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

Giving People a Voice, Choice, and Role

Overview

Most 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, adolescents, transition age youth and young adults, such as peer mentors, youth support groups, statewide youth leadership conferences, youth leadership courses, and weekend youth retreats.

How to begin

Although most programs that care for young people 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. Some 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 youth 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 youth.

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.

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. Help the youth strategize about needed changes within the program. As direct recipients of service, they know what helps, what does not, and what changes they would like to see. Solicit their expertise!
- Also seek input from children formally by including them in programmatic decisions and understanding that all 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.

- 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" not as indicators of the need for punishment.
- Ensure that the child and family have input in decisions about the child's privileges. Time spent at home, time spent outdoors, time in normative activities, regular snacks and spending time 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 and/or a judicial order that prevents contact.
- Set up treatment planning and treatment review practices that fully involve children in their treatment. Have them sit at the head of the table. Have them determine who they want to attend their meeting and write invitation letters to those they want to attend. Treatment meetings should include the children's views of their challenges 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.
- Several times a day, point out individual strengths of children and talk with them about how their strengths will help them be successful. *Make sure that statements that highlight strengths significantly exceed the number of 'directives' that are given.* Keep the message positive and strength-oriented. Who likes to be reminded about what you are doing incorrectly or not well?
- 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 and 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, dispute resolution, negotiation, making good choices and decisions, being responsible, offering suggestions/feedback, saying no, disagreeing with others, reporting whereabouts, building trust, honesty, expressing concerns, etc.

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, coaching 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.

- 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

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

- 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).
- participate in program development and design
- survey peers for in put on organization training, policies, and procedures

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.

- **<u>Youth Council / Student Council Representatives</u>**

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 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) 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 or Peer Mentors**

  Student graduates of a creative arts service are hired as Mentors for this program. 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 Mentors also contribute to the creative process, offer tours of the studio, help explain the 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 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 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 for mental health services. A Statewide Youth Advisory Council was created in 2007 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. 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.

- **Young Adult Outreach Coordinators**

  Young Adult Outreach Coordinators are responsible for engaging and connecting with young adult peers. They also advocate on behalf of youth and young adult needs, organize venues for youth to express their voice (e.g. youth councils, website development, *YouTube* videos), and coordinating efforts as they arise between youth, providers and DMH. They are either part-time or full-time paid positions.

- **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 their transition experiences in “Youth in Transition

Writing Collective: Recovery Stories Written by Inspiring Young Women." The youth writers received stipends for their stories.

- **Youth M.O.V.E. Massachusetts**

  Youth Motivating Others through Voices of Experience (M.O.V.E.) Massachusetts is the Massachusetts chapter of Youth M.O.V.E. National. It is youth-led and sponsored by the Parent/Professional Advocacy League (PAL) in Worcester, MA. Youth M.O.V.E National is "a youth-led national organization devoted to improving services and systems that supports positive growth and development by uniting the voices of individuals who have lived experience in various systems including mental health, juvenile justice, education, and child welfare" (Youth M.O.V.E., 2012).

  Under Youth M.O.V.E. Massachusetts, there are several youth-led groups: *Help Others Promote Equality* (HOPE) for youth ages 14-19, and *Transition Age Group* (TAG) for young adults ages 17-25. Both groups serve as an educational and social support group for youth and young adults with mental health conditions.

  Some of the group's projects have included: development and distribution of public service announcements on mental health stigma; participation on radio and cable shows 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; presentations at community colleges; and, volunteering with community service projects (i.e., sponsoring a family in need, volunteering at an animal shelter). The youth and young adults meet weekly, and they are provided with dinner and transportation to and from the meetings.

Massachusetts *Youth Position Statements on Restraint/Seclusion*

In 2009, youth and young adults from across the Commonwealth of Massachusetts gathered together during three youth-only forums to develop a position statement on the practice of S/R in treatment settings. More than eighty youth, whose peers and personal experiences with S/R ranged from five times to "too many to count," pooled their collective experience to develop the *Youth Position Statement on Restraint/ Seclusion*. Their experiences included being restrained or secluded in acute and continuing care hospitals, residential programs, juvenile justice programs, residential schools and public schools.

These youth experts identified reasons why S/R should not be used; offered pragmatic recommendations on alternatives to S/R; and identified essential values necessary to promote youth-driven care across service systems. They also provided dissemination strategies for the position statement such as posting on relevant websites, placing posters of the position statements next to the DMH Human Rights information on walls

at programs and facilities and providing a copy to all youth, staff and family members upon first contact with a hospital or program. When the youth were asked what they hoped the outcome of their work would be, they said, "Restraints hurt everyone: staff, kids, and families; we want all youth to feel safe and protected."

The youth experts recommended two formats of the *Youth Position Statement on Restraint and Seclusion*, one for youth and one for adults, which are included as additional resources at the end of this section of the *Resource Guide*. It is the first position statement on S/R developed by youth in the country. Please see the Additional Resources at the end of this chapter and the back cover of the *Resource Guide* for the *Youth Position on Restraint/ Seclusion.*

Massachusetts *Youth and Family Report Cards*

Youth and families developed the Massachusetts report cards so youth and families can give real-time feedback to residential leaders. They are used at treatment meetings/reviews to provide essential course correction. The report cards are also used at the time of transition/discharge to assess satisfaction with the residential intervention. Copies of the report cards are included as additional resources at the end of this chapter.

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 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-briefer then makes 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 received a federal grant early on to eliminate restraint 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.

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.

- **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 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.

- **Family Partners/Mentors**

  Family 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. 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.

Parent experience

Laura H. Myers, MSW, Ed.D., is a parent who has had a great deal of experience navigating mental health services. She is the Director of Parent & Community Engagement for the Department of Psychiatry at the University of Massachusetts Medical School.

The transformation to family-driven care

"The journey for a family whose youth has a mental illness or has experienced a severe trauma that has manifested itself in behavior that brings them to a long term care psychiatric unit is devastating. Whether signs and symptoms revealed themselves prior to adolescence or whether a youth's world

began to fall apart in the early years of that vulnerable developmental stage, the panic, guilt, helplessness and sense of isolation are the same. When we arrive at the locked units to admit our child, we are exhausted and have ourselves been traumatized from the out of control behaviors, the self injuries, the anger and the numerous hospitalizations. We are desperate for relief from the pain for both our child and ourselves.

Like all other residential programs entrenched in the medical model, the Adolescent Treatment Programs at Worcester State Hospital took a long time to understand that families and guardians not only have needs, but we can make a significant contribution to our youth's recovery. It was not understood that we wanted to have a voice as we knew our youth better than anyone else, that we wanted to be on our youth's treatment team so that we could share our significant experience and knowledge, that we wanted to know where our youth slept and ate and to meet their caregivers and friends, and that we wanted to be treated with respect.

Changing a culture's values, assumptions and *modus operandi* requires a commitment from leadership. Several years ago, the Commonwealth's Department of Mental Health and the University of Massachusetts Medical School's Department of Psychiatry supported a move that has been transforming the adolescent units and creating a model that has begun to transition parents from being almost "invisible" to having a strong and involved presence.

As a parent whose youth was in one of these Adolescent Treatment Programs for a year as well as hospitalized in multiple settings, I experienced all the emotions of being made to feel like an “outsider” whose opinion was neither sought nor valued. In my position as Director of Parent and Community Engagement for the UMass Medical School Department of Psychiatry, I work on all four Adolescent Treatment Programs with families, guardians, staff and youth. Over the past two years Family-Driven Care has become a mantra that has moved these programs far beyond what they could have ever imagined would become an integral feature of their cultures, values and routines.

With the unwavering support of administration, an open and flexible staff, and families and guardians who were desperately seeking ways to have their voice heard and to be involved in their youth’s recovery, change created its own momentum. Parents are now on treatment teams, families and guardians attend monthly fun gatherings on the units and are invited to community outings where they get to know the staff as “real people” not just their youth’s clinical team. They are invited to all special meetings concerning their youth. “Skyping” and telephone conference calls make it possible for them to “attend” if they are unable to be present in person. They are acknowledged and their opinions and thoughts requested.

Monthly family/guardian support groups help to provide the encouragement needed as people travel through this devastating and lonely journey of having our youth in a psychiatric residential setting. A parent with lived experience

being there for support during preadmission meetings, leading tours of the units before their youth arrives, and being on the other end of the telephone when they need to talk has dramatically changed the experience of families and guardians. With a parent serving as their voice at morning rounds and at administrative and policy setting committees and being present to provide support when they attend meetings concerning their youth, significant change has been made to the old model. The strategy of "divide and conquer" does not work well for youth when their families are on their treatment teams.

Family-Driven Care has made great strides on the four Adolescent Treatment Programs. What helps to engage families are all the things that have become part of the norm on each unit and the plan for implementation of the future changes that will be put into practice.

Being a youth of the 1960's empowered me to believe that I could be a catalyst for change. During all those painful and devastating years that my daughter and I became dependant on psychiatric settings to ensure her safety and help her reach recovery, I felt so disempowered and invisible. The opportunity to be on a team with such fabulous staff and administrators who are transforming residential care for adolescents gives me great hope that programs can and will become accountable to their consumers."

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
- The *Massachusetts Youth Position Statement on Restraint/ Seclusion* (youth version)
- The *Massachusetts Youth Position Statement on Restraint / Seclusion* (adult version)
- A sample of a Massachusetts Program Report Card for youth developed by youth to give real-time feedback about their residential intervention experience and satisfaction
- A sample of a Massachusetts Program Report Card for parents/ guardians developed by parents/guardians to give feedback about their experience and satisfaction with the residential intervention
- 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 thinks 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

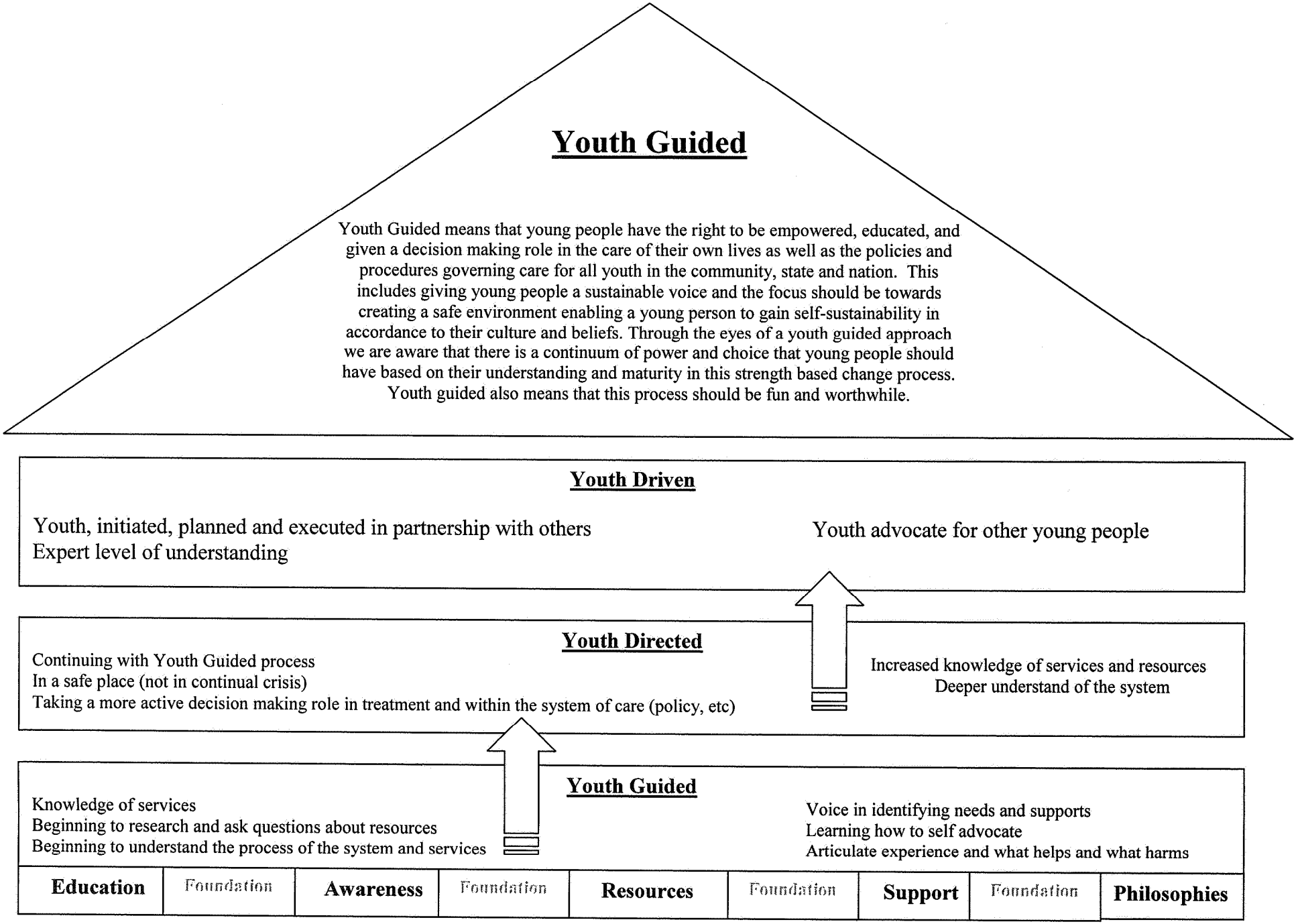
Youth Guided Individual	• Youth is engaged in the idea that change is possible in his or her life and the systems that serve him or her. • Youth need to feel safe, cared for, valued, useful and spiritually grounded. • The program needs to enable youth to learn and build skills that allow them to function and give back in their daily lives • There is a development and practice of leadership and advocacy skills, and a place where equal partnership is valued. • Youth are empowered in their planning process from the beginning and have a voice in what will work for them. • Youth receive training on systems players, their rights, purpose of the system and youth involvement and development opportunities.
Youth Guided Community	Community partners and stakeholders have: • An open minded viewpoint and there are decreased stereotypes about youth. • Prioritized youth involvement and input during planning and/or meetings. • A desire to involve youth • Begun stages of partnership with youth. • Begun to use language supporting youth engagement. • Taken the youth view and opinion into account. • A minimum of one youth partner with experience and/or expertise in the systems represented. • Begun to encourage and listen to the views and opinions of the involved youth, rather than minimize their importance. • Created open and safe spaces for youth • Youth are compensated for their work.
Youth Guided Policy	• Youth are invited to meetings • Training and support is provided for youth on what the meeting is about • Youth and board are beginning to understand the role of youth at the policy-making level • 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. • Adults value what youth have to say in an advisory capacity. • Youth have limited power in decision making. • 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. • Youth are compensated for their work.

Youth Directed

Youth Directed Individual	The young person is: • Still in the learning process. • Forming relationships with people who are supporting them and are learning ways to communicate with team members. • Developing a deeper knowledge and understanding of the systems and processes. • Able to make decisions with team support in the treatment process and has an understanding of consequences. • In a place where they can share his or her story to create change. • Not in a consistent period of crisis and his or her basic needs are met.
Youth Directed Community	• Youth have positions and voting power on community boards and committees. • Youth are recruiting other youth to be involved throughout the community. • There is increased representation of youth advocates, and board and committee members throughout the community. • Everyone is responsible for encouraging youth voice and active participation. • Community members respect the autonomy of youth voice. • The community is less judgmental about the youth in their community • Youth are compensated for their work.
Youth Directed Policy	• Youth understand the power they have to create change at a policy making level. • Youth are in a place where they understand the process behind developing policy and have experience being involved. • Youth have an enhanced skill set to direct change. • Youth have understanding of the current policy issues effecting young people and be able to articulate their opinion on the policy. • Policy makers are in a place where they respect youth opinions and make change based on their suggestions. • All parties are fully engaged in youth activities and make youth engagement a priority. • Youth receive increased training and support in their involvement. • There is increased dialogue during meetings about youth opinions and action is taken. • There is increased representation of youth and a decrease in tokenism. • Equal partnership is evident. • Youth are compensated for their work.

Youth Driven

Youth Driven Individual	• The youth describes his or her vision for the future. • The youth sets goals for treatment with input from team. • The youth is aware of his or her options and is able to utilize and apply his or her knowledge of resources. • Youth fully understands his or her roles and responsibilities on the team. • The youth and all members of the treatment team are equal partners and listen and act upon youth decisions. • The youth facilitates open lines of communication and there is mutual respect between youth and adults • 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. • The youth knows how to communicate his or her needs. • Youth are mentors and peer advocates for other youth. • Youth are giving presentations based on personal experiences and knowledge. • The youth is making the transition into adulthood.
Youth Driven Community	• Community partners are dedicated to authentic youth involvement. Community partners listen to youth and make changes accordingly. • Young people have a safe place to go and be heard throughout the community. • There are multiple paid positions for youth in every decision making group throughout the system of care and in the community. • Youth are compensated for their work. • Youth form and facilitate youth groups in communities. • Youth provide training in the community based on personal experiences and knowledge.
Youth Driven Policy	• Youth are calling meetings and setting agendas in the policy making arena • Youth assign roles to collaboration members to follow through on policy. • Youth hold trainings on policy making for youth and adults. • Youth inform the public about current policies and have a position platform. • Youth lead research to drive policy change. • Youth have the knowledge and ability to educate the community on important youth issues. • Youth are able to be self advocates and peer advocates in the policy making process. • Youth are compensated for their work. • Community members and policy makers support youth to take the lead and make changes.


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.
Youth Driven
Youth, initiated, planned and executed in partnership with others
Expert level of understanding
Youth advocate for other young people
Youth Directed
Continuing with Youth Guided process
In a safe place (not in continual crisis)
Taking a more active decision making role in treatment and within the system of care (policy, etc)
Increased knowledge of services and resources
Deeper understand of the system
Youth Guided
Knowledge of services
Beginning to research and ask questions about resources
Beginning to understand the process of the system and services
Voice in identifying needs and supports
Learning how to self advocate
Articulate experience and what helps and what harms
Education
Foundation
Awareness
Foundation
Resources
Foundation
Support
Foundation
Philosophies

Youth Position Statement on Restraint/Seclusion

Created by The Massachusetts Statewide Youth Experts

In August, September, and December, 2009, eighty youth from across the state of Massachusetts gathered together for youth-only forums to develop a position statement on restraint and seclusion prevention. These forums were comprised of youth experts who experienced restraint and seclusion in mental health, child welfare, juvenile justice and school settings. Their experiences with restraint and seclusion included witnessing restraint and seclusion used with peers and personal experiences ranging from five times to "too many to count." The results of these youth forums are listed below. The youth proposed reasons, practices and values to prevent the use of restraint and seclusion:

1) Restraint and seclusion should be prevented because they:

a. are overwhelmingly traumatizing experiences and emotionally stressful for youth, staff, and families
b. injure youth and staff and cause a loss of self-respect and dignity
c. impact relationships and create a loss of trust between youth and staff
d. slow treatment progress for youth and result in longer treatment
e. make people scared and can trigger other youth
f. create an unsafe unit with unsafe behaviors

2) Things that help prevent restraint and seclusion are:

a. using sensory strategies such as comfort rooms, music, coping skills, and blanket wraps
b. having the support and leadership of peers
c. creating comfortable environments that feel more like home
d. having more individual time with staff
e. allowing appropriate physical contact – youth need contact, too
f. conducting community meetings and encouraging participation in activities such as sports, art, and music can be helpful for youth
g. using strong communication skills and listening skills
h. encouraging youth to be active and fully engaged in their treatment
i. using nonjudgmental positive language and tone of voice and nonthreatening body language
j. respecting confidentiality
k. eliminating the use of point and level systems

3) The values that all programs should adopt to prevent restraint and seclusion are:

a. communication
b. patience and understanding
c. respect and appreciation
d. compassion and support
e. recovery
f. acceptance
g. confidence
h. honesty
i. responsibility

We the Youth of Massachusetts,

in order to form more trauma-sensitive and positive healing environments, provide choice for youth, and to ensure that all youth feel safe, protected, and respected do ordain and establish this Youth Position Statement on Restraint and Seclusion

Article I.

We believe restraint and seclusion should be prevented because they are overwhelmingly traumatizing experiences that are emotionally stressful for youth, staff, and families. Restraint and seclusion can physically hurt youth and staff. In addition, they emotionally hurt and cause a loss of self-respect, dignity, and trust between youth and staff. Restraint and seclusion can also
hurt an entire unit/program/classroom by making people feel scared, unsafe, trigger other youth, and delay treatment progress.

Article II.

We believe these helpful practices should be used instead in order to prevent restraint and seclusion. These positive practices can help youth feel better and more hopeful.

♦ Create a safe and supportive environment that is comfortable and home-like that teaches alternatives like sensory strategies, comfort rooms, music, and blanket wraps and uses positive language: words, tone, and body language. Provide youth with activities such as: sports, art, music, individual support and attention, and appropriate physical contact.

♦ Create a respectful environment that promotes youth involvement, peer leadership, and peer support. Give youth a voice in the program: hold Community Meetings and create Youth Councils. Encourage youth to be active in their treatment. Respect every youth's right to confidentiality and show respect by listening to youth and communicating with youth. Eliminate point and level systems.

Article III.

We believe all programs should embrace essential values
in order to prevent restraint and seclusion. Important values that reflect good care should be adopted such as: communication, recovery, confidence, honesty, responsibility and respect. Other essential values that reflect kindness should be embraced as well, including: acceptance, patience, compassion, support, appreciation, and understanding.

Massachusetts Department of Mental Health
Program Report Card Youth Version

Youth Name: **Date of Birth:**

Program Name: **Date Completed:**

	In the program:	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1	**I got to choose my treatment goals.**					
2	**Staff supported me.**					
3	**I had someone to talk with when I had a hard time.**					
4	**I felt respected.**					
5	**I felt safe here.**					
6	**I felt heard here.**					
7	**Overall, I am satisfied with my care.**					

Comments:

	As a result of the services here:	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
8	**I cope better, even when things go wrong.**					
9	**I get along better with the important people in my life.**					
10	**I am doing better in school and/or work.**					

Comments:

Massachusetts Department of Mental Health
Program Report Card Youth Version

What was helpful for you here?

What would you change about the program?

Overall, I'd give the program a grade of: _____ (A,B,C,D,F)

Thanks for taking the time to answer these questions!
This survey was adapted from the State Indicator Project and the Family Satisfaction Questionnaire.

Massachusetts Department of Mental Health
Program Report Card Parent/Guardian Version

Youth Name: **Date of Birth:**

Program Name: **Date Completed:**

	In the program:	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
1	I helped to choose my child's treatment goals.					
2	I was part of my child's care and treatment.					
3	Staff respected my family's religious and spiritual beliefs.					
4	Staff were sensitive to my family's cultural and ethnic background.					
5	Overall, I am satisfied with the services my child received.					
6	I would recommend this program to friends and family.					

Comments:

	As a result of the services my family and I received:	Strongly Disagree (1)	Disagree (2)	Undecided (3)	Agree (4)	Strongly Agree (5)
7	My child copes better, even when things go wrong.					
8	My child gets along better with family members.					
9	My child gets along better with friends and other people.					
10	My child is doing better in school and/or work.					

Comments:

Massachusetts Department of Mental Health
Program Report Card Parent/Guardian Version

What has been most helpful about the services you and your child received here?

What would improve the care you received here?

Overall, I'd give this program a grade of: _____ (A,B,C,D,F)

Thanks for taking the time to answer these questions!

This survey was adapted from the State Indicator Project and the Family Satisfaction Questionnaire.

SOURCE 01 STUDY # ID #____
INITIALS: ___ DATE COMPLETED_____

RECOVERY ASSESSMENT
FINDING THE HIDDEN ASSETS TO RECLAIM A LIFE

SYMPTOM HIGHLIGHTS	MEDICAL HIGHLIGHTS	BEHAVIOR HIGHLIGHTS

SOURCE 01 STUDY # ID #____
INITIALS: ___ DATE COMPLETED_____

NEUROPSYCHOLOGICAL HIGHLIGHTS

SOCIAL HIGHLIGHTS

STRENGTHS AND SKILLS

WISHES AND DREAMS

CURRENT PLAN

SOURCE 01 STUDY # ID #____
INITIALS: ___ DATE COMPLETED_____

THE HIDDEN ASSETS

OTHER POTENTIAL UNTAPPED RESOURCES

PROPOSED STRATEGIES

Giving People a Voice, Choice, and Role

Bluebird, G. (2007). *Paving new ground: Peers working in in-patient settings.* National Association of State Mental Health Program Directors, National Technical Assistance Center. http://www.nasmhpd.org/general_files/publications/ntac_pubs/Bluebird%20Guidebook%20FINAL%202-08.pdf

Goldstein, A.P., Sprafkin, R.P., Gershaw, N.J., & Klein, P. (1980). *Skillstreaming the adolescent.* Champaign, Illinois: Research Press.

Merriam-Webster Dictionary. (1997). Springfield, MA: Merriam-Webster.

Parent/Professional Advocacy League. (2007). www.ppal.net

Wallerstein, N. (2006). *What is the evidence on effectiveness of empowerment to improve health?* (Health Evidence Network report). Copenhagen: World Health Organization Regional Office for Europe. http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf