132.

Regan, K. (2003). *Restraint & Seclusion: What Parents Need to Know*. [Brochure]. Boston: Adoptive Families Together, Massachusetts Society for the Prevention of Cruelty to Children.

Ruef M., Posten D., & Humphrey K. (1999). *PBS: Putting the "positive" into behavioral support: An introductory training packet*. Lawrence, KS: University of Kansas, Beach Center on Families and Disability.

### **Videos (Strength-Based Treatment)**

Galvin, M. (Producer & Director). (2003). *The Massachusetts Department of Mental Health Contract for Safety* [Motion picture]. United States: Commonwealth of Massachusetts, Department of Mental Health.

Available from:

Massachusetts Department of Mental Health

25 Staniford Street

Boston, MA 02114

Phone: 617-626-8000

[dmhinfo@dmh.state.ma.us](mailto:dmhinfo@dmh.state.ma.us)

### **COLLABORATION**

#### **Articles (Collaboration)**

Greene, R.W. & Ablon, J.S. (2005). *Treating Explosive Kids: The Collaborative Problem Solving Approach*. New York: Guilford.

Greene, R.W., Ablon, J.S., & Martin, A. (2006). Use of collaborative problem solving to reduce seclusion & restraints in child & adolescent inpatient units. *Psychiatric Services*, 57(5), 610-612.

Mercer J. (2005). *Coercive Restraint Therapies: A Dangerous Alternative Mental Health Intervention*. *Medscape General Medicine*. 7(3), 6. Retrieved online from [www.bridges4kids.org/CoerciveRestraintTherapies.pdf](http://www.bridges4kids.org/CoerciveRestraintTherapies.pdf) on September 22, 2006.

### **Videos (Collaboration)**

Hathorne Mental Health Units at Tewksbury Hospital, Department of Clinical Social Work. (2006). *Reducing Seclusion and Restraint: Hand in Hand, Side by Side* [Motion picture]. United States: Commonwealth of Massachusetts, Department of Mental Health Units at Tewksbury Hospital.

Available from:

Massachusetts Department of Mental Health

25 Staniford Street

Boston MA 02114

Phone: 617-626-8000

[dmhinfo@dmh.state.ma.us](mailto:dmhinfo@dmh.state.ma.us)

### **Websites (Collaboration)**

Center for Collaborative Problem Solving:

[www.explosivechild.com](http://www.explosivechild.com)

### **GIVING PEOPLE A VOICE, CHOICE & ROLE**

#### **Articles (Voice, Choice & Role)**

Davies, J., & Wright, J. (2008). Children's voices: A review of the literature pertinent to looked-after children's views of mental health services. *Child and Adolescent Mental Health*, 13(1), 26-31.

Day, C. (2008). Children's and young people's involvement and participation in mental health care. *Child and Adolescent Mental Health*, 13(1), 2-8.

Goldstein AP, McGinnis E (Rev. ed., 1997). *Skillstreaming the adolescent: New strategies and perspectives for teaching prosocial skills*. Champaign, IL: Research Press.

Matarese, M., McGinnis, L., Mora, M. (2005). *Youth involvement in systems of care: A guide to empowerment*. Washington, D.C.: Technical Assistance Partnership, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. Retrieved online from [www.tapartnership.org/youth/youthguide.asp](http://www.tapartnership.org/youth/youthguide.asp) on March 25, 2008.

Osher, T., Osher, D., & Blau, G. (2006). *Ambassador's guide to family-driven care*. Rockville, MD: Families for Children's Mental Health.

Worrall-Davies, A., Marino-Francis, F. (2008). Eliciting children's and young people's views of child and adolescent mental health services: A systematic review of best practice. *Child and Adolescent Mental Health*, 13(1), 9-15.

### **Videos (Voice, Choice & Role)**

Bluebird, G. (Producer). Lies, L. (Director). (2006). *Leaving the Door Open: Alternatives to Seclusion and Restraint* [Motion picture]. United States: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Available from:

Substance Abuse & Mental Health Services Administration  
Center for Mental Health Services  
P.O. Box 42557  
Washington, D.C. 20015  
Phone: 1-800-789-2647

Cain, L., Gross, D., Stromer, T., Prescott, L. (Producers). Cain, L., Gross, D., (Directors). (2007). *Behind Closed Doors* [Motion picture]. United States: Maryland Disability Law Center, Galler 144 Productions & Sister Witness International.

Available from:

Maryland Disability Law Center  
The Walbert Building  
1800 North Charles Street, 4<sup>th</sup> Floor  
Baltimore, Maryland 21201  
Phone: 1-410-727-6352

[www.behindcloseddoorsthefilm.com](http://www.behindcloseddoorsthefilm.com) or [www.lmdlcbalto.org](http://www.lmdlcbalto.org)

Deegan, P., Strecker, T., Advocates for Human Potential Inc. (2004). *Inside Outside: Building a Meaningful Life After the Hospital* [Motion picture]. United States: U.S. Department of Mental Health & Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Available from:

Substance Abuse & Mental Health Services Administration  
Center for Mental Health Services

P.O. Box 42557

Washington, D.C. 20015

Phone: 1-800-789-2647

[www.nmhicstore.samhsa.gov/publications/ordering.aspx](http://www.nmhicstore.samhsa.gov/publications/ordering.aspx)

or

[www.patdeegan.com/index.html](http://www.patdeegan.com/index.html)

### **Websites (Voice, Choice & Role)**

Boston University Center for Psychiatric Rehabilitation:

[www.bu.edu/cpr](http://www.bu.edu/cpr)

The Center for Teen Empowerment:

[www.teenempowerment.org](http://www.teenempowerment.org)

Federation of Families for Children's Mental Health (FFCMH):

[www.ffcmh.org/index.htm](http://www.ffcmh.org/index.htm)

M-Power and the Transformation Center:

[www.m-power.org](http://www.m-power.org)

META Certification:

[www.metaservices.com](http://www.metaservices.com)

National Alliance on Mental Illness (NAMI) – Child & Adolescent Action  
Center: Young Minds of America:

[www.nami.org/youth](http://www.nami.org/youth)

National Association of State Mental Health Program Directors – Office of  
Technical Assistance Center for Peer Networking:

[www.nasmhpd.org/consumernetworking.cfm](http://www.nasmhpd.org/consumernetworking.cfm)

National Center on Youth Transition:

[ntacyt.fmhi.usf.edu/index2.cfm](http://ntacyt.fmhi.usf.edu/index2.cfm)

National Foundation for Self-Directed Care:

[nationalsdcfoundation.org](http://nationalsdcfoundation.org)

Parent / Professional Advocacy League

[www.ppal.net](http://www.ppal.net)

Substance Abuse & Mental Health Services Administration –  
Consumer/Survivor Mental Health Information:

[mentalhealth.samhsa.gov/consumersurvivor/about.asp](http://mentalhealth.samhsa.gov/consumersurvivor/about.asp)

Substance Abuse & Mental Health Services Administration, Systems of Care  
– Family-Driven:

[www.systemsofcare.samhsa.gov/headermenus/deffamilydriven.aspx](http://www.systemsofcare.samhsa.gov/headermenus/deffamilydriven.aspx)

Technical Assistance Partnership for Child and Family Mental Health:

[www.tapartnership.org](http://www.tapartnership.org)

University of Illinois at Chicago Mental Health Services Research Program:

[www.psych.uic.edu/MHSRP](http://www.psych.uic.edu/MHSRP)

US Psychiatric Rehabilitation Association:

[www.uspra.org](http://www.uspra.org)

## **VALUING FAMILIES**

### **Articles (Valuing Families)**

Burns, J.B., & Hoagwood, K. (2002). *Community Treatment for Youth, Evidence-Based Interventions for Severe Emotional and Behavioral Disorders*. Oxford University Press: New York.

Children's Health Act. (2000). *Public Law 106-310* (codified at 42 USC 2010). Retrieved on August 11, 2006 from [frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106\\_cong\\_public\\_laws&docid=f:publ310.106.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106_cong_public_laws&docid=f:publ310.106.pdf)

Kamradt, B. & Connolly, C. (2003). *Re-engineering Residential Treatment Challenges and Opportunities for Purchasers and Providers*. Paper prepared for the Center for Health Care Strategies, April 20, 2003.

TASH. (2005). *In the Name of Treatment: A Parent's Guide to Protecting Your Child From the Use of Restraint, Aversive Interventions, and Seclusion*. Retrieved on September 23, 2006 from [www.tash.org/publications/parentguide/index.htm](http://www.tash.org/publications/parentguide/index.htm)

[ntacyt.fmhi.usf.edu/publications/what-we-learned.pdf](http://ntacyt.fmhi.usf.edu/publications/what-we-learned.pdf)

### **Websites (Valuing Families)**

The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion:  
[www.aprais.org](http://www.aprais.org)

Children Injured by Restraints & Aversives:  
[users.1st.net/cibra/index.htm](http://users.1st.net/cibra/index.htm)

Family Alliance to Stop Abuse and Neglect:  
[www.thefamilyalliance.net](http://www.thefamilyalliance.net)

Federation for Children with Special Needs:  
[www.fcsn.org](http://www.fcsn.org)

Federation of Families for Children's Mental Health (FFCMH):  
[www.ffcmh.org/index.htm](http://www.ffcmh.org/index.htm)

Massachusetts Association for Mental Health (MAMH):  
[www.mamh.org](http://www.mamh.org)

National Alliance for the Mental Ill (NAMI/Massachusetts):  
[www.namimass.org](http://www.namimass.org)

Parent/Professional Advocacy League:  
[www.ppal.net](http://www.ppal.net)

Research & Training Center on Family Support & Children's Mental Health:  
[www rtc.pdx.edu](http://www rtc.pdx.edu)

Substance Abuse & Mental Health Services Administration, Systems of Care – Family-Driven:

[www.systemsofcare.samhsa.gov/headermenu/deffamilydriven.aspx](http://www.systemsofcare.samhsa.gov/headermenu/deffamilydriven.aspx)

TASH:

[www.tash.org](http://www.tash.org)

Teaching-Family Association:

[www.teaching-family.org](http://www.teaching-family.org)

## **TRAUMA**

### **Articles (Trauma)**

Cole, S.F., O'Brien J.G., Gadd, M.G., Ristuccia, J., Wallace, D.L., & Gregory, M. (2005). *Helping traumatized children learn: Supportive school environments for children traumatized by family violence*. Boston, MA: Massachusetts Advocates for Children.

Jennings A. (2004). *Models for Developing Trauma-Informed Behavioral Health Systems and Trauma-Specific Services*. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD), National Technical Assistance Center for State Mental Health Planning (NTAC).

*Practice Parameters for the Assessment and Treatment of Children and Adolescents with Posttraumatic Stress Disorder*. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37:10 supplement, October 1998.

### **Websites (Trauma)**

The Child Trauma Academy:

[www.childtrauma.org/default.asp](http://www.childtrauma.org/default.asp)

Institute for Health & Recovery:

[www.healthrecovery.org](http://www.healthrecovery.org)

The National Child Traumatic Stress Network:

[www.nctsn.org](http://www.nctsn.org)

National Traumatic Consortium:

[www.nationaltraumaconsortium.org](http://www.nationaltraumaconsortium.org)

Pennsylvania Department of Public Welfare:

[pacassp.psych.psu.edu/DPWACT/home.htm](http://pacassp.psych.psu.edu/DPWACT/home.htm)

The Sidran Foundation:

[www.sidran.org](http://www.sidran.org)

The Trauma Center:

[www.traumacenter.org](http://www.traumacenter.org)

### **NURTURING INTERVENTIONS**

Bardill, N. & Hutchinson, S. (1997). *Animal-assisted therapy with hospitalized adolescents*. *Journal of Child & Adolescent Psychiatric Nursing*, 10(1), 17-24.

Champagne, T. (2003). *Sensory modulation and environment: Essential elements of occupation*. Southampton, MA: Champagne Conferences & Consultation.

Champagne, T. (2003). *Creating nurturing environments and a culture of care*. *Advance for Occupational Therapy*, 19(19), 50.

De Sousa, A. (2005). *The role of music therapy in psychiatry*. *Alternative Therapies*, 11(6), 52-53.

Holyoake, D.D., & Reyner, C. (2005). *Moving body and mind: A nurse-led dance group for young with a mental illness*. *Paediatric Nursing*, 17(4), 36-39.

Hussey, D.L., & Layman, D. (2003). *Music therapy with emotionally disturbed children*. *Psychiatric Times*, 20(6). Retrieved August 14, 2006 from [www.psychiatrictimes.com/article/print.jhtml?articleID=175802471](http://www.psychiatrictimes.com/article/print.jhtml?articleID=175802471)

Pratt, R.R. (2004). Art, dance, and music therapy. *Physical Medicine & Rehabilitation Clinics of North America*, 15(4), 827-41, vi-vii.

Rosenblatt, P. & VanderVen, K. (2005). *Perspectives on point and level systems in residential care: A responsive dialogue*. *Residential Treatment for Children and Youth*, 23(3), 1-18.

### **Websites (Nurturing Interventions)**

Art therapy:

[www.arttherapy.org/about.html](http://www.arttherapy.org/about.html)

Music therapy:

[www.musictherapy.org](http://www.musictherapy.org)

Pet Therapy:

[www.deltasociety.org](http://www.deltasociety.org)

The Touch Research Institute:

[www.miami.edu/touch-research](http://www.miami.edu/touch-research)

### **SAFETY TOOLS**

#### **Programs (Safety Tools)**

Child Assessment Unit at Cambridge Hospital

1493 Cambridge Street

Cambridge, MA 02139

Phone: (617) 498-1000

Boston Medical Center Intensive Residential Treatment Program  
85 East Newton Street  
Boston, MA 02118  
Phone: (617) 414-2058

UMass Transitions Intensive Residential Treatment Program  
Worcester State Hospital  
305 Belmont Street  
Worcester, MA 01604  
Phone: (508) 856-1455

### **Videos (Safety Tools)**

Jonikas, J., Laris, A., Cook, J. (2002). *Increasing Self-Determination: Advance Crisis Management with Mental Health Consumers in Inpatient and Other Settings* [Motion picture]. United States: University of Illinois Chicago, Department of Psychiatry, National Research & Training Center.

Available from:

National Research and Training Center of Psychiatric Disability (NRTC)  
Center on Mental Health Services Research and Policy  
University of Illinois Chicago – Department of Psychiatry  
1601 W. Taylor Street  
Chicago, IL 60612  
Phone: 312-355-1696

[www.cmhsrp.uic.edu/nrtc/dep-training.asp](http://www.cmhsrp.uic.edu/nrtc/dep-training.asp)

### **SENSORY APPROACHES**

#### **Books: For Health Professionals & Educators**

Anderson, E. & Emmons, P. (1996). *Unlocking the Mysteries of Sensory Integration*. Arlington, TX: Future Horizons.

Ayres, J., (1979). *Sensory Integration & The Child*. Los Angeles: Western Psychological Services.

Bissell, J., Fisher, J., Owens, C. & Polcyn, P. (1988). *Sensory Motor Handbook: A Guide for Implementing and Modifying Activities in the Classroom*. Torrance, CA: Sensory Integration International.

Bundy, A., Lane, S., & Murray, E. (2002). *Sensory integration theory and practice* (2nd ed.). Philadelphia: F. A. Davis.

Campbell, D. (1997). *The Mozart effect: Tapping the powers of music to heal the body, strengthen the mind, and unlock the creative spirit*. New York, NY: Avon Books.

Champagne, T. (2006). *Sensory Modulation & Environment: Essential Elements of Occupation, Second edition*. Southampton, MA: Champagne Conferences & Consultation.

Clements, Rhonda L., Ed.D., Editor (2000). *Elementary School Recess: Selected Readings, Games, and Activities for Teachers and Parents*. Boston: American Press.

Heller, S. (2003). *Too Loud, Too Bright, Too Fast, Too Tight: What to Do If You are Sensory Defensive in an Overstimulating World*. New York: Harper Collins.

Henry, D. (1998). *Tool Chest for Teachers, Parents & Students: A Handbook to Facilitate Self-Regulation*. Youngtown, AZ: Henry Occupational Therapy Services.

Kranowitz, C. (1998). *The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction*. New York: Perigee.

Kranowitz, C. (2003). *The Out-of-Sync Child Has Fun: Activities for Kids with Sensory Integration Dysfunction*. New York: Perigee.

Miller, L. (2006). *Sensational kids: Hope and help for children with sensory processing disorder*. New York: Penguin Books Ltd.

Moore, K (2005). *The Sensory Connection Program: Activities for Mental Health Treatment*. Manual and Handbook. Framingham, MA: Therapro, Inc.

O'Brien-Palmer, Michelle (1998). *Sense-Abilities: Fun Ways to Explore the Senses (Activities for Children 4 to 8)*. Chicago: Chicago Review Press.

Roley, S., Blanche, E. & Schaaf, R. (2001). *Sensory Integration with Diverse Populations* Tuscon, AZ: Therapy Skill Builders.

Schneider, C. (2001). *Sensory Secrets: How to Jump-Start Learning in Children*. Siloam Springs, AR: Concerned Communications.

Smith, K. & Gouze, K. (2004). *The Sensory-Sensitive Child*. New York: Harper Collins.

Thelen, E., & Smith, L. (2000). *A Dynamic Systems Approach to the Development of Cognition and Action (4<sup>th</sup> ed.)* Cambridge, MA: MIT Press.

Trott, M., Laurel, M., & Windeck, S. (1993). *Sense Abilities—Understanding Sensory Integration*. Tuscon, AZ: Therapy Skill Builders.

Williams, M.S., & Shellenberger, S. (1992). *An Introduction to How Does Your Engine Run? The Alert Program for Self-Regulation*. Albuquerque, NM: Therapyworks.

Young, S.B. (1988). *Movement Is Fun: A Preschool Movement Program*. Torrance, CA: Sensory Integration International.

#### **Books: For Children**

Koomar, J. & Friedman, B. (2002). *Hidden Senses: Balance Sense*. Rockville, MD: AOTA.

Koomar, J. & Friedman, B. (2002). *Hidden Senses: Muscle Sense*. Rockville, MD: AOTA.

### **Video, Audio Cassette Tape &/or Booklet Sets**

Koomar, J., Szklut, S. & Cermak, S. *Making Sense of Sensory Integration* (Audio Cassette and Booklet). Boulder, CO: Belle Curve Records.

*Sensory Processing for Parents: From Roots to Wings.* (Video)  
Reisman, J., University of Minnesota.  
To order, go to [www.pdppro.com](http://www.pdppro.com)

Kranowitz, C. & Szklut, S. *Teachers Ask About Sensory Integration* (Audio Cassette & booklet). Boulder, CO: Belle Curve Records

### **Websites**

The Alert Program:  
[www.alertprogram.com](http://www.alertprogram.com)

OT-Innovations:  
[www.ot-innovations.com](http://www.ot-innovations.com)

The Out-of-Sync Child:  
[www.out-of-sync-child.com](http://www.out-of-sync-child.com)

The Sensory Connection:  
[www.sensoryconnectionprogram.com](http://www.sensoryconnectionprogram.com)

Sensory Integration Resources Center:  
[www.sinetwork.org](http://www.sinetwork.org)

### **Where to Buy Sensory Resources**

Abilitations:  
[www.abilitations.com](http://www.abilitations.com)

Flaghouse:  
[www.flaghouse.com](http://www.flaghouse.com)

GAIAM Inc:

[www.gaiam.com](http://www.gaiam.com)

Harcourt Assessment:

[www.harcourtassessment.com](http://www.harcourtassessment.com)

Hemi-Sync R:

[www.hemi-sync.com](http://www.hemi-sync.com)

Integrations:

[www.integrationscatalog.com](http://www.integrationscatalog.com)

Pocket Full of Therapy:

[www.pfot.com](http://www.pfot.com)

Professional Development Programs:

[www.pdppro.com](http://www.pdppro.com)

Quiet Quilts:

[www.quietquilt.com](http://www.quietquilt.com)

Rhode Island Novelty:

[www.rinovelty.com](http://www.rinovelty.com)

ROMPA:

[www.rompa.com](http://www.rompa.com)

S&S Worldwide:

[www.ssw.com](http://www.ssw.com)

Salt of the Earth Weighted Gear:

[www.saltoftheearthweightedgear.com](http://www.saltoftheearthweightedgear.com)

Sensory Comfort:

[www.sensorycomfort.com](http://www.sensorycomfort.com)

Sensory Resources:

[www.sensoryresources.com](http://www.sensoryresources.com)

Southpaw Enterprises:

[www.southpawenterprises.com](http://www.southpawenterprises.com)

Special Needs Toys:

[www.tfusa.com](http://www.tfusa.com)

Therapro, Inc:

[www.theraproducts.com](http://www.theraproducts.com)

Therapy Shoppe:

[www.weightedblanket.com](http://www.weightedblanket.com)

Weighted Wearables:

[www.weightedwearables.com](http://www.weightedwearables.com)

Western Psychological Services:

[www.wpspublish.com](http://www.wpspublish.com)

Whole Person Associates:

[www.wholeperson.com](http://www.wholeperson.com)

### **OT Assessment Tools and Checklists**

\*Many of these tools are completed by caregivers or the child/adolescent (with assistance as needed), and are used as part of the OT assessment process.

#### **Infants:**

##### **Test of Sensory Function in Infants**

by De Gangi & Greenspan, 1989

4-18 months

OTR evaluation tool

**Infant/Toddler Sensory Profile™**

by Dunn, 2002

Birth - 36 months

\*Caregivers complete this profile

**Sensory Integration Observation Guide**

By Schaaf, Anzalone & Burke, 1989

Birth - 3 years

\*Caregivers complete this checklist

**Sensory Rating Scale for Infants**

by Provost & Oetter, 1993

0-9 months - Form A

9-36 months - Form B

\*Caregivers complete this checklist

**Infants & Toddlers Checklist**

by Koomar, 1999

Birth - 2 years

\*Caregivers complete this checklist

**Children:**

**Sensory Integration and Praxis Test**

by Ayres, 1989

Developed for children ages 4 years - 8:11

\*OTR evaluation tool - requires SIPT certification

**Sensory Profile™**

by Dunn, 1999

Developed for use with children ages: 3-10

\*Caregivers complete this profile

**Sensory Profile School Companion™**

by Dunn, 2006 (Coming out this Fall, 2006)

Developed for children ages 3 years - 11:11

\*Teachers complete this profile

**The Touch Inventory for Elementary School Aged Kids**

by Royeen, 1986

Developed for use with children aged 6-12

\*Caregivers may complete or assist with completion

**DeGangi-Berk Test of Sensory Integration**

by Berk & DeGangi, 1983

Developed for use with children ages: 3-5

\*OTR evaluation tool

**Pre-school Checklist**

by Koomar, 1999

Developed for use with children ages: 3-4

\*Caregivers complete this checklist

**School-Aged Checklist**

by Koomar, 1999

Developed for use with children ages: 5-12

\*Caregivers &/or children complete this checklist

**Adolescent/Adult:**

**Adolescent/Adult Sensory Profile™**

by Brown & Dunn, 2002

Developed for use with adolescents ages 11 through adulthood

\*Adolescents and adults complete this profile individually or with assistance

**The Sensory Modulation Screening Tool: Adolescent/Adult Version**

by Champagne, 2006

Developed for use with adolescents age 12 years through adulthood

\*\*Adolescents and adults complete this profile individually or with assistance

**The Sensory Defensiveness Screening Tool: Adolescent/Adult Version**

by Champagne, 2006

Developed for use with adolescents age 12 years through adulthood

\*\*Adolescents and adults complete this profile individually or with assistance

**Adolescent/Adult Checklist**

by Koomar, 1999

Developed for use with children ages: 12 through adulthood

\*\*Adolescents and adults complete this profile individually or with assistance

**TOUCH**

**Books**

Field, T. (2000). *Touch Therapy*. London: Churchill Livingstone.

Field, T. (2003). *Touch*. Cambridge, MA: MIT Press.

**Websites**

OT-Innovations:

[www.ot-innovations.com](http://www.ot-innovations.com)

Touch Research Institute:

[www.miami.edu/touch-research](http://www.miami.edu/touch-research)

**PHYSICAL ENVIRONMENT**

Kinkead G. (2003, December 23). *A room comes alive with color and sounds*.

The New York Times. Retrieved July 25, 2006 from [www.nytimes.com](http://www.nytimes.com).

Moffat, N., Barker, P., & Pinkney, L. (1993). *Shoetzelen: an experience for people with dementia*. ROMPA. Chesterfield.

Pinkney, L. (1997). *A comparison of the Snoezelen environment and a music relaxation group on mood and behaviour of patients with senile dementia*. *British Journal Occupational Therapy*. 60(5); 209-212.

Pinkney, L. (1998). *Exploring the myth of multi-sensory environments*. *British Journal Occupational Therapy*, 61(8).

### **PROMISING PRACTICES**

#### **Articles (Promising Practices)**

Beach Center on Disability: The University of Kansas. (undated) *Positive Behavior Support*. Retrieved on September 19, 2006 from [www.beachcenter.org/?act=view&type=General%20Topic&id=9](http://www.beachcenter.org/?act=view&type=General%20Topic&id=9)

The Center for Autism and Related Disorders. *What is Applied Behavioral Analysis?* Retrieved on September 19, 2006 from [www.centerforautism.com/aba/whatisaba.asp](http://www.centerforautism.com/aba/whatisaba.asp)

Criste, T.R., Sterba, M.N., & Davis, J.L. (2000). *Boys Town's Psychoeducational Treatment Model: Helping Behavioral Health Professionals Care for and Treat Troubled Children and Adolescents*. Boys Town, NE: Boys Town Press.

Cohen, J.A., Mannarino, A.P., Berliner, L., & Deblinger, E. (2000). *Trauma-focused cognitive behavioral therapy for children and adolescents: An empirical update*. *Journal of Interpersonal Violence*, 15(11), 1202-1223.

National Child Traumatic Stress Network. (undated). *Sanctuary Model*. Retrieved on September 19, 2006 from [www.nctsn.org/nctsn\\_assets/pdfs/promising\\_practices/Sanctuary\\_Model\\_2-11-05.pdf](http://www.nctsn.org/nctsn_assets/pdfs/promising_practices/Sanctuary_Model_2-11-05.pdf)

SAMHSA. (undated). *Trauma Focused-Cognitive Behavior Therapy: SAMHSA Model Program*. Retrieved on September 25, 2006 from [www.modelprograms.samhsa.gov/pdfs/FactSheets/TFCBT.pdf#search=%22trauma-focused%20cognitive%20behavioral%20therapy%22](http://www.modelprograms.samhsa.gov/pdfs/FactSheets/TFCBT.pdf#search=%22trauma-focused%20cognitive%20behavioral%20therapy%22)

### **Websites (Promising Practices)**

Girls and Boys Town:

[www.girlsandboystown.org](http://www.girlsandboystown.org)

Positive Behavioral Support::

[www.beachcenter](http://www.beachcenter) or [rrtcpbs.fmhi.usf.edu](http://rrtcpbs.fmhi.usf.edu)

Psychoeducational Treatment Model:

[www.girlsandboystown.org/pros/training/behavioral/index.asp](http://www.girlsandboystown.org/pros/training/behavioral/index.asp)

Rehabilitation Research & Training Center on Positive Behavior Support:

[rrtcpbs.fmhi.usf.edu](http://rrtcpbs.fmhi.usf.edu)

Sanctuary Model:

[www.sanctuaryweb.com](http://www.sanctuaryweb.com)

Teaching Family Association:

[www.teaching-family.org](http://www.teaching-family.org)

Teaching-Family Model:

[www.teaching-family.org/tfamodel.html](http://www.teaching-family.org/tfamodel.html)

### **EXPERTS SHARE**

#### **Articles (Experts Share)**

Barnett, H., Lapsley, H. (2006). *Journeys of despair, Journeys of hope: Young adults talk about severe mental distress, mental health services and recovery*. Wellington, Aotearoa/New Zealand: Mental Health Commission. Retrieved online from [www.mhc.govt.nz/publications/2006/Journeys.pdf](http://www.mhc.govt.nz/publications/2006/Journeys.pdf) on March 25, 2008.

Heckman, J., & Veysey, B., Markoff, L., Mazelis, R., Russell, L. (2006). *It's my time to live—journeys to healing and recovery*. Washington D.C.:

Substance Abuse & Mental Health Services Administration, Center for Mental Health Services. Retrieved online from [download.ncadi.samhsa.gov/ken/pdf/nctic/ItsMyTimeToLive\\_07.pdf](http://download.ncadi.samhsa.gov/ken/pdf/nctic/ItsMyTimeToLive_07.pdf) on April 3, 2008.

### **Websites (Experts Share)**

National Empowerment Center  
[www.power2u.org](http://www.power2u.org)

National Association of State Mental Health Program Directors – Office of Technical Assistance Center for Peer Networking:  
[www.nasmhpd.org/consumernetworking.cfm](http://www.nasmhpd.org/consumernetworking.cfm)

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services:  
[mentalhealth.samhsa.gov/nctic/publications.asp#self](http://mentalhealth.samhsa.gov/nctic/publications.asp#self)

### **Video (Experts Share)**

National Association of State Mental Health Program Directors (NASMHPD). (2007). *Paving New Ground: A Dialogue with Peers and Family Members* [Motion picture]. United States: NASMHPD, Office of Technical Assistance Center for Peer Networking.

Available from:

NASMHPD

OTA – Center for Peer Networking

66 Canal Center Plaza, Suite 302

Alexandria, VA 22314

703-739-9333

[OTAinfo@nasmhpd.org](mailto:OTAinfo@nasmhpd.org)

### **LEGAL PERSPECTIVE**

Bazon Center for Mental Health Law:  
[www.bazon.org](http://www.bazon.org)