The Peter and Elizabeth C. Tower Foundation

Strategic Plan

Date of Adoption: September 24 2012

EXTERNAL COPY (MAY BE DISTRIBUTED)

THE PETER AND ELIZABETH C. TOWER FOUNDATION

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Contents

THE PETER AND ELIZABETH C. TOWER FOUNDATION

I.OVERVIEW

The Peter and Elizabeth C. Tower Foundation was established in 1990 with contributions from Peter and Elizabeth C. Tower. To date, the Foundation has distributed approximately $28 million in grant awards. Grant awards have been made in a variety of areas, including mental health, developmental and intellectual disabilities, evidence-based practice as well as technology planning and implementation initiatives, and community partnerships.

In 22 years, the Foundation has grown in scope and size. Initially managed solely by an Executive Director, the Foundation currently employs an Executive Director, three Program Officers, and two Administrators. Presently, the Foundation maintains assets of approximately $72 million and awards an average of $2.5 million in grants annually. In the next few years, grant awards are expected to average $7 million annually.

Highlights of more recent accomplishments and exemplary project funding include:

- *Rapid Pediatric Psychiatric Consultation Initiative – Erie County*
  Through this initiative, primary care doctors are able to consult with pediatric psychiatrists by phone for assessment and on-going case management of their patients. This model provided an immediate solution to the severe shortage of pediatric psychiatrists in the community and provided psychiatric support in the primary care setting. The model was so successful it was adopted by the New York State Department of Mental Health and is being replicated in other communities across the state. It was a Foundation grant that bridged this critical gap and seeded this very important work.
- *Data Driven Instruction Initiative – Entire Geographic Footprint*
  This five-year special initiative provides training and technical assistance to support teachers' use of data to improve classroom instruction. School districts in the Foundation's geographic footprint were selected to participate. While the initiative is not yet complete, The Foundation already is seeing positive trends and encouraged about the culture shift happening in the schools. Teachers are seeing the merit of using data and are embracing informed instruction as a way to improve performance.
- *Technology Grants – Throughout Footprint*
  The Foundation has always supported efforts to strengthen the capacity of partner organizations. One way this is done is through technology grants. The Foundation has awarded more than $2,150,00 to 23 organizations for technology planning and implementation, providing agencies the ability to develop and upgrade the systems needed to work in a more efficient and effective manner.
- *Institute for Trustees – Essex County*
  The Essex County Community Foundation holds this annual training session for individuals serving on Boards. The one-day training covers a wide range of topics and has been considered very successful. The feedback from attendees, especially the novice board member, has been very positive. Board development is an important part of the Foundation's capacity-building efforts.

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [4]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

While the Foundation continuously has operated to assist targeted populations – using defined, embedded criteria addressing specific funding categories – and though it has sustained grant cycles on a regular annual calendar, certain key factors are helping to reshape its operations. Integral among these future-defining influences are:

- A change in executive leadership
- A transition in generational leadership
- An overall trend toward collaboration
- An anticipated, significant asset infusion, and
- The culmination of a strategic planning process in which the entire organization – Foundation Trustees and staff – has been intimately engaged.

The strategic planning process, expressly, has led to an internal operational refinement that will allow the Foundation to maximize resources and grow its outward effect. Much of these process improvements and external gains will be the result of the adoption of:

- A pre-emptive and prescriptive grant-making model
- Results-based accountability in funding
- A nested funding structure
- An open-source grant management database.

Perhaps the most vital directive is the aim for greater collective impact in the form of strong support for healthy communities and capacity building, both enriching our focus and furthering our affect on substance abuse, learning and intellectual disabilities, and mental illness.

The predicted outcome of our strategic planning process is two-fold:

- A more tactical, tangible, and traceable set of operational guidelines that more easily flow into successful Foundation work plans for staffing, solicitation, communication, evaluation, and asset distribution; and
- A more agile Foundation – one that is able to better support activities at multiple levels and from a variety of angles.

The upshot is, in addition to continuing its role in detailed programmatic support, the Foundation will be positioned to function as a leader in partner strengthening and coalition building in desired areas. The expected result is a powerful and deep cumulative effect on communities over time. With a future asset infusion, this positive result should intensify.

II.STRATEGIC STATEMENTS

In order to best guide our operations moving forward, an updated set of guiding statements—mission, vision, and value—are presented for adoption herein. We've retained the existing single-sentence mission and vision statements; the value statement is new. We've then added a sentence or two to each area, in an effort to highlight the results of our strategic work.

Mission Statement

The Peter and Elizabeth C. Tower Foundation supports community programming that results in children, adolescents, and young adults affected by substance abuse, learning disabilities, mental illness, and intellectual disabilities achieving their full potential. The Foundation is dedicated to societal impact through healthy communities and capacity building. We work diligently to foster a sense of empowerment and an environment of collaboration.

Vision Statement

The Peter and Elizabeth C. Tower Foundation will serve as a strategic partner and catalyst for positive community change. The Foundation believes in the power of sustainable, healthy communities and the effectiveness of coalitions and self-advocacy—success as measured by stakeholder partnership and growth as defined by constituent action and understanding. We hope to inspire others to honor strength in difference and identify opportunity in challenge.

Value Statement

The Peter and Elizabeth C. Tower Foundation disperses assets strategically, to fund community programs and projects that boost societal and partner capabilities and lift young individuals to an enhanced quality of life. We prioritize funding that leads to improved systemic and organizational capacities in screening/assessment, education/awareness, transition/service navigation, evidence-based practice, efficiency, and technology solutions in Erie and Niagara County, NY and Barnstable, Dukes, Essex, and Nantucket County, MA.

The next section moves these guiding concepts into daily practice, detailing the results of our strategic planning process and the impact on day-to-day operations.

III. FROM THEORY TO PRACTICE

All foundations hold a philosophy that shapes their "theory of change" or beliefs about the nature and intensity of intervention that will best facilitate the types of change they seek to make. For The Peter and Elizabeth C. Tower Foundation, this ideology is based in a strong desire for healthy communities.

Early on in the strategic planning process, Foundation Trustees and staff were asked to define what a healthy community looked like. They described communities that seek to help children and adolescents affected by substance abuse, mental health, learning disabilities, and intellectual disabilities to achieve their full potential. They discussed the importance of creating a safety net and promoting community-wide health and wellness through cooperative integrative networks that build capacity and mobilize for social change. They highlighted the importance of partnering with like-minded providers and funders to create environments that enable community members to secure and maintain high quality of life and productivity.

From these varied definitions came an overarching Healthy Communities vision and strategy.

> *The Peter and Elizabeth C. Tower Foundation's vision for a Healthy Community is one in which young people live high quality, purposeful, fulfilling lives. Through its Healthy Communities approach, the Foundation aims to improve the health and wellness of children, adolescents, and young adults facing or at risk for intellectual disabilities, learning disabilities, mental illness, and substance abuse.*

> *The Tower Foundation's strategy for Healthy Communities involves convening local stakeholders to identify the issues and needs relevant to children, adolescents, and young adults in their communities. In response to these needs, the Foundation seeks to collaborate with new and existing community coalitions to foster cooperative, integrated systems that deliver effective, holistic, accessible services.*

In order to put this vision and strategy into regular practice, Trustees and staff engaged in an exercise to clarify their grantmaking goals based on Joel Orosz's *The Insider's Guide to Grantmaking: How Foundations, Find, Fund, and Manage Effective Programs*. The exercise required members of the Board of Trustees and staff to choose between four basic approaches to grantmaking as described below:

> The Passive Foundation responds to unsolicited requests and does little or nothing more than release general guidelines for giving. The Passive Foundation simply chooses the best proposals available in hand when the funding cycle comes to an end and it usually does very little to share results or lessons learned with others.

> The Proactive Foundation is more energetic in making its interests known to others. It tends to have well-defined priorities and sends its program staff out to actively search for good grantees. While still open to unsolicited requests, the Proactive Foundation

---

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [7]   info@thetowerfoundation.org

generally makes grants clustered around related subjects and they sometimes network their grantees in order to maximize the number of lessons that can be learned from them as well as maximizing benefits to the grantees themselves and to society

The Prescriptive Foundation clearly defines its interests and expects its program officers to identify relatively narrow fields of activity and to concentrate their efforts in those fields. The Prescriptive Foundation tends to do its grant making in an initiative-based format through strategically structured grants with applicants responding to formal and well-defined requests for proposals. The Prescriptive Foundation retains the capacity to respond to a few unsolicited requests, and it sometimes operates its own programs. Its focus is on its defined interests.

The Peremptory Foundation is agenda-driven and focuses on alignment with its core interests. It chooses its grantees directly - sometimes through a request for proposal or through non-public selection. Peremptory Foundations often operate their own programs or initiatives and rarely if ever accept unsolicited proposals.

Based on their interest in identifying their own initiatives as well as receiving requests from the larger community that are aligned with a specified set of goals, Foundation Trustees and staff selected a mixed grantmaking model based on the Prescriptive and Peremptory Foundations described above. This decision enables the Foundation to actively and strategically engage good organizations in partnerships that will ensure needed programming is available within communities. The approach also enables the Foundation to support larger community- and systems-change initiatives and to share information about its efforts with interested parties.

Use of Results-Based Accountability

After defining their Healthy Communities approach and mixed grantmaking model, Trustees and staff sought to identify a methodology that could be used relative to the Foundation's four substantive focus areas: substance abuse, mental health, intellectual disabilities, and learning disabilities. They were also interested in selecting a methodology with a strong emphasis on measurement, collaboration, and capacity building – a practice that is deeply rooted in the Foundation's history.

Results-Based Accountability offers a disciplined way of thinking and taking action to improve quality of life in communities as well as the performance of programs, agencies, and service systems (Friedman, 2005). The approach has been used by countless groups in the United States and around the world and has been lauded as an exceptional method for monitoring the effect of investments in social programming. Results-Based Accountability follows a step-by-step process, which requires participants to consider desired end states (or "results") for specified populations within communities and to determine the means necessary for achieving these results.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Individuals begin use of Results-Based Accountability by identifying their desires for a specified population (i.e., we want children who are healthy, happy, etc.) and crafting easy to understand "results statements" which encapsulate these desires. Participants then identify community-level indicators for use in determining overall progress towards these goals. Initial baseline data are recorded in graphical form on selected community indicators and a story describing current conditions is provided. In addition, possible strategies for addressing community conditions are identified along with a list of partners with a potential role to play. Once key strategies and partners are selected, their performance is also reviewed on a regular basis. Results-Based Accountability operates under the assumption that by improving program- or initiative-based performance, communities' will also see desired changes in related conditions.

One critically important feature of the Results-Based Accountability approach is its emphasis on two levels of measurement: Population and Performance. Population Accountability focuses on the well-being of a specified population and measures results by examining the changes in the community-level indicators (e.g., rates, percentage change) described above. Performance Accountability focuses on the well-being of client populations and seeks to determine the answer to three questions regarding the performance of health and human service programs: How much did we do? How well did we do it? Is anyone better off?

Taken alone, neither of these measures provides a complete picture of the successes or failings of an intervention or set of interventions. Together, however, Population and Performance Accountabilities can provide a powerful and more exacting account of results achieved over time. The approach will enable the Foundation to regularly review progress on identified goals and to share this information with other foundations, health and human service organizations, interested parties, and the community at large.

Secondly, Results-Based Accountability explicitly recognizes that organizations cannot make the kind of community-level changes needed individually. As such, the approach places high priority on the identification of varied partners that have a role to play in achieving specified results. This aspect of the Results-Based Accountability approach specifically connects with the goals of The Foundation and its emphasis on collaborative partnerships.

Finally, Results-Based Accountability regularly highlights opportunities for capacity building – through the regular collection of data at the program performance level, efforts to track progress at the population and program level, inclusion of continuous improvement measures, and use of the Talk to Action reports which identify best practices and strategies to deliver results throughout the process.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Trustees and staff from The Peter and Elizabeth C. Tower Foundation drew on the Results-Based Accountability approach while engaging a six-step process – diagrammed below – to determine key results in each of four substantive focus areas (intellectual disabilities, learning disabilities, metal health and substance abuse).

Determining Results

Planning the Move from Talk to Action

Identifying Indicators, Strategies, & Partners

Engaging Community Members

Crafting Draft Results Statements

Defining Populations of Interest

Defining Populations of Interest

Foundation Trustees and staff began by examining the scholarly literature related to each substantive focus area and developing definitions related to each population being targeted. Within Results-Based Accountability, a population is the group of people being examined or the group for whom strategies and solutions are being developed. As such, it is critically important to be clear as to whom the Foundation is interested in supporting through its investment. In each focus area, children, youth, and young adults (up to age 26 years of age) were selected as the group targeted for primary intervention, as they experience myriad challenges that may hinder their ability to reach their full potential. Families and communities are also identified as being in need of supportive assistance and are identified in select results statements.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

DEFINITIONS RELATED TO POPULATION GROUPS –
THE PETER AND ELIZABETH C. TOWER FOUNDATION

Substance Abuse

The Tower Foundation defines substance abuse as:

> The use of illegal drugs or the use of prescription or over-the-counter drugs or alcohol for purposes other than those for which they are meant to be used, or in excessive amounts. Substance abuse may lead to social, physical, emotional, and job-related problems.

Mental Health

The Tower Foundation defines mental illness as:

> Medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life.

The Tower Foundation has a particular interest in serious mental illnesses, including major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD), and borderline personality disorder.

Intellectual Disabilities

An intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. Intellectual functioning refers to general mental capacity, such as learning, reasoning, and problem-solving.

Adaptive behavior comprises three skill types:

- Conceptual skills (*e.g.,* language and literacy; money; time; number concepts; self-direction)
- Social skills (*e.g.*, interpersonal skills; social responsibility; self-esteem; gullibility; naïveté; social problem solving; ability to follow rules/obey laws and avoid being victimized)
- Practical skills (*e.g.*, personal care; occupational skills; healthcare; travel/transportation; schedules/routines; safety; use of money; use of telephone)

Learning Disabilities

Learning Disabilities are defined as neurological disorders affecting the brain's ability to receive, process, store, and respond to information. These constitute disorders in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest in the imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations. These disorders do not include learning problems that are primarily the result of visual, hearing, or motor abilities, of mental retardation, of emotional disturbance, of traumatic brain injury, or of environmental, cultural, or economic disadvantage.

Crafting Draft Results Statements

As part of their second step, Foundation Trustees and staff went through a series of exercises during which they drew on their understanding of each substantive focus area and began to identify the key results they would like to see achieved. Within Results-Based Accountability, a result is a condition of well-being for children, adults, families and communities, stated in plain language. A result is also sometimes described as an outcome or goal.

Engaging Community Engagement - Vetting Results Statements

After completing a set of draft result statements in each substantive area, the Foundation reviewed these statements at a series of community vetting sessions. Participants included professionals from each respective field; educators; governmental representatives; law enforcement personnel; health and human service practitioners; parents, guardians and other family members; and the individuals directly affected.

During the community vetting sessions, participants were asked to offer their critique of the results statements based on their personal and/or professional experience. More specifically, they were asked to discuss what they liked and did not like about the statements and to identify problems with the language, sentiment, or philosophy. Session participants were also asked to recommend additions and/or modifications to improve clarity and to ensure that statements accurately reflected desired changes within communities.

In total, more than thirty community vetting sessions were held related to the four target areas (six related to substance abuse; eight related to mental health; nine related to intellectual disabilities; eight related to learning disabilities). Sessions took place in Erie and Niagara Counties within New York and Essex, Barnstable, and Dukes Counties in Massachusetts. Feedback from each of the sessions was used to modify draft result statements.

Engaging Community Members - Identifying Possible Indicators, Strategies, and Partners

Participants at community vetting sessions also made suggestions for possible indicators to be used in tracking progress on result statements as well as strategies that might be undertaken to address existing community conditions. They also identified various individuals and organizations that have a potential role to play related to each strategy.

Within Results-Based Accountability, indicators are measures that help to quantify the achievement of a result. These measures typically provide information at the community- or population-level and are useful in tracking community trends. Baseline data are secured on each selected indicator (at least two to three years of) with additional information collected in subsequent years to determine if sufficient progress is being made on a particular goal. Strategies include a wide variety of programmatic, educational, awareness-raising, and other activities undertaken to improve community conditions.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Planning the Move from Talk to Action

Following the community vetting sessions, a set of preliminary materials – known as Talk to Action Reports – were created within each substantive area. These materials included data describing existing conditions within the Foundation's catchment area (when available) as well as review of the literature on suggested strategies – emphasizing best practices and state–of-the-art interventions. Using this information, Foundation Trustees and staff engaged in a series of "Strawman" conversations in order to clarify potential funding interests moving forward.

Determining Results

Finally, Foundation Trustees and staff incorporated feedback from these various sources (e.g., vetting sessions, community data, best practices) to complete results statements in each substantive focus area.

RESULTS STATEMENTS - THE PETER AND ELIZABETH C. TOWER FOUNDATION

SUBSTANCE ABUSE
1. Community members understand the prevalence and harmful effects of alcohol and drugs, and work to address them.
2. Resources for substance abuse prevention, treatment, and recovery are readily available.
3. Families provide safe environments that support healthy and informed choices about alcohol and drugs.
4. Young people make healthy and informed choices about alcohol and drugs.

MENTAL HEALTH
1. Stigma related to mental illness is eliminated.
2. Children with social, emotional, and behavioral challenges are identified early and connected to appropriate services.
3. Young people with mental health challenges understand and manage their conditions and behaviors.
4. Families understand mental health challenges and help members live productive lives.
5. Communities offer meaningful opportunities and appropriate support to young people with mental health challenges and their families.

INTELLECTUAL DISABILITIES
1. Children with intellectual disabilities are identified early and receive services that meet their evolving needs.
2. Young people with intellectual disabilities are engaged in meaningful social, vocational, and educational pursuits.
3. Families understand intellectual disabilities and secure needed supports.
4. Communities embrace persons with intellectual disabilities and provide them with a full-range of supports and opportunities to engage in community life.

LEARNING DISABILITIES
1. Children with learning disabilities are identified early, diagnosed and connected to services that meet their on-going individual needs.
2. Youth with learning disabilities understand how they learn and pursue resources that support them accordingly.
3. Young adults are confident and do not view their learning disability as a liability
4. Young adults with learning disabilities are ready for work and/or educational pursuits
5. Families are informed about learning disabilities and are able to identify and navigate available services.
6. Communities value persons with learning disabilities and accommodate their needs.

IV.FUNDING STRUCTURE

The selection of a nested funding structure (illustrated below) provides The Foundation with the flexibility to support a wide-range of activities that are strategically aligned to achieve the identified results and the overall vision of Healthy Communities. The structure makes it possible for the Foundation to fund (or otherwise support) activities that operate at multiple levels – from individual- and family-focused programming to organizational capacity building efforts to initiatives that focus on the broader community – in an effort to change prevailing social norms, policies, and systems. It is anticipated that this manner of funding will yield a powerful cumulative effect and lead to improvements in community conditions over time.

The funding structure includes three major components.

First, the structure incorporates opportunities to fund core programs and services that seek to prevent (where possible) or directly address the needs of individuals and families affected by substance abuse, mental illness, intellectual disabilities, and learning disabilities.

The table on the next page lists various strategies identified at community vetting sessions and determined to be of "greatest interest" to the Foundation following a review of best practices and use of Strawman exercises. Notably, there is considerable overlap in the types of services needed within each of the Foundation's four substantive focus areas.

The identified activities will be incorporated into four funding categories: screening and assessment, individual education (for young children, adolescents, and young adults), family education, and transition/service navigation. This incorporation will make it possible to

standardize language used to describe Foundation funding interests and to measure performance across disciplines. It will also allow the Foundation to fund efforts that cross long-established disciplinary silos to more effectively address he wide variety of co-occurring conditions experienced by individuals today.

---

a) STRATEGIES IDENTIFIED OF GREATEST INTEREST –
THE PETER AND ELIZABETH C. TOWER FOUNDATION

SUBSTANCE ABUSE
- Prevention Programming
- Life Skills Development
- Peer Mentors
- Screening and Assessment Activities
- Transitional Support/Service Navigation
- Family Education on Substance Abuse
- Family Peer Support

INTELLECTUAL DISABILITIES
- Screening and Assessment
- Life Skill Development
- Peer Mentors
- Recreational Programming (Art, Music)
- Educational Advocates
- Career Preparation and Engagement
- Transitional Supports/Service Navigation
- Family Education on Intellectual Disabilities
- Family Peer Support

MENTAL HEALTH
- Screening and Assessment
- Use of Socio-Emotional Curriculums
- Life Skills Development
- Peer Mentors
- Educational Advocates
- Transitional Supports/Service Navigation
- Family Education on Mental Illness
- Family Peer Support

LEARNING DISABILITIES
- Screening and Assessment
- Life Skill Development
- Peer Mentors
- Use of Technology (Kurzweil, iPads)
- Recreational Programming (Art, Music)
- Educational Advocates
- Career Preparation and Engagement
- Transitional Supports/Service Navigation
- Family Education on Learning Disabilities
- Family Peer Support

Second, the Foundation will continue to serve as a leader in its support of efforts to strengthen organizations and programs within each of its substantive focus areas. This will include providing training dollars or otherwise supporting staff members who incorporate evidence-based practices into their programming; funding innovative projects aimed at increasing organizational efficiencies and/or effectiveness; offering technology solutions to support strategic and programmatic goals; and engaging in other forms of capacity building. Once again, funded activities may be population-specific or may be universal in scope. These efforts are undertaken in the hope of bolstering partner organizations and advancing the substance abuse, mental health, intellectual disabilities, and learning disabilities fields.

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [16]   info@thetowerfoundation.org

Finally, the Foundation will seek to support broader initiatives (including coalition-based activities) aimed at improving system responsiveness through improved coordination; providing opportunities for professional development related to the Foundation's four substantive focus areas for individuals who do not work in these fields (e.g., physicians, nurses, child care workers, educators, first responders); engaging community members in greater education and awareness-raising activities; and supporting the development and/or modification of policies that impact the lives of individuals experiencing substance abuse, mental illness, intellectual disabilities, and learning disabilities and their families.

These latter activities will require greater engagement of community partners potentially including, but not limited to: child care and Head Start workers, teachers, educational administrators, other school personnel, school district leaders, academics, health and human service professionals, physicians, nurses, other health professionals, government, public officials, first responders, courts, businesses, non-profit organizations, media outlets, faith and community groups, block clubs and other neighborhood organizations, parents and guardians, and the individuals directly affected.

Overall, the nested funding structure will provide the Foundation with opportunities to initiate ("seed") and extend ("stem") various activities. Community partners will be able to identify activities for funding based on their assessment of need or activities may be identified and initiated by the Foundation itself.

Funding Criteria
To operate as effectively and efficiently as possible, Foundation Trustees and staff have already begun to identify criteria to be used to ascertain the "goodness of fit" between the Foundation's goals and the various funding applications.

All applicants will be screened related to their alignment with Foundation mission and goals, connection to specific result statements, and ability to address the needs of targeted population group(s).

In the Healthy Communities area, the Foundation will seek funding partners that have:
- A clear plan and the capacity to deliver on that plan
- Appropriate buy-in from a range of stakeholders/members
- Ability to leverage available resources and to sustain the effort
- Measurable outcomes and plan for evaluation.

The Foundation will also look for opportunities to make a critical difference in project efforts while seeking out other collaborators who are interested in supporting the project monetarily or through other resources. When possible, applicants should attempt to devise interventions that can be replicated and/or used in other organizations or communities.

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [17]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Related to opportunities to strengthen partners, Foundation Trustees and staff have expressed interest in funding efforts that:

- Improve quality and/or variety of services available to clients
- Improve efficiency or effectiveness by freeing up time and talent
- Create or support leadership
- Offer opportunities to sustain and potentially replicate an intervention
- Promote greater accountability.

Finally, core programs and services must be able to demonstrate a(n):

- Ability to develop and use an appropriate project design or business plan
- Awareness of required resources necessary for their program or service
- Strong organizational and/or programmatic leadership or capacity
- Familiarity with program evaluation and the ability to secure specific measureable results.

V.ADDENDA

On the following pages are addenda deemed useful as supplements to this document.

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [19]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Results-Based Accountability Definition Page

Results-Based Accountability Definitions

Population: Identify the group that is being examined or for whom strategies and solutions are being developed.

Result: A result is a population condition of well-being for children, adults, families and communities, stated in PLAIN Language. Keep it simple and easy to understand. Results are sometimes known as outcomes or goals.

Examples:

- Healthy Children
- Children Ready for School
- Children Succeeding in School
- Strong Families
- Elders Living in the Community with Dignity
- A Safe Community
- A Clean Environment

Indicators: Measures that help quantify the achievement of a result and answer the question, "How would we recognize this result if we fell over it?" Tells us if we are getting results or not. Should list several indicators and choose the best one(s) based on Communication Power, Proxy Power, and Data Power as defined below.

- *Communication Power* – Does the indicator communicate to a broad and diverse audience?
- *Proxy Power* – Does the indicator say something of central importance about the result?
- *Data Power* – Do you have quality data on a timely basis? Is the data reliable and consistent? To what extent do you have data at the state, county, city, and/or community levels?

For each indicator, you will want to locate baseline information.

NOTE: Sometimes the process of identifying indicators highlights the need to secure or develop data collection strategies. This is known as a Data Development Agenda.

Story Behind the Baselines: What is the story behind the baseline? What are some of the causes and forces at work in your community for this indicator? If we can understand the primary causes, we can decide which actions to take. Ask the question "why" three times to get at root causes.

Questions:
- What are the key factors that make this indicator worse?
- What are the key contributing factors to improving this indicator?

Partners with a Role to Play: Who are the partners with a role to play in helping you do better? Each partner has something important to contribute to turning the curve.

What Works? Examine the research literature and brainstorm what works to address these causes and forces. Include at least one low-cost, no-cost idea as well as at least one off-the-wall, outrageous idea. Select your top these ideas by addressing the questions below

What strategies can help you to "turn the curve?"
- *Specificity*: Is the strategy specific enough to be implemented? Can it actually be done?
- *Leverage*: Does the strategy have the leverage to "turn the curve"? How much difference will the proposed action make on results, indicators and turning the curve?
- *Values*: Does the strategy meet community, organizational, cultural and systems of care values? Is it consistent with what we stand for and how we work?
- *Reach*: Is the strategy feasible and affordable? Can it actually be done and when?

Action Plan and Budget: What needs to be done first, by whom, and what will it cost?

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [20]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Alphabetical List of Individuals and Entities Touched by the Strategic Planning Process

Individuals & Entities Touched by the Strategic Planning Process	
Individuals/Independent Advocates	**State**
Education Consultant	-
Parents - Gow School	NY
Parents - Martha's Vineyard Regional High School	MA
Parents of Children with Addiction Issues	NY, MA
Parents of Children with Intellectual Disabilities	NY, MA
Parents of Children with Mental Health Issues	NY, MA
Students - Gow School	NY
Young Adults with Mental Health Issues	NY, MA
Agencies/Organizations	**State**
Albion Public Schools	NY
Alcohol and Drug Dependency Services, Inc.	NY
Amesbury Public Schools	MA
Anchor to Windward, Inc.	MA
Aspire of WNY	NY
Association for Behavioral Healthcare (ABH)	MA
Autistic Services	NY
Baker Victory Services	NY
Bringing People & Services Together (BAMSI)	MA
Barnstable Counseling Associates (also Cape Cod Justice for Youth Collaborative)	MA
Beacon Center	NY
Big Brothers Big Sisters of Erie County	NY
Bornhava	NY
Bridgewell	MA
BryLin Hospitals, Inc.	NY
Buffalo Federation of Neighborhood Centers, Inc.	NY
Buffalo Hearing & Speech Center	NY
Cantalician Center for Learning	NY
Cape Behavioral Health Center	MA
Cape Cod Child Development	MA
Cape Cod Child Development-Early Intervention	MA
Cape Cod Child Development-Head Start	MA
Cape Cod Justice for Youth Collaborative	MA
Cazenovia Recovery Systems, Inc.	NY
Center for Health and Social Research	Buffalo State College	NY
Child and Adolescent Treatment Services (CATS)	NY
Child and Family Services	NY
Children's Friend and Family Services	MA
Children's League of Massachusetts	MA
Clarence High School	NY
Clarence Police Department	NY
Class	MA
Clearview Treatment Services	NY

Coastal Connections, Inc.	MA
Community Action Organization of Erie County	NY
Community Connection of WNY	NY
Community Connections, Inc.	MA
Community Health Center of Buffalo-Niagara	NY
Community Health Center of Cape Cod	MA
Community Services for Developmentally Disabled, Inc.	NY
Compass House	NY
Compeer of Greater Buffalo	NY
Council on Addiction Recovery Services, Inc. (CAReS)	NY
Cradle Beach Camp	NY
Crisis Services	NY
Edgartown School	MA
Eliot Community Human Services	MA
Erie 1 BOCES	MA
Erie Community College	MA
Erie County Council for the Prevention of Alcohol and Substance Abuse, Inc.	NY
Erie County Dept. of Mental Health	NY
Erie County Dept. of Mental Health	NY
Erie County Medical Center Outpatient Chemical Dependency Services	NY
Erie County Senior Services	NY
Erie County Sheriff's Department	NY
Essex County Community Foundation (facilitated by NCHC) Danvers, MA	MA
Excalibur Leisure Skills Center, Inc.	NY
Falmouth Human Services	MA
Family Continuity	MA
Fellowship House, Inc.	NY
Gateway-Longview, Inc.	NY
Goodwill Industries	NY
Gosnold on Cape Cod	MA
Grace Community Services	NY
Group Ministries, Inc.	NY
Harwich Youth Services	MA
Healing Abuse Working for Change (HAWC)	MA
Healthy Community Alliance, Inc.	NY
Heritage Centers	NY
Heritage Christian Services	NY
Horizon Health Services	NY
Horizon Village	NY
Jewish Family Service of Buffalo and Erie County	NY
Kaleida Health	NY

2351 North Forest Road
716 689-0370
Getzville, NY 14068-1225
(fax)
716 689-3716
www.thetowerfoundation.org
[22]
info@thetowerfoundation.org

Kennedy Donovan Center - Family Support	MA
Kids Escaping Drugs	NY
Lake Shore Behavioral Health	NY
Landmark School	MA
Latham Centers	MA
Learning Disabilities Association of Western New York	NY
Lew-Port Public Schools	NY
Lyndonville Public Schools	NY
Lynn Community Health Center	MA
Lynn Public Schools	MA
Martha's Vineyard Community Services	MA
Martha's Vineyard Regional High School- Special Education	MA
Martha's Vineyard Schools	MA
Massachusetts Rehabilitation Commission	MA
Massachusetts Society for the Prevention of Cruelty to Children (MSPCC)	MA
May Institute | Department of Developmental Services	MA
Mental Health Association of Erie County	NY
Mid-Erie Counseling and Treatment Services	NY
Monsignor Carr Institute	NY
National Association of Mental Illness (NAMI) Cape Cod	MA
National Association of Mental Illness (NAMI) MA	MA
Native American Community Services	NY
New Directions Youth and Family Services	NY
New Life Residential Center, Inc.	NY
New York State Education Department	NY
New York State Office of Mental Health | Western Office	NY
Niagara Cerebral Palsy	NY
Niagara County Health Department/Special Needs Division	NY
Niagara County Mental Health Association	NY
Niagara University	NY
Niagara Wheatfield Central School District	NY
Northeast ARC	MA
Northeast Behavioral Health	MA
Northeast Center for Healthy Communities (NCHC) Lawrence, MA	MA
Northpointe Council, Inc.	NY
Northshore Education Consortium	MA
Oak Bluffs School	MA
Opportunities Unlimited of Niagara	NY
Orleans-Niagara Board of Cooperative Educational Services	NY
Parent to Parent of New York State	NY

Peabody Public Schools	MA
People and Possibilities, Inc. (subsidiary Niagara Falls Housing Authority)	NY
Plummer Home for Boys	MA
Preventionfocus, Inc.	NY
Professional Center for Child Development	MA
Research Institute on Addictions	MA
Rivershore, Inc.	NY
Roy Hart Learning Center	NY
Seven Hills Community Services	MA
Spectrum Human Services	NY
Stutzman Addiction Treatment Center	NY
Suburban Adult Services, Inc.	NY
Summit Educational Resources	NY
Tisbury School Principal	MA
Tri-Town School Union	MA
Turning Point, Inc.	MA
United States Drug Enforcement Agency	-
University at Buffalo Social Work	NY
University Psychiatric Practice (@ UB)	NY
Villa Maria College	NY
West Tisbury School	MA
Western New York United Against Drug and Alcohol Abuse	NY
Windrush Farms Therapeutic Equitation, Inc.	MA
WNY Developmental Disabilities Service Office (DDSO)	NY
WNY Independent Living, Inc.	NY
END OF LIST	-

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

[24]

716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Copies of Stakeholder Reports (4)

SUBSTANCE ABUSE FOCUS GROUPS
FOLLOW UP REPORT TO STAKEHOLDERS

Focus Group Demographics

Six Focus Groups:
- Erie County (3)
- Niagara County (1)
- Essex (1)
- Lawrence (1)

Stakeholders Involved:
- Substance Abuse Professionals
- Educators
- Government
- Parents/Family Members
- Service Providers
- Community Members

Report Glossary

Result: A result is a population condition of well-being for children, adults, families and communities, stated in plain language. Results are sometimes known as outcomes or goals.

Indicators: Measures that help quantify the achievement of a result and answer the question, "How would we recognize this result if we fell over it?"

Strategy: a plan or method for obtaining a specific goal or result.

Reactions to Original Substance Abuse Results Statements

Statement 1: Children are engaged in positive activities.

Key Themes from Focus Group

- Positive activities do not, in and of themselves, counteract drug and alcohol use – in some cases, positive activities actually encourage drug/alcohol use (e.g. sports teams, student council)
- Positive activities in the community are often offset by non-positive home environments (e.g., parental substance use, absent parents)
- Need for positive activities varies by community
- Focus should be on promoting healthy activities – versus positive activities – and availability of resources in the communities of concern (access, availability, affordability)

Statement 2: Youth make healthy choices about alcohol and drugs.

Key Themes from Focus Group

- Some debate in the field about youth being able to make healthy choices about alcohol and drugs (abstinence only vs. experimentation of youth vs. move to addictions)
- Youth need to make informed choices about alcohol and drugs
- Need to address social pressures found among youth today – not just one on one peer pressure anymore – media, social groups, family pressures
- Concerns about self-medication because of the lack of other needed resources (e.g. mental health services, dual diagnosis treatment)

Statement 3: Children (and youth) have a safe place to go with adequate personal support.

Key Themes from Focus Group

- Implies that communities need only "one" safe place for children and youth to go when, in fact, children and youth need a variety of places and people that they can turn to
- Need different types of venues for different types of kids
- Highlight concerns about accessibility and availability of safe places (e.g., transportation concerns)
- Concerns about the term "adequate" which is really about the bare minimum – appropriate personal supports are needed

Statement 4: Community members are aware of the dangers of substance abuse.

Key Themes from Focus Group

- Needs to be much more than education and awareness about the dangers of substance abuse – greater commitment to wellness, understanding of prevalence and severity, actively working to address concerns
- Challenge and address social norms; increase accountability of parents, schools, police, courts, and other community members
- About changing social values regarding acceptance and tolerance regarding substance use and abuse
- Should emphasize alcohol, drugs, and use of medications not just "substance abuse"

Statement 5: Community provides supportive services to meet identified needs.

Key Themes from Focus Group

- Must focus on substance abuse services – too vague
- Should look at substance abuse prevention, intervention, recovery – provision of a full continuum of services and multiple treatment interventions (including dual diagnosis)
- Need to make sure community supports are available, accessible and affordable
- Must also work to address silos across various systems (courts, schools etc) including policy

Other thoughts

- Need to focus on families as a source of negative or problem behaviors (intergenerational transmission of alcohol and drug use/abuse; permissive parents)
- Families can disrupt all the good done in schools/social programs in a matter of hours
- Families should be engaged in programming with children and youth

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Revised Substance Abuse Results Statements and Suggested Measures Using Focus Group Input

Foundation staff revised the original Substance Abuse statements based on strength of commentary and key themes. In their revision, Foundation staff focused on:

- Community Awareness/Education/Action;
- Resources (various levels from prevention to recovery);
- Importance of Family; and
- Role of Young People Themselves (Children, Adolescents, and Young Adults)

REVISED STATEMENTS
Note: The revisions resulted in one less results statement.

Statement 1: Community members understand the prevalence and harmful effects of alcohol and drugs, and work to address them.

> Reflects the importance of safe and supportive environment

Possible Indicators/Measures:
- Community Survey on Substance Abuse
- Policies to Address Youth-Related Substance Abuse Passed/Implemented
- Arrests – Youth-Related Substance Abuse
- Media Coverage (Positive/Negative/Neutral)
- Community Events

Statement 2: Resources for substance abuse prevention, treatment, and recovery are readily available.

> Provides a full continuum of supports – emphasizing availability, accessibility, affordability (attractiveness); Encompasses safe/supportive environment, safe/supportive people; safe/supportive activities

Possible Indicators/Measures:
- Environmental Scan (Identification of Available Resources)
- Comparison to Community Standards in Substance Abuse Treatment
- Gaps Analysis
- Waiting Lists

Statement 3: Families provide safe environments that support informed healthy choices about alcohol and drugs.

> Emphasizes the criticality of the home environment

Possible Indicators/Measures:
- Parent/Guardian Surveys
- Court Interventions
- Arrest Rates (Drunk Driving, Underage Drinking, Hospitalizations)
- Media Coverage

Statement 4: Young people make informed, healthy choices about alcohol and drugs.

> Reflects a philosophy that abstinence may not be a realistic option for all young people

Possible Indicators/Measures:
- o Youth Behavioral Risk Survey (Age of Onset, Engagement, Usage)
- o School Discipline Reports

THE PETER AND ELIZABETH C. TOWER FOUNDATION

INDIVIDUAL FOCUS GROUP REACTIONS

2011-05-13
FOCUS GROUP | Providers
Host: Office of Alcohol & Substance Abuse Services (OASAS) Meeting

Review of Original Results Statements

Statement 1: Children are engaged in positive activities.
   Stakeholder Response-
   - What constitutes a positive activity in one community is different from what constitutes a positive activity in another community
   - Positive activities in and of themselves don't necessarily counteract use
   - In many cases, children are involved in positive activities AND drug/alcohol use (e.g., sports teams)
   - Need alternative activities to combat boredom
   - Suggested Change: Children are committed to a healthy lifestyle without drugs and alcohol -OR-
   - Suggested Change: Children are engaged in activities that are free of drugs and alcohol

Statement 2: Youth make healthy choices about drugs and alcohol.
   Stakeholder Response-
   - In the past, smoking was cool. Today, this is less so. What happened? Need to learn more about processes that made smoking uncool – education, awareness of the health effects
   - Combine motivation to change with educational activities

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
   Stakeholder Response-
   - Implies that only one safe place needed
   - Need to have many safe places where children and youth can go
   - Perhaps safe community is better than safe space

Statement 4: Community members are aware of the dangers of substance abuse.
   Stakeholder Response-
   - More than just awareness – need a commitment to wellness (wellbriety)
   - Individual use occurs within a context; social norms and mores are important
   - May want a separate results statement that focuses on normative issues; changing social values (acceptance/tolerance); real consequences
   - Example: Communities maintain policies and norms that discourage misuse of drugs and alcohol
     o Changing social norms about drugs/alcohol
   - Example: Communities hold children, youth and parents accountable -OR- Communities do not condone negative behaviors related to alcohol and drug use
     o Parents are involved in negative behaviors
     o Schools allow behaviors by not punishing or holding people accountable - Example of college students getting good grades but binge drink on the weekends – considered acceptable
     o Communities must have a response to drug/alcohol use that is consistent with community standards
   - Education is not enough – need social policies, changing community norms, zero tolerance

---

Statement 5: Community provides supportive services to meet identified needs.
  Stakeholder Response-
- "Identified needs" is a little vague – treat addiction/addictive behaviors and related issues
- Stronger focus on recovery, wellness
- Recognize substance use as part of a response to trauma
- Add something about related issues as well (e.g., housing, education, vocational, life-skills)

Strategies Associated with Original Results Statements

Statement 1: Children are engaged in positive activities.
- Mentoring
- Exercise/Arts
- Prosocial Behavior – Engagement with Peer Group
- Education on Health and Wellness
- Leadership Development
- Service Learning
- Medicine Wheel Concept: Physical/mental/emotional/spiritual health
- Groups with Parents and Kids (intergenerational activities)
- Strengthening Families Approach
- Harm Reduction
- Life Skills Training
- Prevention Focus – With Recovery Values

Statement 2: Youth make healthy choices about alcohol and drugs.
- Education about drugs/alcohol
- More Advanced Life Skills Training (Youth) - Start young and don't stop
- Fundamentally same strategies as above, just with different age group
- Motivational Interviewing
- Prevention Counseling
- Not just classroom based – interventions in the community
- Dropout Programming
- Aspirational Programming (College/Vocational)
- Develop Positive View of Self - need to develop a positive view about themselves/their futures
- Risk Mitigation Strategies (need to understand vulnerability – e.g., buzzed driving campaign)
- Trauma/Bereavement
- Suicide Prevention

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- Community Centers
- Afterschool Programming

Statement 4: Community members are aware of the dangers of substance abuse.
- Public education campaigns
- Parenting Classes
- Early Intervention
- Zero-tolerance Policies
- Consistency with interventions/consequences; follow through with policy

- Adult self-awareness of alcohol/drug issues and where they fit into things
  - o Especially for families with first generation addiction issues
- Trauma
- Bereavement/Grief and Loss

Statement 5: Community provides supportive services to meet identified needs.
- Treatment/Intervention (Many Forms)
- Maintenance
- Ancillary Supports:
  - o Education (GED, College)
  - o Vocational Training
  - o Tutoring
  - o Housing
  - o Independent Living Skills
  - o Case Management
  - o Other Engagements
- Recovery Services (active and on-going)

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-06-01
FOCUS GROUP | Providers
Host: Niagara Substance Abuse Providers Meeting

Review of Original Results Statements

Statement 1: Children are engaged in positive activities.
    Stakeholder Response-
- Daycare at treatment facilities is tricky; not always paid for, availability is a little thin
- Makes sense as a goal for the community
- Sounds like an enormous challenge, especially in the context of the casino
- Financial barriers associated with accessing positive activities are an issue
- Positive activities in the community are often offset by non-positive home environments (e.g., parental substance use, absent parents)
- Transportation/parental support not always available
- Lifestyle: families engaged in substance use as a normative condition

Statement 2: Youth make healthy choices about alcohol and drugs.
    Stakeholder Response-
- Abstinence is the only choice
- Issue with idea of, "healthy choices" -- there is no healthy choice other than abstinence from their perspective
- Suggestion: Youth are abstinent from alcohol and drugs
- Suggestion: Youth learn benefits of abstinence
- Youths can help loved ones (family) make healthy choices

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
    Stakeholder Response-
- Accessibility
- Availability
- Safe place to live
- "will have" a safe place to go
- Positive activities should be happening in the safe places (connection between positive activities result statement and safe place to go result statement)

Statement 4: Community Members are aware of the dangers of substance abuse.
    Stakeholder Response-
- Agree with the goal overall
- Large undertaking
- Need to understand resources available for prevention, treatment, and recovery – should include this in the "education"
- De-stigmatizing treatment is important. Many people don't go into treatment because of the stigma
- Treatment and recovery must be valued; respect for people who are trying to better themselves
- Differential standards/valuation between DWI/DUI folks versus drug users
- People have faulty rationalizations about use
- Lifestyle/socialization
- Recovery is valued once folks understand that addiction is a brain disorder
- Alcohol isn't viewed as a drug. Beer versus hard liquor distinction; don't view the former as alcohol/drinking
- Substance abusing "lifestyle"

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [32]   info@thetowerfoundation.org

- Education more so than just awareness…should say community members are educated about substance abuse and options for prevention, treatment, and recovery

Statement 5: Community provides supportive services to meet identified needs.
   Stakeholder Response-
- Meet treatment and recovery needs, instead of, "identified needs"
- Recovery -- supports around recovery

Possible Indicators/Measures

Statement 1: Children are engaged in positive activities.
- School absenteeism
- Arrest rates
- Underage drinking
- Do they regularly see doctor or dentist
- Teen pregnancy
- Curfew
- Graduation rates
- Enrollment in community recreation programs

Statement 2: Youth make healthy choices about alcohol and drugs.
- Drug Testing
- Age of onset
- Drug Use (by drug)
- Graduation Rate
- Drug Court Utilization
- Recidivism in Court

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- Number of programs available
- Coverage and accessibility of programs
- Enrollment within programs
- Decline in youth shelter participation
- Decline in absenteeism
- Parent participation rates in programs, PTA, school
- Decline in involvement in Child Protective Services (CPS)

Statement 4: Community Members are aware of the dangers of substance abuse.
- Increase in information and referral calls
- Reduction in DWI
- Reduction in alcohol and drug arrest
- Increase in use of environmental strategies (public education, awareness campaigns)
- Office of Alcohol and Substance Abuse Services (OASAS) survey – community perceptions and usage
- Decrease in ER/other hospital utilization related to substance use and abuse

Statement 5: Community provides supportive services to meet identified needs.
- Decline in substance abuse related deaths
- Number of programs available
- Attendance and utilization of programs

- Decline in waiting periods for programs
- More people successfully complete programs
- Increased use of NA/AA
- Recidivism
- Shorter relapse time to treatment

Strategies Associated with Original Results Statements

Statement 1: Children are engaged in positive activities.
- Prevention education in schools; start young
- Community recreation programs need to exist
- Market programs to the demographic; needs to be cool
- Up-to-date tech
- Proximate, affordable, accessible
- Transportation to Services
- Positive role models
- Field trips

Statement 2: Youth make healthy choices about alcohol and drugs.
- Prevention education in schools
- Reward abstinence/consequences associated with not abstaining
- Health fairs
- Parental engagement
- Parenting skills
- Marketing - working against culture (e.g., Facebook, TV)

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- After-school programs, day care
- Vocational education programs
- Access to jobs (esp. Teens)
- Legitimate counseling availability
- Earlier intervention (e.g., counselor that's available to talk/screen/assess/refer/treat)
    - Youth Engagement
    - Screening/Assessment
    - Treatment
- Child/youth-specific programs

Statement 4: Community members are aware of the dangers of substance abuse.
- Public education (e.g., social marketing, flyers)
- Teacher/staff member education
- Parent education
- Team approach
- Physician and health professional education; address drug-seeking behavior
- Educate mental health providers (psychiatrists, psychologists, counselors)
- Drug collection Efforts in the community

Statement 5: Community provides supportive services to meet identified needs.
- Parenting skills (related to substance use and abuse)
- Testing for children's developmental delays (for kids whose parents are addicted)

- Treatment provision for adolescents
- Family programming
- Adolescent mental health
- Transportation
- Codependency
- Supportive housing/recovery and beyond services
- Where do kids go while parents are in treatment

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-06-23 (11:00am-12:30pm)
FOCUS GROUP | Providers, Drug Enforcement, School Administrators, Parents
Clarence High Schools Session I Meeting

Review of Original Results Statements

Statement 1: Children are engaged in positive activities.
   Stakeholder Response-
- Positive activities does not mean that children/youth will not engage in drug/alcohol use
   - e.g., athletes and student council students and prescription drugs
- Measurement of this item
- This is an entrenched issue – attitudes of parents, teachers, coaches
- Must be accountability for all – cannot just blame educators
- Need a family focus – not just about programs and schools
- Culture of positive activities – address competition in sports; activities can just be about health/wellness, esteem, stress relief
- Family and children should be engaged in activities together

Statement 2: Youth make healthy choices about alcohol and drugs.
   Stakeholder Response-
- Stop lying to kids about drugs and alcohol – provide them with an accurate picture of what happens when you use drugs/alcohol (not just say no! – increases curiosity)
- Cannot be afraid to be honest; don't assume that youth cannot process issues
- Age appropriate –need to start when they are young
- Stigma
- Community acceptance of experimentation with drugs and alcohols - permissible; parents allow it
- Distinction needs to be made between "healthy choice" and moderation thinking
- Family focus is needed – school day ends and all that educators have taught can be undone in an hour by the family
- Instead of Healthy – think about correct, smart, or right choices and recognize consequences

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
   Stakeholder Response-
- Place must be visible and accessible
- Kids need to feel that they fit in – different types of kids, different types of appeal
- Will kids want to go there
- Need to get to kids
- Funding/sustainability of these types of ventures (practicality)
- Needs to be more than one place, more than one type of kid

Statement 4: *Community Members are aware of the dangers of substance abuse.*
   Stakeholder Response-
- Biggest battle is the lack of awareness about the problem itself – its prevalence
- Awareness needs to be stark as it is not seen as a problem or people disregard the issues
- Politicians are either in denial or concerned because this problem is not politically expedient
- Communication across systems is critical (schools, courts, etc.)

- In many cases, when talking about these issues you are really preaching to the choir instead of reaching those who really need to hear it
- Should modify the statement: community members are aware of the prevalence of drug and alcohol abuse; Focus on awareness and prevalence instead of the dangers
- Most people, at some level, understand the dangers of drug and alcohol abuse

Statement 5: *Community provides supportive services to meet identified needs.*
   Stakeholder Response-
- Statement is too broad
- Need to also be able to address regulations and policy (re: disposal of prescription drugs for example)
- Personalized support services
- Adult connections
- Single point of referral
- Better system responses

Possible Indicators/Measures

Statement 1: Children are engaged in positive activities.
- Prevalence of activity usage
- Improvement on developmental assets – specific indicators within this survey?

Statement 2: Youth make healthy choices about alcohol and drugs.
- Police reporting on alcohol and drug use by teens
- Referral to services
- Attendance at school
- Survey of kids
- Age of initiation into drug/alcohol use
- Use of specific drugs
- School suspensions/discipline related to drug and alcohol use

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- None identified

Statement 4: Community Members are aware of the dangers of substance abuse.
- Community survey about attitudes (change in attitudes)
- Development of community dialogue (needs to include people who have had the experience)
- Increase use of disposal

Statement 5: Community provides supportive services to meet identified needs.
- None identified

Strategies Associated with Original Results Statements

Statement 1: Children are engaged in positive activities.
- Youth centers/one-stop shop
- Family support centers within schools
- Therapy and mental health programming
- Generalized sports/wellness programming in communities
- Boys and Girls Club in community

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [37]   info@thetowerfoundation.org

- Afterschool activities – cannot just be academic programming
- Programs that focus on self-esteem/age appropriate
- Must have a "coolness" factor for kids
- Awareness and prevention activities

Statement 2:   Youth make healthy choices about alcohol and drugs.
- Youth centers/one-stop shop
- Family support centers within schools
- Therapy and mental health programming
- Generalized sports/wellness programming in communities
- Boys and Girls Club in community
- Afterschool activities – cannot just be academic programming
- Programs that focus on self-esteem/age appropriate
- Must have a "coolness" factor for kids
- Awareness and prevention activities

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- Youth centers/one-stop shop
- Family support centers within schools
- Therapy and mental health programming
- Generalized sports/wellness programming in communities
- Boys and Girls Club in community
- Afterschool activities – cannot just be academic programming
- Programs that focus on self-esteem/age appropriate
- Must have a "coolness" factor for kids
- Awareness and prevention activities

Statement 4: Community members are aware of the dangers of substance abuse.
- Drug disposal programs
- Education programs
- Events – family events

Statement 5: Community provides supportive services to meet identified needs.
- Individualized services
- Early identification
- Coordinated care – referral systems
- Avoid duplication of services

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-06-23 (3:30pm-5:00pm)
FOCUS GROUP | Providers, Drug Enforcement, School Administrators, Parents
Clarence High Schools Session II Meeting

Review of Original Results Statements

Statement 1: Children are engaged in positive activities.
  Stakeholder Response-
- Children need to *want* to be involved in positive activities
- Depends on who is directing the engagement
    - Positive: If school or adult-directed; otherwise, not a positive activity
    - Believe children can engage in positive activities of their own direction
- May want to connect more to the developmental assets – focus on the availability of positive adult figures in children's lives, activities, engagement
- Focus should be on healthy activities (not positive – too vague); activities that promote physical, mental, spiritual well-being

Statement 2: Youth make healthy choices about alcohol and drugs.
  Stakeholder Response-
- Make *informed* choices that are healthy; healthy informed choices
- Really should be youth and parents; more of a family connection
- Must recognize situational issues
- Not just one-on-one peer pressure anymore – more like social pressure that children are facing
    - They don't identify peer pressure – pressure more so of the social group
- Fighting against curiosity and experimentation which occurs during adolescence – however, can ruin the rest of their lives if they go down a pathway
- Youth need help being informed and need access to other resources as well
    - Some youth turn to drugs/alcohol to self-medicate for mental health issues and experience of trauma
- Need to know about and access other needed resources to make informed choices

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
  Stakeholder Response-
- This may actually be two statements: Safe place to go <u>and</u> adequate personal supports
- Concerned about the word –adequate which means the bare minimum; appropriate personal supports based on individual needs is what is needed
- Supports seems vague – what are these supports – caring loving adults, positive role models, helpful peers, persons with life experiences, non-judgmental
- Need different channels for different kids (example of guitar club)
- Safe places – different locations

Statement 4: Community Members are aware of the dangers of substance abuse.
  Stakeholder Response-
- Needs to say alcohol not just substance abuse
- Need to include medicine possibly
- Really concerned about the abuse of alcohol, drugs, and medicines
- The dangers and range, scope or prevalence of the problem
- The impact of the problem (community impact: crime, employment, prison, taxes)
- Requires a willingness to admit to problems at a community level

---

- In many cases, kids are moving from experience/experimentation to addiction
- Danger is not limited to the person using but to the family and community
- Education – more research that highlights the physical changes in the brain caused by drugs, connections to pregnancy, etc.

Statement 5: Community provides supportive services to meet identified needs.
Stakeholder Response-
- Supportive services is a big word – too vague
- Community supports are available and accessible at a cost that is affordable
- Difficulties getting into the system
- Community needs to be actively engaged
- Need various services to be available in the community while many are not – detoxification centers; specific programming for people 18-26; youth treatment is extremely limited

Strategies Associated with Original Results Statements

Statement 1:   Children are engaged in positive activities.
- Awareness of available activities
- Achieve "coolness" factor/current activities
- Appropriate volunteers to participate in activities
- Accessibility and transportation
- Get kids moving, food
- Positive feedback

Statement 2:   Youth make healthy choices about alcohol and drugs.
- Start very early and continue to engage in prevention activities
- Use a curriculum that is age appropriate for children and youth – long-term engagement on curriculum
- Discuss the element of exploitation inherent in the drug/alcohol "industries"

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
- Make engagement an important part of education/culture of schools/community
- Provide various locations to go for different types of kids
- Engage parents in these safe places

Statement 4: Community Members are aware of the dangers of substance abuse.
- Utilize "real" presenters/people with experiences in the education/awareness activities
- Parent education – require it as part of other meetings
- Corporate responsibility
- Media

Statement 5: Community provides supportive services to meet identified needs.
- Coordinated services
- One-stop shop
- Single point of entry for referral
- Greater collaboration across different systems
- Need for adolescent detox center, early detection, treatment modalities
- Extended rehabilitation
- Education, vocational training
- Transportation

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011.8.4
FOCUS GROUP | Providers
Essex County Community Foundation (ECCF), Danvers, MA

<u>**Review of Original Results Statements**</u>

Statement 1: Children are engaged in positive activities.
   Stakeholder Response-
- Build on positive activities that already exist
- What's already working
- Expand access
- Improve transportation options
- Empower youth to identify positive activities
- Be authentic in engagement of youth
- Provide broad diversity of programming beyond sports
- 2:00 – 6:00 p.m. time frame
- Position/promote/identify "activities" in a different way; kids don't want "activities" per se
- Create more opportunities for job growth
- Build personal skills
- 1:1 engagement of youth is critical
- All youth are at-risk; all need someone to talk to, safe place
- Culturally competent adults
- Stress that their voice counts, validated, leaders, the future
- Self-identify what they need
- Encourage community/parent involvement
- Understand the political will
- Seek funding for programs
- Address the Criminal Offender Record Information (CORI) barrier for parents

<u>**Strategies Associated with Original Results Statements**</u>
- Activities lead, created, and promoted by teens
- Have youth create opportunities
- Teen/youth survey to figure out what they need/want
- Focus on process of engaging teens/feel involved
- Have youth at coalition meetings to change adult perspective
- Identify other ways to reach and understand youth, such as street outreach program

Statement 2: Youth make healthy choices about alcohol and drugs.
   Stakeholder Response-
- Make it safer for youth to self identify
- Create policies that don't become barriers to successful outcomes
- How effective is "zero tolerance"
- Help youth make healthy choices
    o Not just drugs
    o Driven by youth, such as creation of Public Service Announcement (PSA)
    o Coach/train youth in healthy decision-making
- Identify role models/"heroes"

THE PETER AND ELIZABETH C. TOWER FOUNDATION

- Take an environmental strategy approach; create positive environment for youth (needs to involve schools families, and the community)
- Empower youth to influence policy, change norms, and educate younger population
- Reduce college binging/drugging

Possible Indicators/Measures
- Youth Risk Behavior Survey (YRBS) results
- Guidance counselors
- Arrests

Strategies Associated with Original Results Statements
- Address social norms/misperceptions about alcohol for teenagers; target 4th grade
- Pre K-12 substance abuse curriculum or part of health class curriculum
- Forums for youth – safe with adults
- Look at alternative consequences (reflect in social policy)
- Identify effective ways to reach and help isolated youth that are using alone
- Stress consequences of Alcohol, Tobacco or Other Drugs (ATOD)
- Utilize social media to work/communicate with youth

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
  Stakeholder Response-
- Identify who the champions in the community are – what characteristics define them
  - What role can young adults play in the lives of 12-18 year olds
  - How can teachers/coaches play a role in identifying disengaged youth and reaching out to them
  - Champions need training and support – 1 to 1 mentoring and leadership development
- Create a space/a community in which youth feel safe/have a voice/are able to talk openly
  - Law enforcement
  - Coalition meetings
  - Family/community support
  - The neighborhood (how can neighborhoods play a role in supporting youth)
  - Schools

Possible Indicators/Measures
- Schools – Youth Risk Behavior Survey (YRBS) have identified person/teacher feel able to turn to
- After schools – environment (community safety, programming, mentoring- peers)

Strategies Associated with Original Results Statements
- Create social marketing tool – share information
- View substance abuse problem at a macro level to reduce rates
- Get policies in place

Statement 4: Community members are aware of the dangers of substance abuse.
  Stakeholder Response-
- Need to foster a sense of responsibility and acceptance within the community for substance abuse problems
- Support parents/other adults in gaining understanding and empowering them
- Parent support groups
- Avoid singling out parents; stigma associated with drug abuse in family
- Parents, coaches, other adults in community have experienced substance abuse – how to leverage
- Break cultural barriers/stigma
- Encourage involvement of families, schools, community

- Create political will
- Takes time - recovery is possible
- Need to be educated such as in the case of marijuana (What is the drug? What is the addiction? What is prevention? What is treatment? What are results?)
- Identify problem areas in a community, as a community
- Role of law enforcement as first responder
- Social host policy in place

Strategies Associated with Original Results Statements
- Youth-driven initiatives
- Education of adults regarding substance use and culture of use
- Addressing drug paraphernalia
- Parent prom initiative
- Youth summit (small focus groups)
- Social marketing
- Empower parents
- Connect parents to share information to address isolation and stigma (feel like in it alone)
- Share family stories (access to treatment, hospitals) – influence cultural and social change
- Involve Parent Teacher Organizations (PTOs) at elementary school level
- Parent orientation for transitions to elementary, middle and high schools (resources, support, etc.)
- Education on pain management for doctors and other prescribers (need to develop trust with patients)
- Communities need to work together (prevention to recovery stages)
- Promote resources/tools
- Drug Alcohol (DA) diversion programs
- I Can Help.org program
- Decision making
- Motivational interviewing

Statement 5: Community provides supportive services to meet identified needs.
   Stakeholder Response-
- Interactions between youth and adults is critical
- Understanding their needs
- Adults need to operate outside of comfort zone
- Leadership is key
- Identify individuals to share family stories/experiences (peer leaders, mentors in community to help
- Youth trust and discover safe place
- Political will and support/community readiness
- Prevention is norm
- Treatment is a full continuum of care
- Create policy change
- More facilities available to meet demand for services
- Create more opportunities for their growth, challenging themselves (career skills, higher education etc.)
- Identify individuals to share experiences with families and youth (peer leadership in community, mentor promotes change)

Strategies Associated with Original Results Statements
- Drug Alcohol (DA) diversion program

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Results Statements

Statement 1: Children are engaged in positive activities.
   Stakeholder Response-
- Supporting adult and youth leaders (champions in communities)
- Supporting volunteers/mentors
- Youth as leaders in the community
- Youth role modeling for other kids
- Funding staff to watch youth is an issue
- Youth want to contribute positive feedback
- Leadership development needed
- Affordability and access issue
- Transportation
- Weekend activities are needed
- Diverse settings and activities
- Disconnected youth and families
- Find ways to engage youth
- Youth and families do not feel engaged/included
- Acknowledged youth
- More neighborhood involvement/neighborhood activities
- Same youth are always involved (have money and support from family)
- Job employment for youth

Statement 2: Youth make healthy choices about alcohol and drugs.
   Stakeholder Response-
- Parents play an important role
- Parents modeling positive Alcohol, tobacco and Other Drugs (ATOD) behaviors
- Parental disapproval influences youth choices around drugs
- Peers play important role
- DARE, Junior SADD chapters, Haverhill VIP program (identify around healthy and safe choices)
- Youth visible in community making positive choices
- Reversing role; positive youth be loud about it to overshadow the students making negative choices around Alcohol, Tobacco and Other Drugs (ATOD)
- Ways to mentor youth
- Changing social norms or perceptions of norms
- Change attitudes to substance abuse risk- cultural sensitivity
- Make a healthy choice the easy choice
- Environmental change
- Change perception/peer pressure
- High achievers – how it affects different individuals
- Need more broad-based support for healthy choices

Statement 3: Children (and youth) have a safe place to go with adequate personal support.
  Stakeholder Response-
- Language and definitions need to be relevant depending on socioeconomic and other factors
- Wording "safe place" and "adequate," not defined properly, different for every community
- Safe place looks different factors at – school, community, home
- Example: large house in affluent neighborhood does not make it a safe house for youth
- Single parent homes
- Informal community supports
- Family support
- Example Librarian - informal mentor looks out for youth safety
- Neighborhood outreach
- Fosters community relationships
- Knowing someone has their back
- Consistency is key to developing trust
- Formal community supports
- Basic necessities, food, clothes, heat
- Address intimidation felt by youth
- Second language needs mentors
- Have staff/funding to provide consistent presence
- Resources to support infrastructure (building etc.)
- Leverage resources to build support

Statement 4: Community members are aware of the dangers of substance abuse.
  Stakeholder Response-
- Changing social norms or perceptions of norms/how define "dangerous"
- Change wording "dangers of substance abuse"
- Change attitude
- Everyone knows it's dangerous, only the victims and families understand it (their experience is more impactful than awareness/education can provide)
- How do we get the community to understand
- Politicians/clear guidelines- accountability, enforcing
- Getting the information out- broad based, multiple media, risk of harm
- Visible enforcement – makes an impact on substance abuse
- How to use media properly
- Cultural sensitivity in addressing impacted communities (VIP leadership model for youth)
- Engage community assets and resources
- Hold meetings on weekends/bring meetings to families, e.g., church – parents are busy supporting family and can't find time to attend
- Recovery community
- Intergenerational
- Funding for broad collaborative/networks (integrated approach – fill gaps for funding needs)
- Lack of awareness about the untreated
- 5%-10% of population need intervention
- Develop programs to reach the 5% - 10% population
- Develop way to document results/impact

Statement 5: Community provides supportive services to meet identified needs.
  Stakeholder Response-
- Informal community supports
- Addressing multiple issues to impact change in high risk population
- "Connecting the dots" service matrix that joins community services to support youth
- Welcoming feelings, positive interaction
- Strive throughout the year, summer vacation, etc. (include providing basic necessities)
- Bring community services to the neighborhood and schools to support working parents
- Check-in with neighbors
- Moving community before a tragedy happens rather than after
- Border issues/community profiles – not as they appear – being there to see issues
- Engagement
- Volunteerism and community engagement in developing local response to needs
- Youth engagement in designing intentional response to community neighborhood needs
- Thoughtful response and engagement for the disengaged
- Engagement of community members through awareness, accountability, to build neighborhood network and safe places (Geoffrey Canada)
- How to challenge community to step forward to help – "frustrations" in getting support and trusting network
- People want to do good but need help in finding a place to start and projects that are not too daunting
- Peer pressure in neighborhoods needs effective responses (gang related) (big home/Andover)
- Getting community to look up and around to see what is happening
- Involving entire community
- Formal community supports
- Street worker model, e.g., in Cambridge (hire right person to just be out there supporting)
- Quantity verses quality in grant/funding programs
- Community health workers "Charlas" (visit neighborhood/homes to bring services into groups/homes/organizations/intergenerational)
- Getting community to recognize good kids (www.patch.com)
- Strict, clear guidelines
- Broad focus with opportunities to target key issues "rich" kids binging on weekend
- Public forum results in Rumbo/Methuen CATV (Media support)

THE PETER AND ELIZABETH C. TOWER FOUNDATION

MENTAL HEALTH FOCUS GROUPS
FOLLOW UP REPORT TO STAKEHOLDERS

Focus Group Demographics

Eleven Focus Groups:
- Erie County, New York (3)
- Niagara County, New York (1)
- Barnstable County, Massachusetts (4)
- Essex County, Massachusetts (3)

Stakeholders Involved:
- Mental Health Professionals
- Educators
- Government
- Parents/Family Members
- Service Providers
- Youth and Adult Consumers

Report Glossary

Result: A result is a population condition of well-being for children, adults, families and communities, stated in plain language. Results are sometimes known as outcomes or goals.

Indicators: Measures that help quantify the achievement of a result and answer the question, "How would we recognize this result if we fell over it?"

Strategy: A plan or method for obtaining a specific goal or result.

Reactions to Original Mental Health Results Statements

Statement 1: Children with mental illness are identified early and treated.

Key Themes from Focus Group

- To identify children with mental illness requires diagnosis but concerns around stigma, labeling, and prejudgment lead professionals not to identify and/or treat young children – more often, they engage in watchful waiting (not about diagnosis)
- Really want to focus on symptoms at a young age – addressing behavioral/social/emotional challenges
- Treatment must be appropriate (developmentally and age appropriate) and effective - often viewed as a behavioral, social, or parenting issue; and, as a result, appropriate services are not put in place – need to identify causes of behavior and avoid over-diagnosis by unqualified professionals
- Treatment must also be on-going; it is not a single discrete event, must change as the child develops
- Early intervention/identification is the key – health professionals need greater support related to this
- Is "identified early" associated with age? Onset of condition? Both?

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org
[47]

716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.

Key Themes from Focus Group

- Should focus on <u>understanding</u> and <u>managing</u> their mental health challenges – take responsibility, be accountable, appropriate engagement with needed supports – this becomes increasingly important as the youth gets older
- Self-acceptance is a lofty goal, but it may not be developmentally possible for this group – there is a continuum of self acceptance that is on a parallel track with mental illness
    - o Self acceptance can actually include a denial of symptoms;
    - o Self acceptance is also hard to measure
- Want youth to start with managing conditions – actively – this will lead to positive growth, potential, quality of life, etc.
- Must manage stigma first so this can happen (family, peers, community)
- Need to resist labeling – youth and young adults with mental illness – "old language"
- Should acknowledge concerns around dual diagnosis (particularly related to substance abuse but also connected to developmental and learning disabilities); substance abuse is often a symptom of mental illness – need to acknowledge this specifically

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

Key Themes from Focus Group

- Mental health challenges – not conditions
- Emphasis should be on <u>educating</u> and <u>supporting</u> families – including extended family – need to understand the nature of the illness, treatment options and what they can do to help and act on it
- Families need to understand mental health challenges and have support to help family members – commit to doing so (active)
- May want to address the effects of the condition on the family as well
- Intergenerational challenges, diversity, and cultural competency needs to be addressed (All families understand and are supported in order to help family members with mental health challenges… and commit to doing so?)
- Focus should be on productive lives – resistance to notion of "happy" – this should be connected to statement #2 (manage conditions to lead productive lives)

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

Key Themes from Focus Group

- Too vague, should be specific to mental health challenges unless the goal is to support positive youth development more generally?
- About access to resources at its core – education, awareness, programming
- Unclear what is meant by inclusive and responsive – really about communities understanding mental health challenges and providing needed resources
- There is a connection between statements #4 and #5 – do you need stand-alone statements? Can you combine them or connect them?
- What is meant by communities – Broader definition? Communities of practice? Communities of professionals?
- Adequate – minimum; appropriate is better
- System responses need to be considered here – including early intervention system

Statement 5: Stigma related to mental illness is eliminated.

Key Themes from Focus Group

- Statement needs to come first if anything is to happen
- #5 affects 1-4; could be the master result statement with all others serving as objectives
- Note that stigma exists at multiple levels – individual stigma, family stigma, community-level stigma
- Like the use of eliminated – bold statement, challenging
- Requires aggressive, education, awareness, cultural competency continual

Other Concerns:
- Behavioral/Environmental Mental Health Challenges vs. Biological/Organic Concerns
- Global Mental Health Concerns vs. Specific Concerns

Revised Mental Health Results Statements and Suggested Measures Using Focus Group Input

---

Foundation staff revised the original Mental Health results statements based on key themes that emerged during focus group sessions as well as the strength of commentary from community stakeholders. In their revision, Foundation staff focused on:
- Addressing stigma associated with mental illness;
- Identifying individuals as early as possible and connecting them to needed services;
- Ensuring that youth and young adults understand and manage their mental health challenges;
- Reflecting the importance of family – including understanding of mental health symptoms; and
- Need for appropriate community connections and supports for persons with mental illness

Foundation Board members also decided to focus on specific mental health concerns that were biological in nature.

REVISED STATEMENTS

Statement 1: Stigma related to mental illness is eliminated.

> Reflects an understanding that without reductions/elimination of stigma, mental health challenges may continue to go unaddressed for many community members. This result statement was not changed but stakeholders, namely parents, stated it needed to be a top priority. They felt strongly the other results could be achieved if stigma was eliminated.

Possible Indicators/Measures:
- Community Survey on Mental Health (see: Example Measures for Use in Community Survey)
- Media Coverage (Positive/Negative/Neutral)

Statement 2: Children with social, emotional, and behavioral challenges are identified early and connected to appropriate services.

> Describes the importance of timely identification and connection to appropriate services

Possible Indicators/Measures:
- Use of early intervention services (Waiting lists)

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [49]   info@thetowerfoundation.org

- Universal screening – how many children screened in a particular region? Of those screened, how many connected to appropriate services?

Statement 3: Young people with mental health challenges understand and manage their conditions and behaviors.

> Highlights the importance of understanding mental health challenges – while maintaining that the individual is responsible for their behavior and decision-making.

Possible Indicators/Measures:
- Client survey
- Hospitalization/acute stays
- Arrest/Incarceration/Court Appearances (Mental Health Court)

Statement 4: Families understand mental health challenges and help members live productive lives.

> Stresses the importance of family education and support

Possible Indicators/Measures:
- Family Survey

Statement 5: Communities offer meaningful opportunities and appropriate support to young people with mental health challenges and their families.

> Suggests that communities must offer a full range of opportunities and supports to individuals with mental health challenges – just as they would for all community members

Possible Indicators/Measures:
- Community Survey
  - Client / Family Satisfaction Measures
- Access to primary care/psychiatric care/Afterhours care
- Employment Data (persons with mental illness)

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [50]   info@thetowerfoundation.org

---

INDIVIDUAL FOCUS GROUP REACTIONS

2011-08-25 (6:00-8:00 p.m.)
FOCUS GROUP | Parents
Host: Families' Child Advocacy Network (CAN) Meeting (Erie County, New York)

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
- Language – children with mental illness is stigmatizing
- This is BS – not currently identified early – health professionals hold off on diagnosis and assessment because they don't want to label kids
- Avoid giving a diagnosis to avoid stigma
- Treat the family as a problem – don't believe the family members, inadequate response
- Issue of capacity – psychologists, psychiatrists (availability and training)
- Lack of awareness among health practitioners – assumptions about development
- Focus on diagnosis – not on symptoms (working for the insurance code)
- Must include behavioral disorders in statement
- Mental illness is associated with disability – mental health challenges, behavioral challenges
- Must understand the historic view of mental illness
- Lack of consensus on ability for children to have mental health challenges
- Symptoms are identified and acknowledged/addressed
- Symptoms are managed – never fully treated
- Treatment must be goal oriented, outcome focused

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
- Should say mental health challenges – not conditions
- Youth must understand and manage their challenges
- Labeling is a major concern – do not want to be seen as different and must also learn to concur challenges
- Must address stigma first if you hope to move on this results statement at all
- Must be educated young – explain challenges, strategies, etc.
- Parents/families/guardians must also be accepting – this must occur outside immediate family
- Must recognize the generational nature of mental health conditions – runs in families – may not have called them challenges in the past or had different language
- The experience is a baptism by fire for many
- Recognize co-occurring substance abuse/self-medication
- Self identify their triggers – manage symptoms, coping skills/strategies

---

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

Stakeholder Response-

- Need to change mental health conditions to mental health challenges
- Need to understand <u>and</u> manage <u>and</u> parent
- Perhaps: Families are educated and are supported (medically, emotionally, physically) so they may help members live happy and productive lives.
- Really all about the social environment/context the family and child are living in
- Exterior influences – addressing other entities sending messages to the child and to the family – particularly about parenting behavior (e.g., you are a bad parent, the child's behavior is your fault, it is not a mental health condition but your personal failing).
- Must extend beyond the "nuclear" family – extended family members have a major role here in accepting the situation and providing support
- All family – includes siblings and other kids as well

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

Stakeholder Response-

- Should change to communities "must be" or "need to be" inclusive, responsive, etc.
- Need to describe youth as "challenged" no mention of mental health challenges in statement
- Statement feels clinical/all about evidence-based interventions
- Must address the loss of social support within communities; informal supports are critical
- Address fear of needing resources
- Must address teachers/schools in particular – perhaps identify specific locations in the community where inclusion, responsiveness and supports are most needed
- No Child Left Behind has (ironically) led to greater isolation for children and youth with mental health challenges
- Statement needs to state – mental health challenges
- Too general, vague – should be more specific

Statement 5: Stigma related to mental illness is eliminated.

Stakeholder Response-

- This result statement needs to come first.
- Must address NIMBY-ism (*Not in My Backyard)
- Must also address parental fear of having their child identified or labeled
- Education in the community – particularly for consumers (You can't do better until you know better)
- Encourage cultural competency
- Must be done on an on-going basis – no temporary fixes, requires long-term engagement
- Address this issue aggressively
- Result statement is fine but need to really go after it – first and foremost

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

716 689-0370
(fax)   716 689-3716

[52]   info@thetowerfoundation.org

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.

- Train health providers on mental health
- Parent education
- Include teachers in education as well as school administrators
- Young people education, advocacy and awareness (critical)
- Provide education for all kids – not just those kids who have challenges
- Anti-bullying campaigns
- Incentive for providers in training especially in rural areas
- Provide scholarships to encourage training in needed areas/locations
- Train more practitioners
- Build health care practitioners base of knowledge
- Families as advocates – need more credibility, work towards credentials
- Policy work
- Education on resources and knowledge of the system
- Dual diagnosed services for children and youth
- School advocates

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.

- Must promote generational education about mental health
- Health practitioner education – doctors, nurses, - promote screening, assessment, appropriate referrals
- Ensure that health practitioners are securing culturally competent training
- Youth participation and involvement in the development and execution of strategies
- Educate kids and families to engage in self-advocacy
- Youth campaign activities (e.g., Youth Power – Stephanie Orlando)
- Parent youth with like-minded interest groups (normalizing activities)
- Peer-to-peer youth mentoring programs
- Normalized/unconditional acceptance

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

- There is a grief process related to diagnosis – families need to be aware of this and must be offered support through it
- Education activities – inclusion in curriculum
- Recognize that "family of choice" can be more supportive than families of origin/birth
- Parent coaches
- Parent mentors programming
- Court advocates
- Identify what does success look like for children and youth with mental health challenges? This may be different than for other kids. This needs to be okay
- Vocational programming, educational programming for children with mental health challenges – not one size fits all, need to provide people with options
- Respite services are needed for families/parents and siblings too

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [53]   info@thetowerfoundation.org

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

- Public campaign – messages, large scale (think if Glenn Close and her sister – work with NAMI)
- Needs to be long-lasting, large scale effort involving children and youth themselves
- Erase fear of persons with mental health challenges
- Media education with specific use of data and statistics
- Use of media spokesperson (celebrity, recognized expert, known person)
- Road to Recovery Promotion – mental health walk
- Provide teacher training and greater school awareness/training on mental health challenges
- Treatment awareness to promote parents and others understanding treatment options
- Media responsiveness in reporting on things like suicide – accurate, not ignored or glamorized
- Information and referral resources
- Resource awareness – 211 WNY does not work! Need a resource guide for parents/guardians
- Simple, easy to use, accurate, updated tools

Statement 5: Stigma related to mental illness is eliminated.

- Engage youth in developing statements
- Engage in a strong, lasting campaign with a lasting slogan (Remember "I Love NY")
- Encourage media responsiveness
- Ask people to define their experience of stigma (addresses issues of cultural competency and prejudice)
- Define different family experiences
- Work from the "Eliminate the "R" Word Campaign"
- Emphasize connectedness to others who experience mental health challenges
- Focus on acceptance and the choices we make – education about treatment
- Engage local Parent-Teacher Associations

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
   - Early intervention is very important - the earlier you engage with persons with mental health issues the better
   - Challenge is related to early diagnosis - there is a real concern about prejudgment, early judgment, and labeling - but sometimes you cannot get help without a diagnosis
   - Sometimes help needs to be given even before a person is diagnosed - assessment, screening, early intervention

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
   - This may be difficult to reach - need to be sure to discuss other things of interest to youth and young adults beyond talk of mental illness/mental health only - need to connect to activities
   - Self acceptance is important - need to realize that you are not alone
   - Normalizing can be challenging - there needs to be a balance - need to recognize that people want to feel connected and not different while still needing to have special supports when needed
   - Want people to manage their conditions - not just to be able to do so...Want people to be actively managing their symptoms, behaviors, taking care of themselves

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
   Stakeholder Response-
   - Families need to understand the nature of the illness, medication, treatment options and what they can do to help
   - Families historically have hid the problems of individual members or pitied members affected by mental health conditions. Have not reached out for help because they don't want to have their family member labeled. Each family deals with this differently - delicate, unique and challenging situation

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
   Stakeholder Response-
   - Does not exist currently - persons with mental health challenges are consistently left out of the table or are pushed to the side
   - This is because this is not a visible disability in most cases - difficult to understand mental health challenges if you are not experiencing or don't know someone who has

Statement 5: Stigma related to mental illness is eliminated.
   Stakeholder Response-
   - Society can benefit from people with mental health challenges - in terms of employment
   - Recognize that we may never fully eliminate stigma but still want to include the language of eliminate instead of lessen or mitigate as it is the ultimate goal

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.

- Place to meet related to mental health concerns - daily activities, growth, empowerment
- Children - currently no facility for those who need to be hospitalized (Lockport Hospital is planning to develop beds for 5-18 year olds - no provision for young adults 18-26 at present time and this is a gap
- In many cases, children are shipped to Erie or Monroe County - family/friends cannot visit
- Education - teachers (greater awareness of behavior - not just bad or troubled kids), community members, foster care/adoption workers
- Treatment providers must be well educated and consistently trained

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.

- More education for teens/young adults
- Schools - stimulate awareness
- Support groups
- Clinics
- Parent/family meetings
- Sharing tips/advice/concerns
- Start with children when they are very young - teach them that it is a process
- Much reach them young - better chance to maintain routine
- Future Visions - provided a family outside of family - supports, creates a system of supports, social, family network
- Afterschool programming for children who cannot attend other programs or are limited in their ability to attend (2-3 hours); Gives them a place to go where they can made friends, build relationships

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

- Families need to understand mental health concerns, should not separate from other family members
- Address stigma within families
- When you have children in the home - families need to be educated on what to expect, options
- Early intervention - may want to avoid calling it mental health counseling - people get turned off when they hear this - use different language - behavioral health, emotional wellness
- People prefer to be described as people with mental health CHALLENGES as challenges can be overcome just like any other disability; mental illness sounds like an illness or sickness, emotional wellness and behavioral health may not be really understood, and you will have to describe mental health issues or challenges anyway.
- It is interesting that people are willing to see other helping professionals for their kids - doctors, pediatricians, etc., but they are unwilling to see mental health providers who can help address behavioral issues - out of 2500 individuals only 43 volunteered for assessment - need to change this and need to have other professionals network to needed resources
- Need assistance for siblings - especially as many of them will eventually become caregivers - need their own training

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

- Stigma - promotes separation
- There are not enough tools or resources within communities to really provide adequate supports - supports are piece meal, limited and not adequate
- Need a safe place for people with mental health issues to go to discuss issues where professionals are available and have understanding
- Educate schools, teachers, administrator, people who engage with children, youth, and adults
- Law enforcement needs to be much better trained including those who work within jails or interact within the criminal justice system
- Community members need to intervene when they see abuses of persons with mental health challenges - all too often people remain silent when they see something wrong being done or people being harassed - need people to stand up
- Need to share stories - documentaries
- Need to have various transition groups

Statement 5: Stigma related to mental illness is eliminated.

- Support conferences/training for community members to include a panel of speakers from groups like the Mental Health Association in which persons with mental health challenges can share their experiences/circumstances with police, service providers, fire, emergency first responders, politicians, neighbors, etc.
- Similar to Child Protection, require mandated mental health training for all first responders, educators, and individuals who touch the lives of children, youth, and young adults
- Peer-to-peer support
- Continue to support mental health courts as they help to reduce recidivism

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-09-19 (3:00-4:30 p.m.)
FOCUS GROUP | Providers
Host: The Peter and Elizabeth C. Tower Foundation (Erie & Niagara Counties, New York)

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
  Stakeholder Response-
- Are we talking about organic mental illness (biologic) or something environmental/behavioral/system or both? This will have shape language
- Is the Foundation interested in behavioral/environment challenges or strictly organic/biological foundations for mental illness? This will make a big difference in focus and strategies
- Children are identified and treated and then what? This is important and good but there is a lot more that needs to be done to connect them to appropriate services and interventions
- Statement is not true currently….labeling children does not happen early on – parents and physicians are leery to do so
- Earlier state – should focus on treating parents mental illness as children are a young age – connects the genetic challenges but also addresses environmental concerns of raising a child in such a household
- Location of interaction is key to determine what kind of intervention can take place – schools vs. hospitals vs. care facilities – may be limited to mechanisms of intervention available vs. broader range available at the community level
- Concerns about being over-identified primarily based on symptomology
- Early intervention works better and tends to be cheaper than later treatment
- Need to provide early and aggressive treatment
- Concerns around functional impairment – should the focus be on symptom reduction, success in life – regardless of causation
- Not a stick test – challenges of screening and assessment – highly nuanced especially in younger children
- Does the Foundation want to look at emotional health and well-being on par with physical health – can emotional health be considered more acceptable
- Children and youth are getting lost during transitions
- Missed opportunities to work with parents who themselves may have mental health challenges
- Addressing cultural norms
- Family intervention and engagement is critical if you hope to move forward with children and youth

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
  Stakeholder Response-
- Should flip statement – manage conditions first and then move towards self-acceptance
- Self-acceptance (or lack thereof) can actually be a pretty significant barrier to self-acceptance
- Concerns around the term "self-accepting"
- Developmental challenges – identity challenges
- Could leave mental illness out – that would be great for all youth and young adults
- What does manage really mean? What if a youth or young adult is managing the treatment that they have been given but it is not a right fit? How will you know if the person is really managing things

- Can also find unhealthy ways to manage mental health symptoms – self medication, use of drugs….Does it work? Is it healthy
- Question should focus on are we placing supports appropriately for youth and young adults? Are we preparing them for what they will need to know in the future?
- Can accept the reality of their diagnosis but is necessarily positive? Relative to self-esteem, self-worth – can understand and accept experience without fully integrating it
- Mental illness can be on a parallel track – self acceptance is different from quality of life and normative expectations of society – can be doing well and dealing with diagnosis without achieving the quality of life and experiences desired by most others in the society
- Managing can mean that I am successfully taking pills or going to treatment but is that really quality of life? Enjoyment
- Is it realistic to expect that people are self accepting – especially adolescents with their developmental challenges
- Self acceptance is a critical part of adolescent identity formation and the move to young adulthood
- Should we be looking for empowerment, participation in treatment, understanding of their mental health challenges
- Adolescents may not be developmentally ready to reach self-acceptance
- Difference between management of life-long conditions vs. developmental, environmental or behavioral concerns – would need two different engagements for the different groups
- This results statement has lower priority comparatively….unless it is specific to intensive cases

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
  Stakeholder Response-
- This is a very linear framing – really much more synergistic
- Assumes a "negative" view from families
  - Can be about skill development – family members may not be there in terms of skills
  - We want people do well
- Assumes families understand what communities and even professionals may not understand
- Defining mental health vs. mental illness – behavioral and emotional wellness (sounds like fresh air and exercise not the reality)
- Balancing symptoms and functionality – is this mental health
- Broad wide spectrum of health and wellness
- This is really two distinct results statements – Families understand mental health conditions. Families are equipped, committed or engaged to help members live happy and productive lives

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
  Stakeholder Response-
- Oh yes! Please!
- Kids have to get very bad in order to get the help they need - hate to say it but an arrest for something minor is sometimes the best thing that can happen to a child or family – the arrest can be walked back and they can get connected to service

- Better work is being done with higher end, behaviorally active kids – otherwise, the majority are not qualified for services
- Kids can be "autistic-y" but until their behavior goes to a certain level and that diagnosis gets shored up - they are not likely to receive help
- On the other hand, they can lose services once identified – moving from acute services to long-term services
- Connection to other services/departments/systems can be very challenging
- How do you define adequate supports – based on whose definitions
- Cannot underestimate the importance of natural supports
- The term "inclusive" what do you really mean – anti-stigma: could you use nondiscriminatory? Sounds like a buzz word
- Early intervention is critical
- How do you define communities – place-based, identity/affiliation, specialty? Residential? Cultural competency?
- Must address parents mental health needs as well

Statement 5: Stigma related to mental illness is eliminated.
Stakeholder Response-
- Ingrained part of the culture – cultural competency
- Crux of many issues – do not want to be diagnosed, labeled, avoid needed care as a result
- Achieve this – could lead to more positive engagement/involvement
- If you achieve 1-4 you will get 5
- If you achieve 5 you will be able to address 1-4

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
- Screening
- Assessment
- Early Intervention
- Engagement of OB/GYN's to identify mother's mental health issues early on
- Pediatrician training – including monitoring and tracking of children who show symptomology at a early age to see if it develops into organic mental health conditions (ease the case for needing treatment at a later date – be wary of becoming "big brother")
- Assistance with transitions (child to adolescent, adolescent to adult)
- Parental education
- Identification of parental mental health challenges
- Education for pediatricians, teachers, child care workers, Head Start, educational administrators, courts
- Holistic services for families
- Social-cultural models (as undertaken by Native American Community Services) to address social norms, culture, history, and historic trauma

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
- Transitions – children and youth get disconnected from known services; this is not meeting their needs
- There is a loss of services in the transition from child clinics to adult services – loss of continuity and can lead to increased challenges

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org
[60]
716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

- High-end services for more intensive cases tend to be more educationally or age based – once a child gets to certain point they may no longer be available to the child simply because they have passed an arbitrary threshold - this is regulatory but problematic as they might continue to need specific services – developmentally. Must work to change these systems/policies/regulations/insurance coverage
- Keep in mind services available through Adult Single Point of Entry (SPOE) are very different from those available in Child Single Point of Entry(CPOE) – may need to blend them during the period of transition
- Need to provide sustainable funding for pilot programming with adolescents that appeared to be working appropriately – all too often pilot project funding runs out and can no longer be financed even though it is working well
- Must address 16-26 as its own specialty area – much more focus/attention needs to be paid here

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
- Establish family friendly policies especially as it pertains to health insurance
- Increase availability of community supports
- Support groups for families
- Define "family of choice" not just family that fits on prescribed forms – source of natural supports
- Media campaign – education (look at the public private partnership campaign in Australia)
- Social-cultural model
- Ask families what they need
- Empowerment of families
  o Treatment
  o Roles in Advocacy/Policy
  o Board Roles
- Investment in these

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
- Monitoring and tracking high risk individuals to identify their successes – teaches us what enables people to do well
- Research on this is very limited – have a lot of research on risk factors but limited research on what people really need to do well – should be studying this
- Education – terminology promotes stigma
- Need to develop a common language – some of the terms that are used add to the stigma of mental illness (i.e., severely emotionally disturbed)
- Some use of common language minimizes the challenges of mental illness (e.g., you are just depressed – depression is a debilitating condition)
- Communication between service providers needs to be increased – could electronic medical records be used; Not in their current state – efficiency vs. quality of information provided

Statement 5: Stigma related to mental illness is eliminated.
- Collaboration with lay leaders within communities
  o Can assist in identifying issues, barriers, have knowledge, access, community-based, reputation
- Increased resources for education, research, staff/professionals, training
- Must address stigma in the field
- Address publicity – represent ourselves better, must hit on more meaningful issues – ostracizing, discrimination

- Recognize that there is great risk in youth advocating for themselves – but this is very important
- Changing language within the field
- Address isolation – viable groups for adolescents, parents/guardians
- Media campaign for teens and parents
- Survey general community to gain an appreciation of real issues/views/beliefs
- Identify high functioning individuals to share their stories – describes possibility, resilience

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

716 689-0370
(fax)   716 689-3716
[62]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-09-07 (9:00am-10:30am)
FOCUS GROUP | Providers
Host: Child and Adolescent Treatment Services (CATS) Administrative Offices (Session I) (Erie County, New York)

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
* Mental illness should focus on emotional and behavioral issues
* Treated adequately
* Identification may occur too late – need to be proactive not reactive (see: research out of University of Rochester)
* Need to understand the behaviors – symptoms come before diagnosis
* Development of prosocial skills
* The earlier engagement the better
* Mental illness – term may not be culturally appropriate – may not be acknowledged by all groups
* Emotional wellness is a more current term
* Importance of point of contact – connection
* Family role is critical here – including family dynamics
* Emotional, behavioral challenges
* Treatment – pathology, stigma
* Early intervention is most critical - may not identify mental illness

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
* Individuals: Accept help when needed, cooperative, willing to work, proactive, self-actualization
* Is accepting help, cooperative, etc. something they want or something we want as practitioners?
* Don't like use of mental illness
* Statement makes me nervous
* This is "old speak" old language
* Not sure understand "self-acceptance" – continuum of self acceptance can include denial of symptoms or challenges
* Focus on positive growth and potential
* Measurement would be challenging on this
* Focus should be on transition supports
* Developing adaptive/growth skills
* Dual diagnosis and self-medication – how does this fit in
* Aging out – coordination is needed
* Emotional/behavioral challenges better more universal language
* Manage – having a visceral reaction to this language; not a chronic, medical condition

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

Stakeholder Response-

- Change mental health conditions to emotional wellness or mental health challenges
- Individuals versus members – remember that families can be and are self-defined
- Happy and productive lives is relative and person-centered
- Families are also struggling and need own support
- How do you measure commitment – skills-based
- Families increasingly struggling
- Can be source of "negative" supports
- Should be responsive, proactive, positive
- Culturally appropriate
- Beyond language – need to get at stigma
- Families may need to deal with their own issues
- Should not be using mental illness, mental health conditions, could be challenges

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

Stakeholder Response-

- So much together
- Kids kicked out of afterschool programs, day cares
- Should be willing to enhance individual's "self-esteem" but don't love that term – by being inclusive, response, etc.
- Behavioral skills and emotional wellness – measurement of this
- To what end? For What? Why should communities be inclusive, responsive, equipped – to address mental health challenges
- Forcing to normal vs. accepting people where they are
- Creativity – changing, shifting what is considered acceptable
- Coordinated and integrated systems of care

Statement 5: Stigma related to mental illness is eliminated.

Stakeholder Response-

- Generational change in acceptance (look at the change in acceptance of Gay Lesbian Bisexual Transgender (GLBT) communities over generations)
- Understood but not eliminated
- Minimized but not eliminated
- Stigma affects Results Statements 1-4 and is a function of them
- Behavioral health must be integrated into primary care
- No health without mental health
- Emotional wellness is a way of life
- Not symptom management

2351 North Forest Road

716 689-0370
Getzville, NY 14068-1225

(fax)   716 689-3716
www.thetowerfoundation.org

[64]

info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
- Engagement of teachers
- University of Rochester study/positive behavior
- Nurtured heart approach
- Clinic plus – state initiative
- Parent education classes
- Family assistance
- Education of pediatricians
- Preschool, nursery schools, daycare, Head Starts, teachers
- Family education
- Paraprofessionals - Independent Health
- College partnerships and training
- Strengths based intervention models
- Evidence based intervention models
- In classroom/out of classroom modeling
- Early intervention – outreach, engagement, education – integration in schools/centers – not clinic based but in locations where children work, play, and interact

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
- Transition supports – otherwise people fall through the cracks
- Managing stigma, treatment, next steps (Funders, insurance companies allowing for sustainable funding for programming)
- Coordination of services
- Distinguishing between adolescents and young adults
- Peers – youth share experiences with their own peers (own age)
- Skills programming – social interaction
- Professional development so that they are delivering services appropriately
- Bullying programs
- Programs to address dual diagnosis (especially opiates)
- Education to families about use of drugs as self medication and risks associated with having them in homes
- Vocational and educational skill building
- Managed care advocacy and policy work

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
- Family support – especially related to undiagnosed issues
- Financially fragile families
- Easy intervention/transportation
- Home-based intervention for family
- Respect for families

- Kid world – adult work transition (clarity in expectations)
- Defining family – affects the nature of service
- Modeling/parenting skills
- Mobile imagery – one on item is taken out of control other aspects move as well
- Parent/family choice for intervention - funding

Statement 4: *Communities are inclusive, responsive, and equipped with adequate supports for youth and families.*
- Child care, afterschool, school training
- Community education
- Media coverage (Freakonomics – piece on Suicide)
- Anti-bullying campaign
- Collaboration/integration – shared goals, mutual especially between and within systems/silos
- Advocacy policy/budget
- Social emotional wellness
- Media Campaign
- Inclusion – may not be appropriate always – recreation and engagement for individuals who cannot partake in inclusive activities
- Churches and faith institutions involved (trained)
- Criminal justice worlds
- Models of best practice – shifts in thinking
- Funding/sustainability (Culture Shift)

Statement 5: *Stigma related to mental illness is eliminated.*
- Generational experiences
- Anti-smoking campaigns – social marketing
- Natural environment services – integration
- Normalize mental health challenges with famous people – identify
- Anti-bullying partnerships
- Hopefulness

Possible Indicators/Measures:

- University of Rochester Research
- Criminal Justice literature on hopefulness
- School Districts data – BOCES
- Office of Mental Health – Clinic Plus data
- Kids Portal – Office of Mental Health
- Connecticut – Early Intervention/Parental Stress Research
- Federal Agencies
- Stigma – connect to teachers unions
- Care Coordination –Child and Adolescent Functional Assessment Scale (CAFAS)
- Office of Mental Health (OMH) Family Surveys – agency-level, regional, statewide

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-11-29 (6:00pm-8:00pm)
FOCUS GROUP | Parents
Focus Group One – Cape Cod
Host: Massachusetts Society for the Prevention of Cruelty to Children (MSPCC) (Barnstable County, Massachusetts)

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
   - Identified for what? Socio-emotional, behavioral concerns?
   - Treatment – may want to clarify the use of multiple treatment approaches
   - Hard to determine/see in children – what does mental illness look like in children – hard to identify it as a mental health concern and not bad parenting, behavioral problems, socio-emotional
   - Mental illness is a pejorative term, frightening as is the use of the term consumer
   - While mental illness can be used to clarify the situation and the fact that the person cannot control their behavior, it is not the best term
   - Mental illness or perhaps you want to describe it as social, emotional or behavioral challenges especially with children – they display these concerns very differently than adults – hard to diagnose
   - These concerns cause parents to avoid "mental illness" and seeking help because placement in programming often leads to stigma and separation from the peer group
   - Also tends to be addresses inappropriately – for example, the use of behavioral programming becomes like a checklist – the child did this, the child does that – this is not helpful if the child needs help with processing
   - Need to identify the causes for behavior – behavioral programs make assumptions that it is strictly behavior but this may be incorrect
   - Importance of a strengths-based approach – particularly in the competitive school environment
   - Importance of early identification in schools and the adoption of a preventive model
   - "Kids do well if they can do well. If they can't do well, why can't they?" (Ross Green) – skills other than behavioral skills need to be taught (for example, self regulation)
   - Not just poorly behaved or poor parenting
   - Mental illness is very broad - need to be able to categorize it and understand the specifics of the diagnosis
   - Parents know something is not right with their child – they need to be heard and believed and not just viewed as helicopter parents

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
   - Self acceptance is a lofty, likely unattainable goal that requires numerous resources from different arenas of life upon which self esteem is built
   - Developmentally, self acceptance and identify formation is a major developmental milestone of adolescents; they may not get there but can they "deal" with their mental illness as a youth or young adult; this is a time of exploration developmentally
   - Should the focus be on self acceptance or the ability to take responsibility, be accountable, to manage their conditions

- Responsibility becomes increasingly important as the child gets older, this is important societally as the consequences and the punishments become more severe for behavior
- We have filled our jails with people with developmental/mental health issues
- Really should be focusing more on understanding rather than self-acceptance; before self acceptance, there is a need for understanding of conditions and circumstance
- Real concerns around dual diagnosis – substance abuse (self-medication) and mental health concerns – can lead to very destructive behaviors and great challenges for parents and families; assistance that may be available is voluntary programming
- Dual diagnosis is very high in the Cape Cod area – self medicating
- Individuals don't fit in with adult groups or specific substance abuse programming – including them there can be very dangerous

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
  Stakeholder Response-
- Really not about the family – about everyone else including: schools, police, neighbors which makes it harder to get the help that is needed
- If an family member had cancer, outside people would not shun them, stop talking to them, stop allowing their kids to play with them; it is understood that cancer is an illness/disease and not their fault, this is not the case with mental health concerns
- Very difficult for siblings whose lives are often interrupted because of the various needs of the person with mental illness
- Families need to be able to identify next steps and to identify resources that can help them
- Experience is exhausting physically and emotionally - relentless
- Can lead to problems in the marriage as well as other challenges
- This is an important result statement

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
  Stakeholder Response-
- This feels very global – may need to break it down into smaller units
- Like the term "communities"
- Really should be more about communities understanding mental illness in order to get them to be more inclusive, responsive and equipped
- Adequate is better than what we have now but perhaps it is not the ultimate goal (okay for now)
- Adequate can be problematic – allows people to just support the lowest level of care or even use of institutionalization
- May want to move to "healthy" rather than adequate
- Should take cues from the transformation of the treatment of minority groups – African Americans, Lesbian Gay Bisexual Transgender groups – there has been a shift in views on these groups over time – could this happen for persons with mental illness?
- Should not the use the term "mental illness" – this term should only be used if trying to illustrate a point about why someone behaves the way they do and should only be used as a last resort to help people to understand – the term "mental illness" illustrates that it is out of the person's control like any physical illness (would never question the care of someone who has cancer)

- Mental health is too soft a term – may want to use the term "mental health issues" or "mental health challenges" (disabilities)

Statement 5: Stigma related to mental illness is eliminated.
Stakeholder Response-
- You need to start here and work backwards (5, 4, 3, 2, 1)
- This is a lofty goal – needed goal
- Don't shy away from the use of the term "eliminated"
- Root of everything is stigma – lack of mental health parity, difficulty securing treatment, lack of programming
- Trauma and mental health concerns are shrouded in secrecy in our society – what happens to the people who experience trauma or have mental health concerns
- Not part of an open conversation –such a conversation will be necessary if we are to change anything
- Need to help people to see that there is no difference between a mental illness or a physical illness – both need treatment to be addressed – doing so would address the problems with insurance coverage for mental health services and could help move towards mental health parity

<u>Strategies Associated with Original Results Statements</u>

Statement 1: Children with mental illness are identified early and treated.
- Need education for schools, pediatricians, groups that deal with children on mental health symptoms and resources
- Need for more health practitioners – child psychiatrists, psychologists
- Lack of resources
- Day treatment and interim support
- Transitional support from hospital to school, community-based and in between supports
- Parents may keep kids in school but this is a real challenge without supports – the kids are required by law to go to school but they may need additional supports to be able to do so
- Transitions for young adults – specific to population and NOT with adults
- Early childhood connections/training – parents, child care providers, Head Start programs, pediatricians – there is some screening occurring but we need to know more
- Need help teaching parents how to identify mental health concerns
- Play groups for kids having difficult time in play groups – social skills are identified as concerns early on
- Schools need to do a comprehensive evaluation/other diagnoses (dual diagnoses)
- Staff training to identify mental health concerns and needed resources
- Coordination among teachers, counselors, administrators – chronically understaffed (too many Individual Education Plan (IEP) goals, not enough resources)
- Services identified by school require trained people to deliver them including social skills therapist – all too often these services are delivered by people who are not specifically trained to offer them leads to over identification (Autism) and concerns around overmedication (suggested at schools but people who are not trained to make this determination)

- Need to engage parents in the assessment of their children – not just teachers, school personnel and not the child themselves
- Social piece is critical all the way through the child and adolescent years – transitions and unstructured time is the most difficult

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.

- PAL group – self advocacy and peer to peer support is critical
- Availability of therapeutic high schools for children with mental health challenges
- Advocacy leagues, peer support groups, youth leagues (start younger with these)
- Bullying programming – schools tend to ignore the issues, should institute zero tolerance policies, now required by the state to develop a statement on bullying but most are not doing anything more than this; technology has only complicated the issue and schools need to be more responsible
- The process to address bulling can also be very difficult especially for kids with mental illness as they are required to have witnesses to the offense which can be made more difficult related to cyber bullying and its anonymity
- Kids with mental illness need advocates to assist in these situations
- Schools need to move from suspensions towards required anti-bullying programs that provides youth with social skills/support; need a different process for children with mental illness that is protective of them
- Introduction of peer buddy (1:1 adult support) to help children address hallway situations
- Kids with mental illness need preventive strategies, help with coping, tools to use in their everyday lives
- What happens when the child with mental illness leaves schools and is transitioning into life – they are adults but they cannot manage everyday activities – calling for appointments, riding the bus, maintaining a calendar – they need help developing their executive function skills
- Add life skills to curriculum for youth – planning and strategies
- Offer day programming – a post graduate program with transitional services which will serve as a bridge for youth and young adults (especially as parents ability to help is reduced once they come of age)
- Need available resources, connections, to develop a sense of community
- Community homes for youth and young adults with dual diagnoses
- Positive peer support

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

- Provision of respite services (especially on the Cape)
- Family-to- Family education (12-week course offered by NAMI; teaches families that they didn't cause it, can't control it, won't cure it)
- Parent advocacy
- Parent -to-parent support
- Sibling support groups
- Group homes (especially for those individuals with a dual diagnosis)
- Deceleration techniques/skills, tools for parents

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

- Education for churches, schools, etc.
- Public education campaign related to mental illness
- Efforts to shift the language of mental illness to something that reflects the nature of the illness
- Development of a collaborative group/coalition
- Community and professional education

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax) 716 689-3716
www.thetowerfoundation.org [70] info@thetowerfoundation.org

Statement 5: Stigma related to mental illness is eliminated.

- Media campaign
- Education – particularly students, teachers, school administrators, community members
- Communicate the signs of mental illness
- Share stories of the experience of mental illness from the personal/family point of view
- Speaker's Bureaus within communities
- Identification of role models particularly those at a local level
- Support use of the Wellness Recovery Action Model (WRAP) developed by Maryellen Copeland
- Replicate the "What If" Campaign (related to bipolar, depression, etc).
- Improvement of school-based early intervention

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [71]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
- Greater awareness of symptoms – behavioral, social, emotional
- Not just treated and done with children – on-going thing; requires on-going monitoring as youth undergoes developmental and physical changes – don't just do it and you are done, changes at every stage of development
- Need for continuing mental health services and support
- Really about access to developmentally and age appropriate treatment
- Phrasing makes it sound like it is event based when it is really ongoing
- Concerns about "identifying" – parents may not want to have it identified, leads to labeling, segregation of student in schools, maltreatment, problems with insurance and coverage
- Really looking at watchful waiting with younger children and the need to access additional supports

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
- There are real developmental implications here – not sure that self accepting is realistic
- Self acceptance does not necessary mean that they are committed to managing their condition – that is the more important of the two and can lead towards the eventual fulfillment of the goal of self acceptance
- Must start treatment early – early diagnosis and treatment should be oriented towards helping the person to become self-accepting – may not happen when they are a youth or even young adult but this is the ultimate goal
- Reduce stigma by showing that mental illness is treatable – need to recognize that it is a brain disease first to reduce stigma
- Mental illness – need to get clear about the definition – is it inclusive of all mental illness – environmental, physiological disease with environmental components, behavioral? The Foundation should address all levels of mental illness – especially when children are young
- Substance abuse and mental illness – really about self-medication – need to acknowledge this specifically. The two issues are treated differently and siloed in the community, but substance abuse is really a symptom of mental illness
- Need to acknowledge substance abuse particularly as it connects to mental illness
- Must diagnose mental illness early or it can lead to self medication
- Should switch statement #2 and #3
- Need to spell out the developmental issues – managing conditions is most important part of the statement

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
   Stakeholder Response-
- Families are really a part of treatment – should be connected to individual treatment

---

- Multigenerational issues – unfortunately many families will not participate in care of child or family member
- Mandated reporting should be related to mental health – not just physical health – should be able to report families that neglect the mental health of their child members or do not provide appropriate care
- Really about identification of mental health issues – in fact, emotional abuse can be far more damaging
- Child protection requires that families be kept together – not always in the best interest of the child – there is also a push for in-home services which are resource intensive and are a drain on other available services; families are disorganized – home is disruptive to the person in need of care
- If you are not treating the adults, then you are not helping children – the mental health of the family is the mental health of the child – greater potential for intergenerational mental health problems
- No cookie cutter solutions to this issues – not like insulin – variability and the importance of an individualized plan
- Should families accept mental health conditions? No! Greater focus should be placed on commitment to helping family members – committed requires involvement and effort more so than accepting – don't have to accept the situation but still need to do something about it

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
Stakeholder Response-
- #4 and #5 really go together – in order to achieve 4 you need 5
- What does adequate mean?
- Statement is too general and not specific to mental health (brain disease with environmental triggers)
- Be specific – seems that the goal as described here is to support healthy youth development – perhaps it doesn't have to be about mental health especially if you want a phrase that providers can see themselves in – need to be specific about the types of programs/organizations you want to apply for funds – many organizations will be able to find themselves in this statement
- What about the term "necessary" instead of adequate? This should be the baseline
- May want extensive services, or eliminate the term "adequate" altogether
- May need to be augmented – strengthened/greater focus on what the Foundation really wants to do
- Availability of resources is the most important part

Statement 5: Stigma related to mental illness is eliminated.
Stakeholder Response-
- Stigma is both an individual and a community problem
- Stigma as an individual problem – should be able to "shake this off," pull yourself up by your bootstraps and get well, function well
- Stigma as a community problem – lack of understanding, education, desire to intervene and engage, fear of contagion, fear of aggression or violence on the part of the mentally ill individual
- There is no worries about providing a child/adolescent with "talk therapy" but as soon as the conversation moves to medication there is a great deal of stigma concern about this – this is related to the lack of acceptance as a physiological disease
- Should combine #4 and #5 – communities understand mental illness as a disease and work to eliminate stigma related to it.
- #5 is really the results statement and all others are objectives underneath it – if you address stigma, then children will be identified and treated early and in an on-going way, teens and young people can learn to manage their conditions and move towards self-acceptance; families can get the support they need and resources will be available

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
- Education of clinicians and providers
- Recruitment of clinicians, child practitioners – what is available now is younger, less experienced, clinical staff, especially on the Cape
- Provide additional training/professional development – greater access to assistance
- Some of the problems with staffing is related to stigma – no money, not paid well, not respected, physicians do not go into the field because of its stigma, little understood about brain disease in general, soft science
- Child care providers need to be trained to understand symptoms, to access resources
- Use of screening and assessment
- Availability of clinical consultations for those without access to services
- PCP – Primary care physicians and pediatricians should be involved; mental health needs to be part of the regular health check up part of your health; should be implemented as part of a required screening
- Concerns about a Pandora's box – if you screen for it, where will people go for help – give physicians support

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
- New Paths program for adults is very successful need a similar program for young people
- Programming for co-morbid disorders specifically for adolescents
- Schools need to become more open to available community services – as it stands right now most schools/administrators are protective of their environment and do not let the providers in to work with the students – they sometimes attempt to address the issues on their own when they don't really have the appropriate staff. As a result, there is more of a focus on behavioral challenges than real skill building; effect can be punitive in nature – need to have expert providers involved to provide appropriate services
- Peer group supports are critical – skills/coping/strategies
- Young adults need to integrate their social life and treatment
- Population – building social skills into the health curriculum would also be helpful – focusing in on social emotional health – this should be available to every kid not just those with a mental illness/diagnosis
- Emphasis should be on prevention of issues
- Need to understand mental illness – education particularly on medications/interactions
- Lack of resources and lack of things to do – lack of teen centers – need more resources within communities (related to result statement #4)
- Need to move past the stigma of mental illness – better term may not be available – should be able to discuss this like any other illness (diabetes, liver disease) and not blame the individual who has it. The term "behavioral health" was designed to include substance abuse but it sounds like a euphemism, describes the symptoms and a class of diseases; actually feeds stigma as if mental illness was just behavioral, and controllable if the person could just learn to behave - as if this is your fault.
- Could describe the "disease of mental health" – but there is a view that diseases are contagious; we have seen some movement on language related to alcoholism and the acceptance of this as a disease – perhaps the Foundation could look at this (but not at the expense to funding of treatment)

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.

- Education
- Basic needs of the family must be addressed to even hope to address mental health concerns
- Stigma – intergenerational concerns
- Need to integrate mental health care into primary care – make this part of standard care
- There is a great deal of concern about information about child's mental health status being shared with the school – the child will be labeled, tracked, this leads to a lost opportunity for support – need to make it safe to secure assistance for mental health concerns
- Parents are blamed by teachers – need education for professionals about the nature of mental illness, conditions, symptoms, services
- Also must focus on the development of partnerships versus camps – increasingly there is turf and territoriality among providers – need to be working better together

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.

- Need new models of ways to work together to address issues
- Coordination/partnerships – coordinated community response to mental health concerns
- Prevention of mental health challenges through schools/out of school programs
- Alternative programming – out of the box (midnight/late night basketball), post-prom activities everyday; teens need something productive to do with themselves, other avenues
- It is part of the developmental experience of teens to engage in risk taking, experimentation, poor judgment – by providing some alternatives, one might be able to mitigate, this but it is part of development

Statement 5: Stigma related to mental illness is eliminated.

- PR Campaign to address sigma (those don't want to spend tons of money on this rather pay for treatment than engage in basic promotion – promotion should be aimed at prevention)
- Certain amount of education is necessary in the communities but don't want to expend all of the resources on this – should be done in combination with other activities
- Can't just fund treatment only – need publicity/education to create community change – some PR is necessary AND justified – can be very effective – look at the "Real Men, Real Problems" campaign related to suicide prevention – led to greater depression screening
- Educating doctors/pediatricians about mental illness, symptoms, treatment is important as is parent education and education in the community – nurses, teachers, etc.
- Need to normalize mental health conditions – it is okay to be on medications to address these concerns – make it okay
- Workplace education is also very important – businesses need to be more accepting of these situations and their impact on families/employees – very costly
- Should be looking to work toward more family-friendly policies (example: Cape Cod Youth Action Plan – working with employers to educate)

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [75]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-11-30 (1:00-3:00 p.m.)
FOCUS GROUP | Providers
Focus Group Two – Cape Cod
Host: Massachusetts Society for the Prevention of Cruelty to Children (MSPCC) (Barnstable County, Massachusetts)

Review of Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
- Children with mental illness are identified and treated early – the revised statement has more of a prevention orientation
- Look at the Massachusetts Children's Behavioral Health initiative – reaches all MassHealth children but does not reach all children in need of care
- What does early mean? Is it related to age, onset, early in condition, screening for all
- What does treatment mean? Professional treatment, family skills
- Identification goes beyond screening – need to look at familial history and get in front of mental health concerns
- Treated – shouldn't just be treated but treated effectively – intervention, supported, needs are met – what is the goal/outcome of the treatment – not stated in the statement
- Terminology – behavioral health sounds like behavior only and not about mental illness; mental illness is loaded and has stigma attached to it; disorders is not great – mental health concerns, challenges, issues, conditions
- May want to start the phrase "Mental health challenges in children are…" or "Potential mental health challenges…" – captures some of the emotional items
- To what end? Mental health challenges are addressed? Is this specific to organic mental health problems , will you address environmental concerns? Prefer the broad based approach because if environmental concerns are not addressed, you will see higher order concerns in people – need to determine what level of mental health concerns you are interested in addressing – is it all kids at risk
- Early intervention/identification is the key – enables you to develop coping skills and strategies at an earlier age or close to onset of issues
- Need more funding to service younger children up front

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
- Self accepting is like having a sixth finger – nice to have but not necessary; really need to learn how to manage their conditions – this is the most important part of the statement – will allow them to become independent, productive individuals
- Purpose of the statement is unclear? Do you need this as a stand-alone statement
- Really should be youth empowerment language – but the use of the terms youth and young people is questionable in some circles – may not be the best terminology for youth themselves
- How would you measure self accepting? Managing conditions? Could measure the compliance of individuals but self acceptance would be more difficult
- Not sure you want this as your #2 result statement – not as important as the other ones – do you really need this result statement, can you track something else or connect it to #1
- Managing conditions is what is really important

- Should substance abuse language also be included? So many co-occurring issues

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
Stakeholder Response-

- Understand what about mental health conditions – Nature of? Facts of
- Need clarification for substance abuse
- Don't use the word "member" – people, help them
- Hate the word "Happy" – F*CK Happy workshop
- Intergenerational challenges – parents have their own challenges that need to be worked through if the child will make progress
- Education
- Helping the child to manage their conditions is the most important job of the family
- Need to keep the family healthy and productive; address the "effects of the condition on the family" if you want to make progress with individuals
- Critical role of family not stated strong enough
- Should look at effectiveness

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
Stakeholder Response-

- Integrated vs. adequate
- Adequate is a very weak word – just enough, sufficient
- Consider: comprehensive, complete, effective, appropriate
- Inclusive – does this address access issues
- Inclusive is vague for measurement purposes
- Is this about the community as a whole or the provider community? What is the focus? Unit of analysis
- Responsive is very broad. How do you measure it? What do you mean? Level is important – whole community, providers
- Community culture – this requires a level of understanding of mental health issues at the local, grassroots level – not currently there

Statement 5: Stigma related to mental illness is eliminated.
Stakeholder Response-

- This is so important – it is an illness and we can treat it – if treated appropriately, people can experience normalcy
- There is concern that mental illness is contagious
- People don't know what to do when they encounter someone with mental illness or identify a family member who is experiencing symptoms of it
- Physicians are critical to involve in screening of children/adolescents; health care providers
- Possible use of "remission" language - limit acuity
- Cancer is no longer "secreted" in society – need to change social norms/values/moralizing

- Like the use of the term eliminated – means that we are serious about it
- Must recognize shame related to mental illness

Strategies Associated with Original Results Statements

Statement 1: Children with mental illness are identified early and treated.
- Professional development and training for pediatricians, early education staff, school personnel
- Need to recruit more child psychiatrists/psychologists – possibly address levels of reimbursement or develop strategies to recruit more people into the field
- Increase community partners working on these issues – coordinated community responses to child mental health – greater coordination, cooperation, and collaboration
- Development of a community wellness treatment team
- Integration of mental health providers within pediatric health practices – mainstream mental health services and make them a regular part of health related activities
- Parenting groups
- Parent-child engagement programming (including foster homes)
- Address social norms – media campaigns around health and wellness, early identification of mental health concerns, models to promote care
- Education within the community – use of media to facilitate this education
- Home visiting/home intervention models
- Education around the importance of and proper screening/assessment/training

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
- Support groups – less insight focused, more use of Cognitive Behavior Therapy(CBT), age specific
- Education on mental health and how to manage symptoms (psychological aspects, family education)
- Use of technology – smart phone technology; application to connect to counseling outside of regular business hours/scheduled appointments; identification of high risk areas – contact client and the agency (help with recovery)
- Limited availability of research and development funds to try new things, innovative projects
- Could look at medication management using technology

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
- Availability of Trauma-Focused CBT for families
- Family Systems Therapy
- Family programming – engagement and interaction
- Family recovery/wellness coaching (24/7 availability of trained health professional) enables parent/guardian to run concerns by a professional at any time, fills in the spaces between formal assistance/services and other times

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
- Use of data/statistics (available through Barnstable County)
- Use of the Internet
- Comprehensive assessment of community resources and needs

- Training and education
- Youth voice and engagement
- Physicians – assessment and screening
- Availability of resources – knowing where to turn – useful and informed hotline for consultation
- Alternative sources – example: Gateway Connect suicide project – training of Bartenders
- Address the disconnect between physical and mental health
- Cape Maternal Depression Initiative – multiple players/partners working together; successful
- Need to fund basic work and sustain it – don't keep asking providers to create new programs to get money
- Persistence of impact – need to provide multi-year funding
- Transportation
- Resources to maintain well-trained, well-qualified therapists
- Recognize lack of resources related to adolescent/young adult transition – not launching appropriately need more supports in this area

Statement 5: Stigma related to mental illness is eliminated.

- Education
- Media engagement – neutralize media messages
- Use of the Internet
- Ad campaign related to fact that mental illness is brain disease
- Documentary, stories – similar to *I have Tourettes* (HBO) – must be professional pieces
- Un-mute the voices of recovery – have people speak about their experiences – local individuals
- Address the stigma associated with trauma
- Coordinate and integrate anti-stigma campaigns across social problems

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-11-30 (6:00-8:00 p.m.)
FOCUS GROUP | Parents
Focus Group Two – Cape Cod
Host: Harwich Community Center (Barnstable County, Massachusetts)

Review of Original Results Statements | Strategies

Statement 1: Children with mental illness are identified early and treated.
  Stakeholder Response-
- This is a good outcome but how will you measure it? Treated and Identified
- What does treated mean? Pharmaceutical, counseling, use of mindfulness. Mindfulness has gotten very popular on the Cape but the problem is that it can lead to an exacerbation of symptoms among some individuals with mental health challenges – anxiety, etc.
- What level of mental illness counts? There is a lot of diagnosing by unqualified professionals which leads to incorrect diagnosis and overmedicating of children and youth
- In some cases, children are being "culturally diagnosed" out of a desire to do something to address behavioral challenges – teachers, child care providers, administrators are telling parents that children have something wrong and that the child needs medication when they are unqualified to provide such a diagnosis. Parents then go to doctors to get medication
- There is a desire to do something but it may not be the right solution – also leads to labeling of children and youth which further segregates them
- Need to train pediatricians and professionals in proper screening and assessment and need to make sure diagnosis is documented and proper
- Tower should consider the criteria for diagnosis and provide very specific proposed outcome measures to capture this

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
  Stakeholder Response-
- Teenagers we serve are moving in this direction – Southeast Alternative School – range of children along the autism spectrum
- Requires small student to teacher ratios; non-stigmatizing environment
- In many cases, children and youth are self-stigmatizing – feel bad about themselves disproportion to their actual issues; need to address labeling and problems of executive function; they "own" their stigma
- Should look at Woundology (Carolyn Mease)
- Need to move toward positive youth development (40 developmental assets), self esteem
- Could capture this with pre-post survey work, self reports; dealing with traditional barriers of people sharing how they field
- Could also look at arrest rates, court appearances, incarceration
- Really need to get into community supports for teens and young adults especially those with whom they will interact in the community – example, first responders training project with police and firefighters – trained in mental health concerns through role plays – provide them with skills to assist persons with mental health challenges – avoid use of the court system

- First responder training – hands on training, role play situations, held at the firehouse – worked because it addressed the needs of multiple groups – training focused on responding to behavioral styles and diffusing situations; Contact Deb Wood at South Norfolk County ARC (SNCARC) for more information on the project (tell her Steve Brown told you about the project)
- Importance of peer support – trained and equipped with life skills
- Peer support needs to be non-judgmental, non-rescuing by youth with youth
- Want youth to avoid being sucked into stigma – LAMB model (Listen, Affirm, Model, Bless)
- Don't want peers to rescue, advise or project – more in line with appreciative inquiry
- Also major concerns about dual diagnosis – self-medicating, alcoholism and addiction – very limited resources for this on Cape – major problem

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
   Stakeholder Response-
- Need to address cultural literacy – diversity of populations on the Cape – provide assistance in Portuguese, Haitian, Brazilian, various immigrant groups
- Families from historically disadvantaged marginalized groups – past lack of access to services or poor past experience; intergenerational issues
- Need to recognize families from all cultures
- Should provide unstructured family nights, social activities for families with members who have mental illness
- Isolation of families with mental health challenges is profound
- Need for respite care, support, education

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
   Stakeholder Response-
- Definition of communities is key – could be geographic, recommend that Foundation includes communities of shared interest – broader definition
- What does inclusive mean? Children/youth/adults with mental illness feel excluded – exclusion is the worst experience (George Bernard Shaw)
- Being inclusive is very important – will require asking people – measured by how they feel in terms of community
- Encourage inclusion; Should also consider incentivizing diversity – does board represent the age, linguistic, gender, race, ethnicity, sex character of the community – inclusion is key
- Communities are experiencing mental health challenges at a greater level since 9/11 – Post Traumatic Stress Disorder (PTSD), anxiety, mental health issues

Statement 5: Stigma related to mental illness is eliminated.
   Stakeholder Response-
- Really hard to address this – idealistic goal
- Despite training people are uncomfortable with people with mental illness – this is in and of itself stigmatizing – this is demonstrated in the way we provide services to people with mental illness – we concentrate them in settlings that stigmatizes them – shelters, shadowy locations – They deserve the same or better surrounding as everyone else

- Need to diversify meetings
- Perhaps stigma will not be eliminated but acknowledged or addressed
- Work towards inclusion, education, tolerance, training
- Provision of clubhouses and other nurturing and open settings
- Recognize the shame and fear associated with mental illness – especially related to attempted suicide and the reintegration in the community

Other Comments:

- Should emphasize collaboration – related to vision alignment, goals, objectives, and actions
- Requires the ability to let go of need to control things
- Should fund shared goals and ability to add value
- Example: NAS Youth Alliance – Provincetown – multi-age afterschool program; everyone has responsibility for others; working towards shared outcomes – young people are involved earlier and have a specific role
- Unfortunately organizations are habituated to competing for funds
- Dream is to establish a center for nonprofits with shared administrative support, greater efficiency on less specialized tasks
- Could measure joint-shared mission, shared policies, shared procedures
- It is about human, social, and political capital

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [82]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Results Statements | Strategies

Statement 1: Children with mental illness are identified early and treated.
  Stakeholder Response-
* More of them are misdiagnosed
* A lot of them are missed altogether until later in life
* Most are just considered "bad" and are kicked out of many activities
* Parents are being told it's developmental. "He'll grow out of it"

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
  Stakeholder Response-
* Programs for children have to be accepting too. Many times the "rules" of programs or activities for children do not accept children with mental illness because of potential behavioral issues
* Children aren't fully capable of completely understanding their conditions
* Often it's the adults who can't accept the condition and make the children uncomfortable with it
* It's a neurological problem so kids may never really accept it and they just find a way to deal with it
* Start educating the children early about the illness using terms they understand
* Tough for kids with mental health issues and developmental disability issues- many parents are experiencing children with dual diagnosis
* Professional need to be educated with the children with mental health issues
* Children with a dual diagnosis of mental health issues and disability are targets of bullying. This parent talked of her son who has a form of Autism and does not seem to care that his peers know about his mental health status and so he has been bullied many times because of it

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
  Stakeholder Response-
* Families are more than just blood relatives. Many of the mothers in the room feel that the Friday Night group is more like their family than blood relatives
* Extended blood relatives don't really know about the issues
* People gave trouble seeing themselves with the issues. One mother self-disclosed that she has a bi-polar disorder for the first time to the group, and it wasn't until she divorced her unsupportive husband that she was able to get the help she needed for her condition. By helping herself, she was then able to get the help her daughter needed
* Outside families members think you're doing something wrong. "Control you child!" "Why can't you keep your kid in control?"
* There are different ways to be educated

- Culture plays a huge part. This is in reference to being educated. One Latina mother described her ethnic community as not wanting to know about the child's mental health status and that it is very difficult to break through to that community
- The "powers at be" aren't explaining it well for anyone to understand
- Families might support the parent but not the child. One mother describes how her family "feels bad" for her and for the "situation" and how they don't think they could handle it. This type of attitude does not make the mother feel good

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
   Stakeholder Response-
- This statement is too off base from reality to be realistic
- There are still issues even with the Health Parity Law
- The schools are physically holding the children to restrain them and the children have the bruises to prove it
- Parents living in the smaller communities have to drive all over for services
- Communities need the supports too
- Mental health doesn't get the same type of privacy as physical health issues

New Statement: My community is inclusive, responsive, and equipped with accessible supports for youth and families with mental health issues.

Statement 5: Stigma related to mental illness is eliminated.
   Stakeholder Response-
- This is powerful and many of the problems related with mental health stem from stigma
- This statement should be first in the list of statements

Group notes: The energy from this group of parents was remarkable. It felt as if no one had asked them what they thought about their children's mental health within the system. The parents described situations of being powerless within the school system or the medical system because the professionals think they know better. For all of the parents in the group, the Friday Night Dinner group was invaluable to them and the best night of the week. It was a place where they and their children could go without being judged and where others understood them. Many described not being comfortable with relatives and they were more comfortable with their "family" on Friday. Even during the focus group, one woman felt comfortable enough to share her own struggles with her mental health issues because her family was there to support her. It is clear that without this group, many may not have been able to thrive while learning how to cope with the mental health issues of their children.

As far as the result statements, many were not too concerned about the wording because they felt that any goal was better than what was happening right now. Many parents expressed their hopes for more parents and children to be involved with processes like this in the future.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Results Statements | Strategies

Statement 1: Children with mental illness are identified early and treated.
  Stakeholder Response-
- Providers have come away from this and have moved towards focusing on the intervention
- Getting families and youth what they need earlier on
- Early is key
- "Mental illness" vs. "mental health condition"
- Can't intervene early because it's not a mental illness
- Do you really want to diagnose a three- year old
- "Treated," sounds medical and it only happens once
- Treated doesn't always mean a mental health treatment. Sometimes a treatment can be alleviating environmental issues or economic issues
- Without the label of "mental illness", it may not be medical-y enough to get paid by the insurance companies
- Families should be included

New Statement: Children with social, emotional, and behavioral challenges are identified early, appropriately assessed, and are given resources.

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
  Stakeholder Response-
- This is empowering, being responsible for themselves
- Some youth and young adults may not be able to self-accept
- Kids are trying to group up but don't have the resources
- At this age, they may not be able to manage, but they should know where to go for help
- There's a huge crossover with substance use and abuse
- Putting the word "behavior" in the statement would get at substance use/abuse too

New Statement: Youth and young adults with mental health and behavioral conditions are self-accepting, and have the skill and resources to manage their conditions.

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
  Stakeholder Response-
- Who are "members"
- This statement assumes familial capacity and that may not be the case
- If the parents/family also have mental health issues then the intervention will be different
- What is "happy and productive"
- What about the family with conditions
- "Living up to full potential" may be better than "productive"

- Being able to function without a crisis may be a goal

New Statement: Families understand mental health conditions and have the resources to be committed in helping their family members to have meaningful relationships and live up to their full potential.

Statement 4: Communities are inclusive responsive, and equipped with adequate supports for youth and families.
Stakeholder Response-
- This shifts from the individual to the community
- Does "community" include institutions? For this group it does, but some were concerned that for others it may not
- Advocacy with the systems is very important in giving the communities what they need.
- Families should not be on their own
- Adequate= good enough. This isn't a good word. "Meaningful supports" implies that the supports can adapt to specific family situations
- What about the families and children with mental health issues

New Statement: Communities are inclusive, responsive, knowledgeable, and equipped with meaningful supports for children, youth, and families (dealing/coping/identified) as having mental health conditions.

Statement 5: Stigma related to mental illness is eliminated.
Stakeholder Response-
- Great goal
- It needs to happen at all levels but it starts at home and then move towards the professionals
- All other statements also work at eliminating stigma

No change to statement.

Strategies:

1. Education is the cornerstone
2. Staff trainings, which are continuous instead of once a year (or less)
3. Use a multi-faceted approach
4. "Stop and Think" campaign instead of saying whatever negative idea a person has
a. Staff at agencies become anti-parent and this negative attitude affects the interactions with the families

Group notes: While many of the ideas from this group had been heard before, there were some new ideas that should be considered in revising the results statements. After the group was over, many participants were happy to be a part of the group. Some commented that in their professional lives, they do not get the opportunity to really talk about their perceptions of mental health with other professionals. For them, it is helpful to understand how other agencies think about these issues. Other participants also felt re-energized about their work and hopeful for a better future.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2011-12-14
FOCUS GROUP | Providers
Salem Mental Health Groups: Providers
Host: Children's Friend (Essex County, Massachusetts)

Review of Original Results Statements | Strategies

Statement 1: Children with mental illness are identified early and treated.
   Stakeholder Response-
* Early identification is critical and research supports it
* Children become identified through their behavior
* There may be other issues happening that may look like mental health issues but really there's an environmental problem
* "Treated" is not a great word- feels too medical

New Statement: Children with social, emotional, and behavioral challenges are identified early and are engaged in appropriate services.

Strategies:

* Link mental health services with medical services and schools
* Educate the teachers and primary care physicians
* Behavioral health homes
* Educate the pediatricians better
* Make better screenings for mental health
* Community Health Centers in East Boston had great collaboration between health and mental health workers
* Change the curriculum in medical schools to include more mental health components so doctors know when to send patients to mental health professionals
* Increase access to appropriate assessments when available
* Increase access to services that are available

Statement 2: Youth and young adults with mental illness are self-accepting and able to manage their conditions.
   Stakeholder Response-
* What is "self-accepting"
* Youth may not be able to fully understand the impact of their condition on their future
* "Conditions" doesn't feel right but what else do you call it

New Statement: Youth and young adults are knowledgeable and accepting of their mental health needs and are able to access supports to manage their "conditions".

Statement 3: Families understand mental health conditions and are committed to helping members to live happy and productive lives.
   Stakeholder Response-
* Commitment looks different at different levels of family
* A persons potential isn't implied here
* A person can be productive with reaching his or her full potential

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [87]   info@thetowerfoundation.org

- A person can be productive with reaching his or her full potential
- Families can be other than blood relatives, and for some, non-blood relative "family" is more important than traditional family members
- Parents and relatives can also have mental health issues too that are not being addressed
- What's "happy"
- "Committed" is an action word and not passive for this group

New Statement: Families understand mental health needs and are committed to helping each other to reach their full potential to live satisfied and productive lives.

Strategies:

- Families need to access the information
- Mental health practitioners working with the schools because parents feel more comfortable with their schools
- Work with the principals to allow mental health workers into the schools
- Increase wrap around services for families
- Develop/increase mental health phone consults for physicians
- Up-to-date resource guides, both printed and electronic
    - The Boston Bar Association has a similar guide
- Support groups for parents
- Full family education, not just parents, through a variety of ways: webinars, conference calls, in-person workshops. Education is also culturally sensitive
- Use of Family Partners, family mentors, and peer mentors: other people who have gone through similar situations and make these positions a paid position within agencies. Volunteers can become burned out too quickly and this could be an intense job

Statement 4: Communities are inclusive, responsive, and equipped with adequate supports for youth and families.
    Stakeholder Response-
- Need to include "mental health" in the statement
- This is very broad
- Supports may not be mental health related- could be environmental or financial issues that are influencing mental health issues

New Statement: Communities are educated, inclusive, and responsive to provide appropriate and effective supports for youth and families with mental health needs.

Strategies:

- Training law enforcement about mental health issues
- Help stimulate more grassroots initiatives

Statement 5: **Stigma related to mental illness is eliminated.**

    Stakeholder Response-

- It's more than just illness, mental health in general is not a part everyday life
- Stigma related to other issues can drive the stigma of mental health
- What kids are dealing with may not be mental health like being poor, having different clothes, looking different, etc.
- This is very lofty

    New Statement: Families and individuals with mental health needs are better understood to eliminate stigma.

Strategies:

- Early education embedded in the class and it happens all the time. Could be a stronger component of health class
- Impact is at home. Whatever good that happens in the school won't last if it doesn't happen at home too
- TV, radio, internet campaigns: changing the messages about mental health issues
- Make it a public health issues
- Talking about personal experiences in a safe environment will lead to people talking about the issues publically and make the issues less taboo
- Using community based workers to do more outreach and education

Group notes: Like the first group of providers, this group had some ideas that might not have been heard before and echoed many of the same feelings about sharing their thoughts about these issues. Many were appreciative of being involved and there was a sense of renewed energy when the group was over.

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [89]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

INTELLECTUAL DISABILITIES FOCUS GROUPS

FOLLOW UP REPORT TO STAKEHOLDERS

Focus Group Demographics

Number Focus Groups:
- Erie County (4)
- Niagara County (2)
- Barnstable County (1)
- Essex County (2)

Stakeholders Involved:
- Intellectual Disabilities Professionals
- Educators
- Government
- Parents/Family Members
- Service Providers

Report Glossary

Result: A result is a population condition of well-being for children, adults, families and communities, stated in plain language. Results are sometimes known as outcomes or goals.

Indicators: Measures that help quantify the achievement of a result and answer the question, "How would we recognize this result if we fell over it?"

Strategy: a plan or method for obtaining a specific goal or result.

Reactions to Original Intellectual Disabilities Results Statements

---

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*

Key Themes from Focus Group

- Respondents identified a strong dislike for the term "appropriate." Respondents were primarily concerned with who would make that determination and also felt that the term "appropriate" was not necessarily focused on the needs of the child. Preferred: needed, necessary, based on the needs of the child, meets level of need, individualized. They also stressed that the focus should be on *independence and/or inclusion.*
- Respondents expressed some concern about the use of the term "early." They wanted clarification on what was meant and stressed the importance of timely services (from birth or even preventive, if possible). Several respondents suggested the importance of identifying issues or markers early on – even during the pregnancy. Many participants highlighted the importance of early intervention and suggested that individuals are often identified too late to take advantage of early intervention services.

- Respondents stressed that this was an iterative process – with no single fix or cure. They stressed the importance of reassessment of skills, capacities, abilities, and needs over the course of the individual's life. They also identified regression (at about three years) as a key issue.
- Several focus group participants highlighted that co-occurring conditions – often physical in nature - made diagnosis more challenging. They suggested including "diagnosis" as part of the result statement.

Statement 2: Youth and young people with intellectual disabilities achieve their full educational, employment, and civic potential.

Key Themes from Focus Group

- Respondents universally identified a dislike for the term "civic potential." They associated the term "civic" with citizenship, patriotism, voting and suggested social responsibility or community engagement.
- Respondents also universal felt that the most important "potential" was left out – "social" or "relational." Most felt that without emotional/social connections, none of the other forms of "potential" could be realized.
- Respondents strongly objected to the notion that any individual's potential could be measured or defined – whether the person had a disability or not. They further questioned whether this was developmentally appropriate for youth and young adults as this is a time for exploration and identify formation.
- There was a strong dislike of the word "full" related to potential. Respondents' felt that locating one's full potential was a life-long pursuit. They also felt that the result statement put too much responsibility on the target population – more so than their peers without intellectual disabilities. They felt that persons with disabilities should have the same options, choices, and ability to make mistakes as anyone else. As phrased, the result statement appears to single out persons with intellectual disabilities rather than include them as part of the larger community.
- Respondents stressed the idea of "*meaningful engagements*" – whether employment-related, social, or other – as well as support for transitions that will make engagements possible.
- Respondents highlighted that the focus should be on individual choice and self-determination.
- Focus group participants also emphasized the importance of non-segregated, truly inclusive activities within the community. They highlighted challenges that families face locating programming in the community that provides necessary accommodations.

Statement 3: Communities are inclusive, supportive, and provide a full-range of appropriate supports for individuals with intellectual disabilities.

Key Themes from Focus Group

- Respondents were concerned about how community would be defined? Participants stressed the importance of integration and inclusion. They also indicated that identifying a specific community for interaction would be antithetical.
- Likewise, the term "appropriate" seemed, for many focus group participants, to be in contrast with notion of inclusiveness – other terms suggested included: necessary or meaningful.
- Respondents also suggested including the term "opportunities" alongside supports to make the statement more well-rounded and less service driven. There was a strong sentiment for supporting choice and self-determination as well as a desire not to limit individuals to those things where they would be accommodated.
- Respondents also indicated that facilities providing services to persons with intellectual disabilities also faced levels of discriminatory behavior. They stressed that they were often held to a higher standard.
- Respondents also expressed concerns about the measurability of the statement.

Other Concerns: Terminology
- Focus group participants universally struggled with the terminology "intellectual disabilities".
- Definition needed to be read in each session.
- Preferred: developmental disabilities, cognitive disabilities, "cognitive or developmental disabilities" or straightforward use of "intellectual capacity" and "adaptive functioning" (from definition).
- Stressed the importance of adaptive functioning/behavior and risk.

Other Concerns: Need for Family Result Statement
- Respondents clearly identified the need for a family-related results statement.
- Participants highlighted importance of educating parents and ensuring that they understood the services available as well as how to access them.
- Parents, themselves, frequently stated that they wished there was a manual, someone or something they could turn to in order to get their questions answered; to better understand what to expect, etc.
- Respondents stressed that family understanding of the issues and support/advocacy on behalf of their child was absolutely critical for success.

Revised Intellectual Disabilities Results Statements and Suggested Measures Using Focus Group Input

---

Foundation staff revised the original Intellectual Disabilities results statements based on comments made by focus group participants and key themes that emerged during sessions.

REVISED STATEMENTS

Statement 1: Children with intellectual disabilities are identified early and receive services that meet their evolving needs.

> Reflects the fact that the receipt of services is part of an iterative process and the need for services changes over time as the child develops. There is no "one size fits all" solution.

Possible Indicators/Measures:
- Use of early intervention services, waiting lists
- Age at First Diagnosis
- Time from Diagnosis to Treatment
- Committee on Preschool Special Education data

Statement 2: Young people with intellectual disabilities are engaged in meaningful social, vocational, and educational pursuits.

> Reflects: The importance of meaningful engagement and clarifies the importance of social engagements in the lives of persons with intellectual disabilities.

Possible Indicators/Measures:
- Committee on Special Education data
- Cost of Services
- Child and Adolescent Needs and Strengths Data
- Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR)
- Education/Employment Outcomes
- Vocational Educational Services for Individuals with Disabilities (VESID) Data
- Quality of Life Measures

Statement 3: Families understand intellectual disabilities and secure needed supports.

> Reflects: The importance of family understanding and support for individuals with intellectual disabilities.

Possible Indicators/Measures:
- Quality of Life Measures
- New York State Department of Health or Other Family Survey

Statement 4: Communities embrace persons with intellectual disabilities and provide them with a full-range of supports and opportunities to engage in community life.

> Reflects: Desire to fully encompass persons with intellectual disabilities as members of the community. Seeks to recognize the unique gifts and contributions of persons with intellectual disabilities and to move away from a solely "service-based" orientation and towards the provision of a full range of opportunities as well.

Possible Indicators/Measures:
- Community Survey, public dissemination of information
- Education/Employment Outcomes
- Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR)
- Vocational Educational Services for Individuals with Disabilities (VESID) Data
- Quality of Life Measures
- New York State Department of Health or other Family Survey
- National Core Indicators Survey (University of Minnesota)

THE PETER AND ELIZABETH C. TOWER FOUNDATION

INDIVIDUAL FOCUS GROUP REACTIONS

2012-02-16 (2:30-4:00 p.m.)
FOCUS GROUP | Providers
Host: The Peter and Elizabeth C. Tower Foundation (Niagara & Erie County, New York)

Review of Original Results Statements

Statement 1: Children with intellectual disabilities are identified early and receive appropriate services.
   Stakeholder Response-
- Deconstruction of Early Intervention – system issue, parents – State
- Intellectual only
- Past early intervention - there is a lack of transition
- Early – more specific – not age early, upon diagnosis, early as possible, at birth (age), recognize issues/markers early on
- Timely and age appropriate/effective services
- Meaningful – appropriate
- Innovative untested – effective and based on need, sufficient, quantity, quality
- Limited developmental window, prevention – cost effective, life effective
- Children include family

Statement 2: Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.
   Stakeholder Response -
- Don't love the term – civic – social responsibility
- What is the difference between youth and young people
- Emotional needs should be included – relationship, social needs, really most important especially now with the moratorium on residential alternatives
- How do you measure one's full potential? Who determines this?
- Work, learn, and engage in the community
- About options
- Social Capital is important here
- Contributing member of society
- Concerns about educational equity
- Don't like the term "full"- really an on-going, life-long pursuit
- Independence - interdependence
- Employment – really under the microscope on this – not by itself – really about productive activity
- Needs to be meaningful, not just structured workshop
- Informed choice/logistics
- Fit with resources – exploring "fit" first
- Purpose – purposeful instead of "full"

Statement 3: Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.

   Stakeholder Response -

- Consider changing "appropriate" to "meaningful"
- "Appropriate" seems to be in contrast with notion of inclusiveness
- Perhaps necessary
- Not just supports – who are they chosen by – about opportunities
- Community – how does this get defined? – Statewide? Local? Values? Policies? $$?
- Build environments that honor needs of all

Strategies Associated with Original Results Statements

Statement 1: Children with intellectual disabilities are identified early and receive appropriate services.

- Pediatricians, child care providers, - only link to early intervention – need to educate about services
- Family to family interaction
- General education provider training – teachers, administrators, principals
- Cross-system training
- Medicaid redesign – 1115 waiver – need to think differently
- Informed choice – individual and family
- Family centered
- Marketing – awareness of resources
- Parent education
- Training and awareness for pediatricians
- Cultural sensitivity
- Early intervention currently has a prohibition on marketing of services at the county and state level
- Education for providers – referral, connection, staff development
- Healthcare system – early engagers
- Lack of understanding by medical system – doctors, hospitals, community health workers
- Flexibility in funding for innovation
- Addressing silos and regulations
- Focus is on funding first and then treatment should focus on treatment and find the funding

Statement 2: Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.

- Determine quality indicators for transition
- ACCES-VR – Transition
- Educational system – training - what are they seeing identify issue, skills sets
- Life skills training
- Education families/provides about available resources and supports
- Engagement – education of employers
- Parent education
- Individualized capacity assessment
- Eligibility for income supports
- Options for care/resources to use in the community
- Create employment options – educate on them
- Transportation
- Include and inform the child

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [95]   info@thetowerfoundation.org

- Investment in employment supports
- Self-determination
- Advocacy/understanding of their conditions
- Discuss vocational options early on
- Involve higher education

Statement 3: Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.

- Public awareness – get the rest of the world to understand our needs
- Education
- Social marketing
- Accommodations – restaurants, other (quality of life)
- Sensitivity
- Pre-service – teachers, childcare, administrators, etc. need training
- Access to appropriate healthcare
- Teaching kids about kids with intellectual disabilities – address segregation
- Self-Advocacy – teaching
- Fund inclusion opportunities – particularly transportation
- Social language programs
- Partnerships with schools
- Kids/Families share stories and experiences
- Recognize that kids are kids and that child in classroom does not mean not included, co-located
- System advocacy – communication
- Address silos – particularly State Education Department and Adult Career and Continuing Education Services-Vocational Rehabilitation ACCES-VR and/or Vocational Educational Services for Individuals with Disabilities (VESID) – without losing the expertise found within them
- Information-based decision making
- Community wide culture change

Possible Indicators/Measures

Statement 1: Children with intellectual disabilities are identified early and receive appropriate services.

- Family understanding of the system
- Age at first diagnosis/goal standard
- Diagnosis to Treatment time
- Cross System Data Sharing
- Department of Health family survey (Donna Noyes – New York State)
- Early intervention cases (political)
- Referral point – education system, assessment, evaluation data
- School placements and diagnoses
- Ages and stages/pediatricians
- Early Intervention to Council on Preschool Special Education
- Cost of Services
- The Adverse Childhood Experiences (ACES) Study (Scared Sick, Epigenetics)

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*

- Complementary and Alternative Medicine (CAM) data
- Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR)
- Department of Labor
- Questions 13 and 14 on state education materials
- Educational outcomes
- Decreasing wait list
- Quality of life measures for individuals and families
- Medical health outcomes
- Higher education matriculations
- 40 Developmental Assets
- Action club involvement
- WNY Partnership Coalition – Providers, people, [Developmental Disabilities Services Office (Western NY DDSO, West Seneca, NY) – Kirk Mauer]

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

- Social validity tools on families and individuals
- Community assessments/trend information
- University of Kansas has produced standards [Summit Educational Resources (Getzville, NY) has information on this]
- Public transportation
- Cross system needs
- Utilization of safety net among consumers
- National Core Indicator Survey – University of Minnesota

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-02-13
FOCUS GROUP | Parent Group
Host: The Parent Network (Erie County, New York)

<u>Review of Original Results Statements</u>

Statement 1**: **Children with intellectual disabilities are identified early and receive appropriate services.
  Stakeholder Response –
- Should be "all" children are identified for intellectual disabilities early and receive appropriate services
- "Receive" sounds one way
- Appropriate and individualized services
- Appropriate, culturally sensitive, culturally competent
- Choice – self determination
- Concern about the use of the term "appropriate": – who determines what is appropriate
- Identified when diagnoses – early is relative
- Childfind – Special Education Law – appropriate is what is written into the law; for individual – based on present language for Special Education
- Early diagnosis – really a dynamic process – not a "one off" activity – moving targets, iterative process
- Intellectual disabilities may be co-occurring-multiple issues
- Identify in a timely manner – understand child development
- Intellectual challenges may lead to behavioral or other challenges (brain abnormalities can yield social, emotional, behavioral challenges)
- Seldom just one thing – complicated not simple
- Individualized person-centered planning
- Appropriate – proper accommodation?
- Beyond school – recreation, education to providers
- Be aware of the concept of "fix" or "cure"
- Really about engagement and ownership of outcomes
- Accept the person as they are

Statement 2**: **Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.
  Stakeholder Response -
- Youth and young people – should define the ages (not cognitive age)
- Should be aware of choice and natural consequences
- Out of school supports are not available – out of school it is a different system
- Elementary – secondary – adult systems moves from entitlement to eligibility/navigation (going over a cliff)
- Personal potential needs to be considered here – relational, emotional, social, sexual
- Where does choice fit in? We are allowed to make choices to engage or not to engage – shouldn't the same be true for children and youth with intellectual disabilities
- Community opportunities
- Access/options
- Self-determination/choice
- Competitive paid, non-workshop employment

- Truly inclusive
- Full range of employment opportunities
- Recognition of the challenges of the adult system – It is segregated (day habilitation), typically not included in the community
- Family issues – denial, not aware of the skills of the child, disabilities, guardianship – letting go
- Championing individuals

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

Stakeholder Response

- Support self-determination
- Must build relationships
- Capacity building
- Supports and opportunities – capabilities, possibilities
- Citizens that give back – reciprocity, integration
- Contributing member, valued member of the community
- Discrimination in schools
- Should look at Condelucci work – Social Capital – Pittsburgh United Cerebral Palsy Association (UCPA)
- Interdependence

Statement 4: *Consider a FAMILY Result Statement*

Stakeholder Response -

- Navigation/Advocacy
- Have education and are empowered to advocate
- Are knowledgeable about choices
- Heavy reliance on Social Security Income (SSI) – financial dependency
- Recognize the impact of intellectual disabilities – mental, physical, social, emotional, economic impact
- Access
- Need extended caregiving and respite
- Family – isolation (of child/of family) – nuclear and extended
- Family – also need acceptance of siblings

Strategies Associated with Original Results Statements

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*

Stakeholder Response -

- Need parent education
- Universal screening
- Case coordination – appropriate, accommodated
- Committee on Special Education (CSE)-identified – collaborators, consultants, build team of supports, proper accommodation
- Tracking teacher, resource teacher
- Parent education/advocacy – stigma, labeling
- Cultural/ethnic barriers – language, level appropriate
- Parent navigation and advocacy
- Training around the intellectual disabilities

- Parent education – particularly around development
- Testing services
- Limited available resources for children and families

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*

Stakeholder Response -

- Consolidated Supports and Services (NY State-Medicaid)
- Community residence issues – Not in My Backyard (NIMBY)
- Transportation – promotes independence, challenges associated with the Niagara Frontier Transit Autority (NFTA)/Advocacy
- Self-determination/advocacy
- Family education
- Parent leadership
- Respite
- Afterschool supports
- Advocacy training for parents and youth
- Transition services
- Extended community among parents
- Special education Parent Teacher Associations (PTAs) – concerns around isolation

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

Stakeholder Response -

- Advocacy – long term case, developmental disabilities
- School training in self-determination
- College (credit or audit classes)
- Managed care
- Professional development
- Legal support
- Stigma – label = ability to secure service (should not be that way)
- Educational piece for community members – disability awareness - faith groups, communities, schools
- Accessibility NY
- Culture
- Employer education (i.e., government) and training
- Educator training – administrators, counselors, teachers
- Competency-based professional development
- Continuing education requirements
- Health – Circles of Support (Canada)

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-02-27
FOCUS GROUP | Family Members
Host: Aspire of Western New York (Erie County, New York)

Review of Original Results Statements
Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*

Stakeholder Response -
- Already achieved? Not yet – community specific, while we have regulations, training, funding each of these items is incomplete, silos, not necessarily working together
- Community reaction to persons with disabilities is still very troubling – very real, lack of real acceptance
- Accommodation – poor job in specific communities
- Intellectual disability – how it is defined - Cognitive and adaptive component
- Easy to be identified – not as easy to secure assistance
- When identified early it is best
- Best services for disability – not just appropriate, needed, necessary, based on needs of the child
- Feels a bit defining and confining
- All children?
- 1115 Waiver – should equalize across state, school districts are very different, great variation across districts
- Concerns around Individualized Education Program (IEP) diplomas

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*

Stakeholder Response -
- Self-acceptance is needed first and then you can build from there
- This is an important process – but it is lost in communities
- About finding fit within society – how does one find value – societal values are different from opportunities/experiences of disabled youth and adults
- If I am not working full time…Am I not a full person?
- Capability – judgment is a critical component and needs to be assessed – otherwise dangerous
- Lack of internships, vocational exploration
- Need for social connections and maintain through transition through to adult experiences
- Schools provide level of social engagement; need this as adults
- Who defines potential? Who defines what is right for people?
- Young person/adult – should focus on their level of happiness – avoid stretching too far to meet some standard – needs social supports
- About choice and self-determination
- Keep in mind military families who are experiencing the systems/events for the first time, on their own without supports

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*
  Stakeholder Response -

- Definition of communities
- Minimums standards of care – standardized across states through legislation
- "Full-range of services" seems a bit broad
- Who determines what is appropriate?
- Supports – who provides?
- Need to increase exposure to people with disabilities one on one

Strategies Associated with Original Results Statements

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*
  Stakeholder Response -

- Public awareness of early intervention services – early intervention works!
- Pediatricians, obstetricians, child care – need training on symptoms, resources
- Screening/assessment and appropriate referral
- Early intervention/screening – early as possible (before 3rd grade)
- Parent education – acceptance, not alone, availability of peer mentors
- Parent/family awareness of services, understanding of conditions (including teen moms)
- Families result statement: Yes, families are supported and connected to services – reduce isolation and feeling of being overwhelmed
- Schools, teachers, administrators – training education, greater awareness of behavior, how to discuss with parents, hospitals, preschools, etc.
- Committee on Special Education (CSE) meetings – don't decide on services by placing people into slots
- Parents enlisted as peers, equals, advocates, co-pilots
- Parental engagement – not all parents are good parents

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*
  Stakeholder Response -

- Vocational exploration – key to identify formation – part of development that is often lost for youth with disabilities
- Young Adult Life Transitions (YALT) for youth with more limited abilities
- Higher functioning individuals are left on the borders – need for internship coaches/volunteers with supports
- Assessment of potentials – skills and jobs within reach
- Social policy – Individuals with Disabilities Education Act (IDEA)-like opportunities for adults

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*
  Stakeholder Response -

- Value all people!
- Services for military families – new experiences for them, don't know system
- Social policy – Individuals with Disabilities Education Act (IDEA) for adults? Change minds, positions

THE PETER AND ELIZABETH C. TOWER FOUNDATION

- Public education
- Movement to understand the nature of disabilities
- Social marketing – public relations, marketing, share problems, one on one engagement – "we are disabled" campaign
- Systems navigation
- Use of natural supports – formal supports, informal supports
- Societal buy in
- Investigate 1115 waiver
- Same situation as frail seniors
- How do we provide supports in communities
- Re-position the issue – affects all of us

2012-02-29 (6:00-7:30 PM)
FOCUS GROUP | Family Members
Host: Baker Victory Services (Erie County, New York)

<u>**Review of Original Results Statements**</u>
Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
Stakeholder Response -

- Lack of medical professionals
- Difficult to differentiate co-occurring issues
- Who is responsible> Family taking charge? Hard to navigate services
- Silos within systems – agencies don't work well together
- May want to consider adding diagnosis – recognition of issue, early as possible, access to services, eligibility – opens the keys to the kingdom
- "Appropriateness" – challenging given level of care need/resources available
- Needs-based – particularly for younger children
- Stigma
- Circumstances are constantly changing
- Early – can be difficult – regression as a key issue
- Individuals instead of children – can go beyond – degenerative conditions
- What is appropriate? Meets level of need, individualized
- Appropriate should be individualized

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
Stakeholder Response -

- Social aspect is missing – access, connections, relationships – similar needs/experiences
- Live, learn, work and play
- Don't like the term – civic – sounds more like citizenship
- Really much more about community involvement
- Self determination
- Productive member of society
- High expectations are good
- Ask children/youth/young people – what do you want to be?
- As much potential as others
- Healthy potential

Statement 3: ***Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***
Stakeholder Response -

- Early as possible – education needs to be about individual needs, issues, challenges, opportunities
- Volunteerism
- Accessibility – universal design
- Public awareness – general public, schools, institutions, education
- Need for sensitivity
- Nature of community is important

- Communities – may want to define the term
- Mobility
- Requires knowledge – manual
- Conducive realistic relationships – "right fit"
- Quality of life

Statement 4: ***Consider a FAMILY Result Statement***
  Stakeholder Response -

- Supported, educated on disability
- Understand, advocate on their own behalf
- Family unit is solidified, family preservation
- Knowledge of what is available
- Providing information about what parents/families can look forward to
- Create a manual, resource especially for parents just starting out
- Friendship

Strategies Associated with Original Results Statements

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
  Stakeholder Response -

- Training for medical professionals (increase number of professionals)
- Lack of information for families
- Family education – information, resources, help with processing, grieving
- Clearinghouse of resources and information
- Address various access points
- Proper assessment of needs
- Help navigating system
- Legal supports/guardianship
- Don't work well together in systems

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
  Stakeholder Response -

- Support for employment opportunities; training
- Internship/exploration
- Job coaches
- Work Appreciation for Youth – experiential programming
- Young Advocate Leadership Training (YALT) programs
- State education
    - Policy advocacy
    - Regulation
    - Curriculum
    - Standards
    - Regulations
    - Philosophies
- Vocational training options – life skills, soft skills

- Volunteerism
- NY State Special Education (P-12) Integrated; focus on place versus service
- Friendship
- Avoid tracking
- Person centered planning (Rick Banner)
- Circle of Supports – formal, informal
- Recreation – Boy Scouts, Skating Athletes Bold at Heart (SABAH), Moving Miracles
- Self-Advocacy Association

Statement 3: ***Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***

   Stakeholder Response -

- Training for educators, administrators on understanding, sensitivity
- Educate legislators, regular relationship building
- The New York State Association of Community and Residential Agencies (NYSCARA), Developmental Disabilities Alliance of Western New York (DDAWNY)
- Coordinated community approaches
- Transportation = access
- Opportunities to be with regular kids "normal"
- Education – helps with service delivery, growth in professionals in the field
- Education for students – Disability History week
- Early education
- Branches of services – quality of life, available hours – museums, restaurants, movie theatres, libraries
- Special education as a service – not about tracking but mainstreaming

Statement 4: ***Consider a FAMILY Result Statement***

   Stakeholder Response -

- Skills training
- Education of child – inclusion
- Range/spectrum of services – help/understanding of:
    - Behavior
    - Levels of care
    - Medical needs
    - Help for siblings
    - Support groups/peers (need to be credible, zealots)
    - Respite
    - Community options
    - Support/clarify/provide realistic information/expectations

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [106]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-03-14 (9:00-10:30 AM)
FOCUS GROUP | Providers
Host: Essex County Community Foundation (Essex County, MA)

Review of Original Results Statements

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
   Stakeholder Response -
- Identified early – dependent on economic status, related to pediatrician/health care
    - Middle class – screening is available but less available for people from lower socio-economic status, non-native English speakers
- Age – start at infancy
- Receive appropriate services – transitions are the key; dealing with several transitions-pediatric care to early education, elementary school to middle school, middle school to high school, high school to adult system – need assistance through each of these transitions
- Information shared
- Early intervention (birth to three) is critical – reality most individuals are identified at age two or older so very limited time to spend with early intervention programming;
    - Limited access
    - Not equipped to serve
    - Schools resources are limited and their distribution can be political
    - The earlier people are served the better
- Timeframe? Before hitting the school system
- Early intervention – 0-3 is really problematic (especially as there is also a 3 year old regression) should work to expand the age of early intervention
- Transitions to schools and then the schools determine what to provide = this is not the best for the child or the family

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
   Stakeholder Response -
- Limited resources for adults – services and transition
- May want to identify specific goals for youth – education and social activities and young adults – employment
- Full – interpretation of this can be problematic; delivery of services, school district determines
- Good goal – very difficult to achieve
- Achieve full potential – is this reasonable? Developmentally appropriate?
- Social potential should be included
- Get information on career only in 11th grade – this is too late, career ladders – vocational and college; need to achieve
- Population turning 22 years of age is the focus; need to help younger kids – afterschool, social
- Separate but equal – mainstreaming
- Integration into community – employment, etc. - need to fund supports – focus is on natural supports – safety net
- Need to move towards greater employment – part time is obsolete – not really available any more in society, no benefits if working
- Civic – undefined, sounds like voting, citizenship; real focus is on community involvement that would be clearer and broader
- Who decides full potential? Formal and informal or natural supports

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [107]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

    Stakeholder Response -

- Lofty, difficult to achieve, worthwhile
- Variation in communities – welcoming vs. not al all welcoming
- State, Department of Education, Schools – all of these groups need to get on board
- Limited community recreational opportunities
- Partnership – cost effective, combine resources, complementarity, comprehensive – Address Siloes
- Resources for discovery of potential alliances/partnerships
- Full range? Who decides? Appropriate?
- Progress has been happening - there is greater acceptance, integration, community supports, residential care that is more responsive and state of the art, and education yet we still have state institutions
- 0-26 appropriate transitions are the key!

Statement 4: *Consider a FAMILY Result Statement*

    Stakeholder Response -

- Need to have a family result

Strategies Associated with Original Results Statements

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*

- Screening as early as possible
- Bilingual and bicultural services including interpretation, translations, cultural competency, services for persons who have a lower socio-economic status
- Education of medical community – pediatricians, doctors, nurses
- Developmental milestones training for parents
- Trainings for educators/administrators/ intake workers – need to be able to detect issues
- Support for educators to secure services (regardless of socioeconomic status)
- Parent home visiting programs – provide information at hospital, create an immediate connection, support groups
- Parent trained in special education law and early intervention services
- Help navigating the system – meet children's need
- Support parent/family advocacy – training for individuals and employment of paid advocates

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*

- Afterschool programming – provides training in social and life skills, often lacking, resources are most limited at the high school level – should be developmentally appropriate, provide assistance to families during the critical hours when they may need to work (3-7pm)
- Transition programs – especially related to the move from school to adult services; transition services
- One on one mentoring (including employment related)
- Tools for employment – 21-26 years of age, out of school, need something beyond sheltered workshops
- Entrepreneurship (Up Art in Newbury)
- Transportation assistance – getting to work, lack of public transportation, costly to bring people to work especially if a single individual
- Employment supports

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [108]   info@thetowerfoundation.org

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

- Community education – local employers, politicians, civic organizations (Chambers of Commerce, Kiwanis, Rotary Clubs, Philanthropy), first responders (fire, emergency, police), hospitals
- First responders – need to be aware of behavioral incidence (social issues) or beyond
- Independent Living needs to be available
- Partnership
- Advocacy – legislative/budget
- Top down approach – politicians, elected officials, business, employers, others
- Press
- Campaign/Public Education
- National changes – health care reform, resources, human services
- Medicaid
- Accountability mechanisms
-

Statement 4: *Consider a FAMILY Result Statement*

- Support for families
  - o Respite – allows for education, training, support
  - o Quality of life services – recreation, vacation
  - o Develop own services – limited funding, care networks, residential programs that are private pay, creative housing, staff (support from Massachusetts Development?) - Have some of this programming in Brookline, MA
  - o Help exploring the system – where do they turn for help, how should they go about it, options available to them, how does the system work?
- Training for providers about how to effectively work with parents
- Parent advocacy (direct paid advocates and training)
- Move from an entitlement-based system to adult world – available services
- Confusion beyond the child system – they get on a conveyor belt when the child is young and then once the conveyor belt comes to an end, there is not information
- Need help with navigation – next steps

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-03-30 (10:30 AM – Noon)
FOCUS GROUP | Providers
Host: Niagara Cerebral Palsy (UCPA of Niagara) (Niagara County, New York)

<u>**Review of Original Results Statements**</u>

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
   Stakeholder Response -
- What is meant by "identified early" – age, early as possible?
- Services = medical, housing, social, recreation, full complement – focus should be on quality of life
- Appreciate use of the term "intellectual" but will people understand it? Could you use cognitive instead?
- Mental retardation to intellectual disabilities – could be limiting
- Office for People with Developmental Disabilities (OPWDD) requires IQ testing to make determination (creates a limitation in services for children under age 7 for whom IQ testing is problematic) OMWDD also requires that a person has an IQ of 69 or lower to qualify for services, provisional assistance can be offered when identified at an early age – 7th birthday is when they begin the process for services – this creates a large gap
- Early intervention - can you identify intellectual disabilities for very young children? – Can use standard deviations on developmental milestones
- Other issues – such as Fetal Alcohol Syndrome are not attached to IQ
- Important as "preventive strategies"
- Prevention of children being born with disabilities
- Concern around the term "appropriate" – focus should be on services that lead to independence
- Appropriate is too vague – clarify definition, targeted, inclusion, impact on # and % of students who can be mainstreamed

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
   Stakeholder Response -
- Clarify age groups (youth 7-18 and young adults 18-26) Note: these categories work related to health insurance
- Social – requires direct attention – goes to quality of life
- Independence
- Implies "we" know what someone's full potential is
- "Singling out the group so we don't single them out"
- Same expectations as anyone else – dignity of risk, no higher standards either
- Transitions
- Must be person-centered or person-derived
- Full potential –self-reliance, address false sense of empowerment (sometimes comes from parents who set expectations that are too high/overboard)
- Balance is critically important

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

    Stakeholder Response -

- Use of the term, "appropriate" is problematic and doesn't convey what is really desired
- Supports and opportunities choices
- Challenges around measurability – will need to develop community level metrics
- Cannot just be "special engagements" should be integrated as part of the community as a whole
- Should not be an 'unusual' experience to have groups to be part of the community
- Walkability /ease of transportation is also at issue

Statement 4: *Consider a FAMILY Result Statement*

    Stakeholder Response –

- There is a need for a family result statement

Strategies Associated with Original Results Statements

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*

- Prevention activities (even pre-birth)
- Individualized appropriate services
- Development of measures, benchmarks
- Community based research – systems, inclusions (possible indicators include use of early intervention services, movement from early intervention into regular schools, number who move from early intervention to regular schools to graduation)
- Public school – awareness of services – head starts, screening
- Use of Childfind, a component of Individuals with Disabilities Education Act (IDEA)
- Health care providers – primary and pediatrics – educated and refer appropriately to services
- Research on the causes of autism – specifically
- Diagnosis services – wait list for both Erie and Niagara Counties in New York State
- School training – educators – understand the signs
- Parent education – to identify signs and secure needed services
- Policy decisions in schools – don't want to identify because of the costs associated with early intervention
- One stop shops to ease the challenges of service navigation for families

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*

- High school and earlier – transition planning (also need to think about who's wishes that planning follows)
- Person/Parent education and advocacy
- Transportation (very limited busing services in Niagara County on weekends; multiple options for weekend activities)
- Employment – meaningful, vocation, supported employment
- Socialization – social skills, work related interactions
- Art/Music Programming
- Employer education – financial incentives
- Clear outcomes – schools and employment – typically don't promote highest level of success
- Could measure underemployment among disabled populations

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [111]   info@thetowerfoundation.org

- Accountability for schools, etc.

Statement 3: ***Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***
- Respite services
- Need to address waiting lists, funding creativity
- Leadership engagement – key measures within the community – how inclusive is the community?
- Accessibility standards – needs to be expanded – part of planning activities
- Community Education – address Not In My Backyard (NIMBY)-ism; start with engagement of young people, children in schools – interactions
- Volunteering in the community
- Service providers – need greater options in sensible locations to address challenges of transportation
- Spiritual assistance – education of faith community
- Life skills need to include preparation of individuals for engagement in the community – should not be held to a higher standard (particularly service agencies)
- Shift the "culture" of the community – operating under a "one strike" policy
- First responder's education – police, fire, etc.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-03-28 (6:00 – 8:00 PM)
FOCUS GROUP | Family Members and Providers
Host: Opportunities Unlimited (Niagara County, New York)

<u>**Review of Original Results Statements**</u>

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*
Stakeholder Response -

- Any disability should be identified early
- "Intellectual disabilities" as a term is problematic – functional capacity? Why does it need to be differentiated from other disabilities
- The term intellectual disabilities is necessary provides people with an understanding of what the organization wants to fund (substantive)
- Defining the difference between intellectual and learning disabilities is very important
- Person-centered, dislike "labeling" language
- What is appropriate? Should be appropriate and necessary
- "Measurable" services – evidence-supported?
- Labels inhibit the life of a child and their development
- Need to understand distinction
- Beyond "testability" have made progress in this area
- Cognitive disabilities and/or intellectual disabilities
- Would like any information gathered as part of environmental scan work to be made publicly available

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*
Stakeholder Response -

- Need to focus on independence
- Should include social potential, cultural, recreational
- Civic is odd – volunteering, giving back, community – connect that individual to something
- Artistic
- Quality of life, life purpose

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*
Stakeholder Response -

- Use of the term appropriate – easy access and awareness of potential (organic thought)
- Safe and affordable transportation
- Quality supports – not just band aids

Statement 4: *Consider a FAMILY Result Statement*
Stakeholder Response

- There is a need for a family result statement

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Strategies Associated with Original Results Statements

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
- Support for health and safety of children
- Parent training – education on the issues, resources, and information
- Parent "peer" groups – experienced parents sharing with "new" parents
- Medical community – pediatricians educated in assessment as well as in normal development
- Early intervention in school districts – educate about disabilities, identify resources, differentiate
- Need to differentiate between learning disabilities and intellectual disabilities but do not fund one to the advantage of another
- State education department provides definitions related to testing – need to advocate to get services when they are needed
- Certain populations may be left out of the discussion
- Get most assistance available – life-long advocates, life-long learners, fight to get needed services
- Need to be a parent, lawyer, nurse, etc.
- Guardian angels – guide parents, help them to navigate through the system, advocate on their behalf and on behalf of the child

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
- Art programming
- Support for persons in wheelchairs, etc.
- Educate school districts
- Educate families how to advocate
- Service navigation, coordination for everyone
- Coordination of available services
- Employment training
- Implications of the 1115 waiver remain to be seen
- Transportation (funding)
- Open doors to employers, businesses interested in hiring individuals
- Educate policy makers

Statement 3: ***Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***
- Funders collaborative
- Community education – educate parenting groups, Lions Clubs, Rotary, Kiwanis, legislators – work through groups like The Developmental Disability Alliance of Western New York (DDAWNY)
- Use of volunteers
- Collaboration
- Respite/care for children which are barriers to community education and engagement
- Self-directed individuals reaching independence and are safe
- Bringing organizations and community together, networks – clearinghouse of resources, use of the Internet

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-04-11
FOCUS GROUP | Providers
Host: Cape Cod Child Development Center (Dukes County, Massachusetts)

Review of Original Results Statements

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
   Stakeholder Response -
- Result is missing families
- Services, information and supports
- Appropriate - can be a limiting word, need "more services" than other children
- Regarding goal.... should end with "to support independence and/or inclusion"
- Families need to identify and understand at an early age - what to look for
- Federal goals (3) for children and (3) for families - very appropriate to look at...
- Intellectual disabilities should address social-emotional issues
- Children with developmental disabilities - could this be a clearer term for the group
- Intellectual disability (intellectual capacity, adaptive functioning)
- Term - cognitive and developmental disabilities (has implications for eligibility for services)
- Definition is more helpful than current terms - concept of adaptive behavior

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
   Stakeholder Response -
- Term - intellectual disabilities is still problematic
- Social connection is critical - need to do this early on
- Integration
- For any child, it is based on strengths not deficits (why is this not the case for persons with intellectual disabilities)
- Focus needs to be on the individual
- Families need to be part of this as well - can be overly protective
- Can't just place people where it is easy and convenient
- Many times failure points come from social-emotional issues
- Local study of Cape Cod adults with developmental disabilities found that 25% were employed in some form, 25% were interested in work, and 50% not working and not interested with a number indicated that the reasons included fear of failure and fear of stigma (isolation)
- Implies independence - should state it directly
- Family piece - concerns around failure within the family

*Statement 3: **Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***
   Stakeholder Response -
- Concerns around the use of the term "appropriate"
- Supports and opportunities
- Communities need to change to be inclusive - need to fit all of its citizens

---

- Supports for entities in communities - incentives for collaborative/improvements - currently disincentive - Foundations can provide incentives for this
- Specialized supports can remove people from communities - need to be careful about this
- Natural supports need to be identified in communities
- Help for high functioning individuals - often fall through the cracks
- Program participants say that they are not allowed to make mistakes - providers as well
- Community Adult Services - need to be in the community (closure of facilities) need to develop relationships with community members
- Appropriate - should recognize that this is changing, problem of silos, breakdowns by criteria and eligibility - need to be able to address this to move through transitions

Statement 4: *Consider a FAMILY Result Statement*

Stakeholder Response -
- Need information, support, help navigating the system
- Need to be and feel integrated into communities
- Understand disabilities, situation, and secure needed supports
- Be willing to access services - there is a stigma associated
- Much of the focus is on limitations - need to look at strengths and supports
- Changing, iterative process
- Families also need to think about letting go
- Recognize that families really are the experts - especially of their own circumstance
- Need to feel successful, valued, confident
- Need to be part of the community
- Respect child as individual
- Non-judgmental

Strategies Associated with Original Results Statements

Statement 1: *Children with intellectual disabilities are identified early and receive appropriate services.*
- Massachusetts – Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Medicaid - screening, may need to push as an advocacy item
- Pediatricians - screening, assessment, education, case management to link to services (also connected to medical home - urban only pilot through the Substance Abuse and Mental Health Services Administration (SAMHSA)
- Parent education - signs, where to turn for help
- Address stigma - universal screening
- Community education - positive stories (people not disabilities)
- Linkage to pre-school/public schools - not incentivized to address this
- Schools - connecting to families - Headstart to School (IEP) deficit-based model
- Early intervention to Individuals with Disabilities Education Act (IDEA) transition family to child-centered
- Early intervention - avoid losses to system, children who are in early intervention and then fall out of services when they start school - create bridges
- Services - increase capacity, limited funding levels, need for specialists (occupational therapists (OT), physical therapists (PT), and speech and language therapy (SLP))
- Address stigma - integration, natural support
- Family support
- Advocate - be ware of distinctiveness - end goal: inclusion
- Meaningful participation in communities

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [116]   info@thetowerfoundation.org

Statement 2: *Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.*
- Need to be in environments where young person wants to be - training for employers/staff
- Sibling/parent education (coping, network, training, support groups including on-line)
- Family supports
- Recreation
- Social skill building - creates comfort
- Mentoring opportunities - may require additional support and training to utilize typical mentoring programs like Big Brothers, Big Sisters
- Life skills - strategies/interventions (life activities including checkbook)
- Extracurricular activities, integration into these programs whenever possible
- Family recreation
- Transitions (special education to school, vocational training and career, pre-employment programming, transition from school to adulthood)
- Cape Cod - Planning to implement an integrated employment and services but at time of implementation,there was no funding
- Collaboration - Educators and adult system (lose sight of what comes next after education is completed)
- Coordination of services
- Federal Vocational Rehabilitation requires integrated competitive employment; need to move beyond sheltered employment

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*
- Community education
- Efforts to address Not in My Backyard (NIMBY)ism
- Demonstrate the "value add" of persons with intellectual disabilities within communities - communication or public relations marketing strategy (come out of the shadows and share that people are successfully living in various communities
- Advocacy
- Transition - childhood to adulthood (challenges of adolescence) and adolescence to long term adult services - employment, etc. (many families want to avoid these transitions and not let them occur naturally)
- Parent education (protection of their children especially concerned about transitions - emotional time)
- Availability of services (not sure about what is available to older children/families)
- Family mentors (peers)
- Parents with intellectual disabilities
- Technology/adaptive equipment

Statement 4: *Consider a Family Result Statement*
- Education
- Advocacy
- Financial assistance
- Support groups (shared experiences)
- Peer mentor
- Respite
- Community activities

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [117]   info@thetowerfoundation.org

Other things you want the Foundation to know:

- Access, access, access
- Transportation
- Bricks and mortar (how do we make our facilities more inviting?)
- Need staffing to do the work
- Collaboration, support the work
- Not just about skills: adaptive equipment, technology, enabling supports, social opportunities

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-03-16
FOCUS GROUP | Providers
Host: Essex County Community Foundation (Essex County, Massachusetts)

Review of Original Results Statements

Statement 1: ***Children with intellectual disabilities are identified early and receive appropriate services.***
  Stakeholder Response-
  - Appropriate services – who decides, who determines this
  - Not descriptive enough – Early intervention and Beyond?
  - Options for services are critical – not just appropriate services
  - Department of Early Education – language within standards – how do you get away from that language?
    - People may have to fight for appropriate services
      Have to advocate and fight to secure needed services
    - Costly services – especially if they are from a lower socio-economic status, non-native English speakers
    - Navigation can be difficult
  - Locating participants can be challenging for programs – connection with those who need assistance

Statement 2: ***Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.***
  Stakeholder Response -
  - What is the difference between youth and young people
    - Youth 13-18
    - Young adult 28-26
  - Like the use of the term "full potential" – implies a level of input from the individuals involved
  - Addresses employment specifically – this is important
  - Social – this is huge for people
  - Employment – change to career?

Statement 3: ***Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.***
  Stakeholder Response -
  - Absent in the community today
  - Lack of opportunities for persons with intellectual disabilities to engage in public – challenges associated with behavior (including sexual behavior)
  - Lack of clarity related to acceptable behavior
  - Also need to educate the public about what is acceptable behavior – expectations
  - Don't like the use of the term "appropriate"
  - Support and opportunities
  - Presumptions about the population within communities – Segregated and self-segregated (sometimes persons with intellectual disabilities do prefer to be with people like them)
  - Comfort is critical

Statement 4: *Consider a FAMILY Result Statement*

Stakeholder Response -

- Should be included
- Families need to know what is ahead
- Services change overtime – need supports to bridge the various gaps
- Several transitions – from early intervention to school, school transitions (tracking at age 14), ending school and entering into the adult system (age 22)
- At age 22 move from an entitlement system to what is available
- Need navigations support
- Move from a yacht to a dingy

Strategies Associated with Original Results Statements

Statement 1: **Children with intellectual disabilities are identified early and receive appropriate services.**

- Marketing availability of services
- Scholarships/funds for individuals to attend specialized services
- Beyond traditional core, foundational services
    - Enrichment
    - Extras
- Supports to teachers/parents about early markers
- Educating parents – may be in denial, grieving, need supports
- Physicians, nurses, child care workers connect to resources, education
- Assistive technology
- Augmentative communication
    - Transition
    - Early intervention to schools, preschool
    - Regional consultation programs
    - Toddlers transition groups
    - Prepare parents/early childhood staff
    - Intensive

Statement 2: **Youth and young people with intellectual disabilities achieve their full educational, employment and civic potential.**

- Vocational training
- Professional development particularly in the areas of social thinking and communication – cannot typically afford to do the training and share the learning
- Educate community leaders
- Incorporate in city/community/locality plans – liaisons to the intellectual disability community
- Need to include all community members in these plans
- Make aides available, extra supports within the work force
- Individualized programs to address/develop/maintain natural supports
- Transitional supports are critical – school to adult system
- Agency training about what is available
- Resources for parents
- Single Point of Entry systems are being considered

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [120]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 3: *Communities are inclusive, supportive and provide a full-range of appropriate supports for individuals with intellectual disabilities.*

- Social interaction is important
- Need training around sexuality and appropriate behavior within public settings – address behavioral concerns
- Challenges within the community
- Inclusion must start at a early age
    - Must be done with the peer group and general population – greatest level of comfort when people are younger
    - Can lead to increased volunteerism and greater integration
- Parents/family education and recreation activities
- Disability population inclusion in standard trainings within schools and in communities
- Advocacy training for persons with disabilities and their families
- Care for individuals with higher risk behaviors
- Appropriate work opportunities for individuals with disabilities from 18-22
    - Liability and insurance concerns among employers
    - Even problematic with volunteer opportunities
- Support through technology – beyond adaptive equipment, assistance technology, technology supports
- Train therapists in assistance technology and equipment
- Advocacy
- People fall between the cracks – care coordination and navigation
- Employer education – career development
    - Make it less one on one and involve more people

THE PETER AND ELIZABETH C. TOWER FOUNDATION

LEARNING DISABILITIES FOCUS GROUPS
FOLLOW UP REPORT TO STAKEHOLDERS

Focus Group Demographics

Six Focus Groups:
- Essex County, Massachusetts (1)
- Dukes County, Massachusetts (1)
- Erie County, New York (3)
- Niagara County, New York (1)

Populations Involved:
- Learning Disabilities Professionals
- Educators
- Parents/Family Members
- Service Providers

Report Glossary

Result: A result is a population condition of well-being for children, adults, families and communities, stated in plain language. Results are sometimes known as outcomes or goals.

Indicators: Measures that help quantify the achievement of a result and answer the question, "How would we recognize this result if we fell over it?"

Strategy: A plan or method for obtaining a specific goal or result.

Reactions to Original Learning Disabilities Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.

Key Themes from Focus Group

- Respondents indicated that diagnosis is absolutely critical for accessing needed services yet it was difficult to secure a full diagnosis. In some cases, this was due to lack of resources (funding) and/or lack of skill set at the school level. Respondents indicated that the decision to fully assess was often a political or economic item. Likewise, they highlighted variation in the nature of diagnosis from an educational assessment to a full medical diagnosis. Respondents sought clarification on which level of diagnosis was being supported by the Foundation.
- Respondents universally suggested the importance of early identification. In reality, many students with learning disabilities have high IQs and learn to compensate for their learning differences. Respondents indicated that young people must often "fail" in order to be identified and secure assistance. Identification is often delayed due to fear of labeling or lack of knowledge until student becomes more involved with "standardized" tests (3rd, 6th, 9th grade). Respondents stressed the importance of early identification and connection to services (based on individualized needs) as early as possible.

- Respondents highlighted that identification, diagnosis and service connection are part of an iterative process and that regular reassessment is critical.
- They also highlighted that identification and diagnosis is not "one size fits all" – each child is unique and many deal with co-occurring issues (especially mental health and substance abuse as the child gets older).

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.

Key Themes from Focus Group

- Respondents felt that this result statement was critical in order for youth and young people to gain confidence and to be able to fully function in society. Without an understanding of how they learn, individuals with learning disabilities cannot identify the tools and develop the skills they need to be productive.
- Respondents also felt that the statement reflects two important ideas:
    o Understanding how they learn – with some respondents questioning if this is developmentally possible?
    o Knowing how to access resources
  Both of these considerations are extremely important.
- Respondents disliked the language, "will receive" because they felt that it was paternalistic. Many highlighted the fact receiving resources does not mean that you are actually using them. Focus group participants felt that the use of resources should be more active and promote the development of self-advocacy skills as well as personal or individual agency.
- Most importantly, respondents – especially youth – did not want to appear different from others in utilizing the services. They did not want to be singled out (by going to a special resource center) but wanted to emphasize use of tools and skills to make it possible NOT to stand out.

Statement 3: Young adults are confident and do not view their learning disability as a liability.

Key Themes from Focus Group

- Respondents felt that the use of the term "liability" was very stark and that it would certainly (and did) provoke a strong reaction. Some respondents felt that it was overly negative but had difficulty identifying other terms (suggested: barrier, deficit, weakness, disability). Most respondents stressed that the use of the term, liability, was very meaningful and that no other term had the depth (emotion/connotation). They felt that the term liability would pique people's interest.
- Among persons with learning disabilities – some indicated that their learning disability was actually an opportunity. Most, however, felt that liability was an accurate term and that they would need to live with their learning disability as something that was part of them and would always be part of life.
- Focus group participants indicated that this result statement requires knowledge of disability and ability to utilize resources (result statement #2). They likened it to a golf handicap – in the case of learning disabilities, tools and skills make it possible to compete with others with confidence.
- Several focus group participants wondered if you could collapse result statements #2, #3 and/or #4.

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.

Key Themes from Focus Group

- Many respondents disliked the use of the word "equipped". They suggested that the term had different meanings for different people and that it had more of a "skill-based" feeling. Focus group participants pointed out that being equipped for something does not, necessarily, mean that you are ready for it.
- Here again, the individual must have knowledge of their disability and know how to use resources, tools, and skills. As one focus group participant phrased it, "I must see strength in my difference" and have confidence to assume new work and educational roles.
- Several focus group participants wondered if you could collapse result statements #2, #3 and/or #4.

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.

Key Themes from Focus Group

- Focus group respondents felt that family understanding is critical to provide support to children, youth and young adults with learning disabilities.
- In general, participants felt that this result statement was fine with the exception of the word, "navigate" which they felt, sounded "difficult to do."

Other Concerns: Terminology
- Focus group participants struggled with the term "Learning Disabilities."
- Many felt that the term had a negative connotation and/or felt that it was "less specific" or "less accurate." The later comments appeared to be part a reaction to the Individualized Education Plans (IEPs) that typically did not call out the specific issues experienced by the child or youth. Schools often did not want to use specific language.
- In suggesting other language, respondents suggested using "learning differences" to avoid the negative connotation and normalize the experience. They also preferred more specific identification of the learning difference (i.e., dyslexia) or use of more specific terminology.

Other Concerns: Community-Level Result Statement
- Several focus group participants suggested the need to consider a Community-Level Result Statement which would focus on helping community members to better understand how persons with learning disabilities can and do contribute.
- Participants felt that such a result statement could support choice and self-determination for individuals and would make it possible to advocate for needed accommodations. They also felt it would support agencies or organizations providing services.
- Concerns about measurability at a community level were expressed.

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Revised Learning Disabilities Results Statements and Suggested Measures Using Focus Group Input

Foundation staff revised the original Learning Disabilities results statements based on comments made by focus group participants and key themes that emerged during sessions.

REVISED STATEMENTS

Statement 1: Children with learning disabilities are identified early, diagnosed and connected to services that meet their on-going individual needs.

> Reflects the fact that the need for services is part of an iterative, ever-changing process and that connection to services will need to happen as the child develops and learns more about their disability.

Possible Indicators/Measures: Measures:
- Committee on Preschool Special Education (CPSE) data
- Committee on Special Education (CSE) Data
- Age at First Diagnosis
- Time from Diagnosis to Treatment

Statement 2: Youth with learning disabilities understand how they learn and pursue resources that support them accordingly.

> Reflects a more active, person-focused pursuit of resources that will help persons with learning disabilities get their individual needs met.

Possible Indicators/Measures:
- Committee on Preschool Special Education (CPSE) data
- Committee on Special Education (CSE) data
- Cost of Services
- Quality of Life Measures

Statement 3: Young adults are confident and do not view their learning disability as a liability.

> Reflects a desire to maintain this strong, specifically worded statement. Liability is the term meant by The Peter and Elizabeth C. Tower Foundation Board.

Possible Indicators/Measures:
- Quality of Life Measure
- Individual Survey

Statement 4: Young adults with learning disabilities are ready for work and/or educational pursuits.

> Reflects a desire to go beyond having the requisite skills or being equipped to being prepared for or ready to engage in these pursuits.

Possible Indicators/Measures:
- Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR), Education/Employment Outcomes
- Vocational Educational Services for Individuals with Disabilities (VESID) Data
- Quality of Life Measures
- Individual Survey

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.

> Reflects the need to be informed about their family member's disability and able to secure needed support.

Possible Indicators/Measures:
- Quality of Life Measures
- NYD Department of Health or other Family Survey

Statement 6: **Communities value persons with learning disabilities and accommodate their needs.**

> Reflects a deeper level of commitment to persons with learning disabilities at the community level ("value") and addresses the need for accommodation to promote full engagement in community living.

Possible Indicators/Measures:
- Quality of Life Measures
- Individual and Family Survey
- Availability and access to services

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

[126]

THE PETER AND ELIZABETH C. TOWER FOUNDATION

INDIVIDUAL FOCUS GROUP REACTIONS

2012-03-14
FOCUS GROUP| Providers
Host: Essex County Community Foundation (Essex County, Massachusetts)

Review of Result Original Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
    Stakeholder Response -
- When working from a medical model, diagnosis is critical – what model is the Foundation working from? Does diagnosis mean full evaluation, screening, Individuals with Disabilities Education Act (IDEA) process – can't get services without at least an IDEA review – variation, not an exact science
- Medical vs. Educational Screening – difference is important
- How do you define learning disabilities?
- Good goal – lots being done in schools on this issue towards this – great variability across locations
- IQ can compensate for the need for services; therefore, takes a while to identify need and connect to services
- Children with learning disabilities in elementary school often compensate for their issues; identification often starts in middle school. Is this early identification?
- Changing populations – refugees
- Until they fail, they cannot get help
- Difficult to achieve
- Access – can all children be viewed as unique? Can learn!
- Inclusion early on – appropriate methodology is important
- Capacity for support is limited – needs based system; advanced students are not given other opportunities and may not be able to secure needed services
- Assessment is steered toward "development delay" – avoid stigma, stakeholder, cannot get needed services without diagnosis and need

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
    Stakeholder Response -
- Broad result statement
- Diagnosis is required to be able to move through the system (profile is key for treatment planning)
- Rare that youth understand their conditions now
- Metacognition allows them to know what they need
- Medical model – need a prescription for education
- Two ideas in one result statement – understanding how they learn and knowing how to access resources
- Families need this information as well
- Self-advocacy is important – advocate for resources
- Can lead to problem behaviors/other behaviors if not properly addressed – co-occurring issues

---

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [127]   info@thetowerfoundation.org

Statement 3: Young adults are confident and do not view their learning disability as a liability.
   Stakeholder Response -
- Really about social-emotional confidence, self-perception
- Different from the other young adult statement (could combine but two different ideas)
- Real issue – young adults with learning disabilities are less likely to be employed, more likely to be dependent, more self-confidence issues
- Myriad reasons for these concerns – confidence and training
- Assumes, fairly intensive intervention to make this happen
- Requires young adult to understand disability and view it as an advantage
- If result statements #1 and #2 start to work, this could happen. This statement becomes an outcome of statements #1 and #2

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
   Stakeholder Response -
- Equipped – skill based (vs. other result statement which is confidence based)
- Need to understand where they want to go
- Transitions must be part of this
- Limited experiential opportunities
   - Vocational training has limited slots
- Prepare for 20+ years out

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
   Stakeholder Response-
- Understanding is also critical – need to understand the issues, explain to their children, work with their children and youth
- Can discuss issues with family members
- This is highly variable – but very much needed

Statement 6: Consider a Community Result Statement
   Stakeholder Response
- Pooling of resources, families, business, providers, faith, others
- Youth asset model
- Understand how persons with learning disabilities can contribute
- Need to work with employers
- Similar to "deaf" culture

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Support for teachers to differentiate instruction
- Match child needs with instruction strategies
- Reduce likelihood of need for intensive services
- Assessment instruments, research, training educators, evaluators – cohort, need more practice
- Infrastructure support for additional supplemental instruction
- More reading teachers, writing teachers capable of doing evaluation
- Help teachers to understand their teaching – metacognition about their teaching – who am I as a teachers?
- Inclusive

- Coaches (modeling for teachers) – help with evaluation
- Regular educators need to receive more special education instruction; not just an overview course or two; training needs to be embedded at the district level

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
- Promote multiple intelligence
- Varied teaching modalities
- Professional development for educators
- Self-advocacy, skill building – start early, repetition
- Parent training – specific engagement of families otherwise many will be uninvolved – need to remove barriers for them to participate – services or care for children so they can fully participate, food, support, activity, transportation
- Success-based programs – art, music, sports, islands of competence – self-concept, self-advocacy – activities that children with learning disabilities are good at
- Brain-based Learning – educate families – ability to talk about it

Statement 3: Young adults are confident and do not view their learning disability as a liability.
- Islands of Competence (see second result statement)
- Education for youth
- Requires smaller learning communities – advocacy, mentorship
- Relationship building
- Equity training – for whole schools, team-based approach, need to see themselves and others as unique and capable
- Disability Awareness Starts Here (DASH) program – disability training programs should be bigger and broader
- Mentoring
- Peer tutoring program

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
- Transition planning
- Vocational training supports
- More elective courses
- Technology – exposure and utilization; address learning concerns through technology
- Classroom-based technology
- Need to make it directly available to the students themselves
- Teacher instruction
- Innovation opportunities
- Equipment purchase – smart boards, iPads
- Pilot programs, work study, internships – business partnerships

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
- Resource centers – disability intervention programs
- Clearinghouse (reliable information) one-stop shopping
- General information to detect issues and connect to needed resources as early as possible and across transitions (must be reliable)
- Support groups for persons specifically with learning disabilities (again this information must be reliable)
- Parent advocacy – what to ask for? Particular to cultural groups

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [129]   info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-04-11
FOCUS GROUP| Providers
Host: YMCA of Martha's Vineyard (Dukes County, Massachusetts)

Review of Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
   Stakeholder Response -
- Will require a good deal of outreach to make this result possible
- Individual needs (are they great - good – difficult); needs tend to vary; policies are more general - more like a "one size fits all"
- Focus should be within school and community
- Emphasize early - age, timely manner, as early as possible
- Connected to services - assumes knowledge of what is appropriate
- Don't rush or delay diagnosis
- Concern around "label" - wider acceptance for differences
- Transitions from early childhood to school, school to school, and school to adult

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
   Stakeholder Response-
- Focus should be in school and community
- Should be able to advocate for themselves; agency/active engagement
- Difficulty using resources - various reasons - social, fear, isolation
- Adults also don't understand how their children learn
- Framing as disability is problematic - difference thinking skills, innovation
- Students are not involved in development of their Individualized Education Plans (IEPs); kept in the dark about their issues - parents need to learn to talk about issues with children
- Must look beyond just understanding how they learn - need to act on that understanding to secure resources they need
- Will receive - sounds paternalistic
- Celebrate differences as strengths

Statement 3: Young adults are confident and do not view their learning disability as a liability.
   Stakeholder Response -
- Lovely goal - liability always
- Works for some, not others
- Self-advocacy early on is critical
- There is a spectrum/continuum of supports available - some are good, some not so good, must do more to have universal positive supports
- Perseverance and self-acceptance are the key here
- Statement should include: pursue understanding of disability, life-long learning/experience
- Ability to navigate the landscape is important
- Not feeling like a victim, not defined by condition
- Golfer handicap makes it possible to compete with others - skills make it possible to "compete with" / work in same areas as other students

---

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
   Stakeholder Response -
- In school and community too?
- "Equipped" may mean different things to different people
- Workplace parallels to education (is there special assistance for persons with disabilities in employment arena? Accommodations?
- Connects to result statement #3 - do you really need a separate measure?
- Supports may actually serve to enable a person - may also create dependency

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
   Stakeholder Response -
- Available and appropriate services
- Community and school
- Who helps them to navigate? Schools?
- Parents may also have learning disabilities - bad memories
- Barriers - families have lots of "stuff" - not static, stages of grief
- Older kids need greater support

Statement 6: Consider a Community Result Statement

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Support for wraparound services (help families/school) at different ages
- Academics, social, counseling, respite, well-trained staff
- Diagnosis is difficult - support, additional training, consultant available to assist on gray area cases, great variation in language skills, more regular education opportunities and supports for kids in the gray area - Response To Intervention (RTI)
- Risk factors, examine these more frequently
- Research in support of these activities
- Lack of trained personnel to determine/assess gray areas
- Differentiated teaching - faculty support
- Training for faculty on issues - starting in preschool (promote greater understanding of key issues)
- Community education - media, press, make information easy to access, address stigma
- Literature/information for parents, support resources - what to look for?
- Support for families - childcare, transportation, help so parents and guardians can attend, provide different faculty for sessions

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
- Training for educators, etc.
- Education for children - everyone has strengths and challenges
- Parent supports - educate on how to "educate kids"; teach them about their strengths and challenges
- Transitional supports - student involvement
- Advocacy skills
- Community education

Statement 3: Young adults are confident and do not view their learning disability as a liability.
- Advocacy
- Educators trained to enable advocacy present as a strategy and not a handicap
- Early self-advocacy training
- Parent mentors
- Use and celebrate strengths
- Focus on skills that work for individual youth

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
- Workplace supports and accommodation
- Education/advocacy (individual)
- Career and testing/advisement all levels - vocations
- Employer mentoring (Chilmark Chocolates)
- Discussions with employers/trades
- Legal rights
- Specialized training - job coaches, subsidized employment
- Transition supports (school to adult: entitlement/Plans to system navigation)
- Community focus
- Life skill training
- Mentoring programs - work related

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
- Parent mentors
- Language in literature shared with parents should be appropriate (pamphlets, brochures, training materials)
- Parent education/counseling
- Case coordination

Other things you want the Foundation to know?
- Afterschool for all kids - transportation, food, etc. - difficult period of the day for families
- Students as resources for one another
- Community
- Individualized needs - fit within schools

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

[132]

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Result Original Statements

Statement 1: Children with Learning Disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
 Stakeholder Response -
- The first thing that needs to be done (and it should be the first thing done)
- Devil is the details - who is the person or entity deciding how to meet individual needs? Should not have a stake in the educational system. Schools are willing to test based only on what they are "allowed to do" or can "afford to do"
- Told that child is entitled to "appropriate" education, not the best – parents want the best for their child
- Advocates have suggested tests that the school district would only offer "in house" - Erie One BOCES offered the test needed but the school was not willing to pay for the test – Schools provide the basic services - minimal
- Need to identify available services
- Round peg and square hole - may not be willing to pay for extended tests and services
- Difficult to view them as just having a single learning disability - co-occurring issues can create other disabilities (mental health challenges, substance abuse)
- Correct services at the correct time - transition (0-4 years of age - educational advocacy becomes critical) - need for Head Start, Early Intervention
- The only way to properly place the child is through the use of an advocate
- Each transition requires additional testing - new evidence, new skills - iterative process, on-going
- School psychologist cannot diagnose neuro-psychologists

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
 Stakeholder Response -
- Result statement #3 could go into result statement #4
- If you can get result statement #2, you can get result statements #3 and #4
- Limited utilization of knowledge of how children learn at the school level
- Schools are not supportive of individualized needs - cookie cutter approach
- Focus should be on strength-centered learning
- Domains of strength - need to be encouraged - arts, creative. Music - very important, allows the child to shine - need to have extra joy, because s/he has extra amount of stress
- Use of technology, use of dictation can be difficult

Statement 3: Young adults are confident and do not view their learning disability as a liability.
 Stakeholder Response -
- Could combine result statements #3 and #4 - and add to result statement #2 - confidence is importance here
- Concern around "handing answers"- training for educational aides not just to "give" their child the answer

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
   Stakeholder Response -
- Transition should have its own goal
- Need to be communicating with persons with learning disabilities; meeting with a youth group would be helpful
- Community needs to be equipped as well

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
   Stakeholder Response -
- Available services - need to be identified; testing first – requires knowledge of available services
- Each district has a school psychologist - puts kids through "cookie cutter" model - don't want to pay for it or can't
- Many families also have learning disabilities - intergenerational transmission of educational challenges - parents are not empowered to push for resources
- Navigate means a lot - educational advocacy an important piece of this

Strategies Associated with Original Results Statements

Statement 1: Children with Learning Disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Need for early intervention
- Advocates need to know the school system, laws, must be independent, problem solvers, may not require stopping your foot all the time (in the proper time and place)
- Educational Advocates - knowledge, negotiation skills, help within the Committee on Special Education (CSE) meetings - best serve the child
- Engagement of parents in CSE - could be more of an advocate for other families; often more for the school district - could you train the parent to really serve as a advocate (address inherent conflict of interest – worried that their child will see a reduction in services if they advocate too much)
- "Muffin Diplomacy" - parents educating the teachers about their child's needs and concerns - makes teachers more open
- Parents as mentors - huge difference - teaching other parents the ropes
- Parents receiving training, resource information - serve as advocates
- Parents are the major advocate for their child - figuring out tolerances and support child to deliver within these tolerances
- Single parent support, training and respite
- Family support/respite – learning disabled households have more challenges, need quality of life activities
- Pro-active activities - matching the language between parent (at home) and teacher (at school)
- Concerns about labeling - training for the parents, don't understand their own power and rights
- Schools are trying to cut costs on occupational therapy (OT) and physical therapy (PT)
- Educating educators - should be its own result statement potentially
- Dialogue/support groups, sharing between parents and kids
- Strengths centered learning – peer-to-peer engagement
- Limited individuals who can perform diagnosis - may not report to school districts
- Kids work longer and harder than many adults

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.

- Kurzweil - text to speech and speech to text (The Gow School)
- Availability of technology
- Gow Summer Program
- Teaching educators on the use of technology
- Flexibility of programming - no one size fits all
- Trial of different programs, models, and techniques
- School district education
- State does not use terminology - Seven other states have used specific terminology (diagnosed terms - e.g., dyslexia) and it gets included in their Individualized Education Plan (IEP); families can ask for and secure specific resources in these cases - without the correct terms, schools don't have to provide what is needed/ unsupported
- View children as having behavioral problem - can develop negative coping problems (9-11 years)
- Once there is language in the IEP, change can happen - without it, children cannot get the supports they need – greater likelihood of developing negative behaviors

Statement 3: **Young adults are confident and do not view their learning disability as a liability.**

- Need educational aides to have greater skills - not just give answers, or babysit, or help for the teacher
- Would be helpful if aides would understand learning skills of child and help them translate
- Assistive technology
- Integrative classrooms - special education and regular education (be wary of being singled out) - need to try both models; not a level playing field
- Special education progress reports provided on a quarterly basis - meaningless
- In service training - can request that your child's teacher be educated on the issues as well as coaches, gym teachers, librarians, bus drivers, cafeteria workers
- Teachers need additional information, referrals
- Fresh testing needs to be available

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.

- Training for new professionals (teachers, educators)
- Have persons with learning disabilities share their experience
- Young adults need a lot of help - many are told to just go ahead and get General Educational Development (GED) diploma
- Changes to the GED are concerning for this population - dropping accommodations, extended time
- Policy advocacy to address changes to GED
- Employers - need to identify skill sets that may be reasonable for persons with learning disabilities
- Education for human resource professionals
- Educating young adult at an early age – self-advocacy skills
- Business outreach - managers, employers
- Community results statements - educate the community on this issue
- Brown bag forums; educational sessions

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.

- Training on signs that children/youth may have learning challenges
- Parent training, advocacy, empowerment
- Peer-to-peer mentors
- Practical skills to help parents reduce stress level
- It is as if you "reinvent the wheel" with every family/child/youth and the school is on a different wavelength
- Need other parents to share their story/successes to help people to get what they need
- Decisions needs to be out of the school's hands – teachers are not allowed to suggest specific things - worries about budget, not trained to provide diagnosis
- Resource information needs to be available
- Need to connect with one another (student to student)

Anything Else You Want the Foundation to Know

- Educate the educators - school is focused on state requirements, not structured to meet individualized needs (don't care about students beyond their time in school)
- Importance of family advocacy, child/youth self-advocacy
- Community needs to provide resources as a supplement to the school
    - Fits the school's needs while getting what the child needs
- Affordability - respite, afterschool, transportation, socialization
- Rochester - Encompass - Liaison program, afterschool program
- Public advocacy
- Raising awareness

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-04-26
FOCUS GROUP | Higher Education Group
Host: Learning Disabilities Association (LDA) of WNY (Erie County, New York)

<u>**Review of Original Result Statements**</u>

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
> ***Stakeholder Response-***
- "Individuals" with learning disabilities
- Services should include technology and strategies
- Children identified early should be properly diagnosed
- Concern about hyperawareness regarding deficits; concern around labeling - not strength based
- Whenever they are identified
- Don't assume the connections happen
- Need to change educational environment
- Mainstream use of technology – universal design

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly
> ***Stakeholder Response -***
- "Individuals" with learning disabilities
- <u>How</u> they learn is critical
- May not identify "early"
- Receive resources – doesn't mean you will use them
- Must understand how to use resources
- Variation in academic needs

Statement 3: Young adults are confident and do not view their learning disability as a liability.
> ***Stakeholder Response -***
- Peer acceptance
- Is "liability" the right word? – barrier, deficit, weaknesses, disability
- Don't want others to know
- Focus on ability
- Domains of strength – overcome challenges
- Written in negative – young adults are confident because they focus on their strengths

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
> ***Stakeholder Response-***
- Young adult with learning disabilities (could be individuals)
- Focus on disability – realistic, self determination
- Co-occurring issues
- Self esteem, self worth – future orientation
- Labeling is a concern
- Current education system is cookie cutter – assembly line education
- Need for strategies

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.

   Stakeholder Response -
- Concerns around silos
- Need to focus on individual needs
- Term "navigate" makes it sound difficult
- Need to think outside the box
- Trial and error

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Availability of technology
- Training for educators (comfort)
- Understand and train on technology
- Parent education – where to turn for support
- Assessment (Woodcock-Johnson Tests of Achievement/Cognitive Abilities)
- Broader assessment/universal screening
- Response to intervention

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
- Classroom resources (audio, kinesthetic) – de-stigmatizing
- Education in learning disabilities – parents, education, what it is? What it is not?
- Opportunities to support universal design
- Training/teacher education – particularly as it relates to universal design
- Training on how to use resources
- Trial and error on different strategies
- Training for educators (including release time)
- Available to other students as well
- Educate regular education about different learning styles – Frustration, Anxiety and Tension (FAT) City

Statement 3: Young adults are confident and do not view their learning disability as a liability.
- Volunteerism, internships, placements – real application
- De-stigmatizing activities
- Tutoring
- Leadership
- Sports, music, jobs, drama, arts, etc.
- Technology – available at home too, available in more places (libraries, computer labs, dorms, study areas)
- Universal design
- Instruction in math/stem instruction – revising examples

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
- Career assessment
- Career information/expectations/requirements
- Peer to parent education
- Career exploration
- Public messaging – celebrities, successful people with learning disorders
- Peer- to-peer programming
- College camp
- Support
- Role modeling
- Training for teaches, peers, employers
- Life skills
- Current college students share their experiences with youth – annual college night
- Part of the culture "normal"
- Transitional support
- Financial intelligence (money skill, CASH flow)
- Realistic expectations
- Manual – effective college planning – make this more available
- Transition specialist

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
- Technology assistance for students, assessment and trial equipment through the Center for Assistive Technology
- Co-occurring conditions assistance
- Transitions, employers
- Increase staff available
- Funding college night activities for youth and young people with learning disabilities
- Fund grassroots efforts
- Adjunct staff development at the college level
- Often too reactive
- Premier–Universal design
- Policy– related to financial aid
- Family education/expectations
- Peer-to-peer mentoring

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Review of Original Result Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
   Stakeholder Response -
- Learning "differences" – not learning disabilities
- Early – this is the key
- Diagnosed as soon as possible – fully
- Need to identify during the early grades
- Good idea – kids who didn't get diagnosed are now trying to find out why they had trouble
- Identification with school – early testing – costs associated with testing
- Schools don't have specialized programs = not a "one size fits all"
- Disabilities – differences
- Variation in boys and girls

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
   Stakeholder Response -
- Understand – should it be "are informed"?
- Needs to become second nature
- Need to have this by the time they reach high school
- As early as possible
- Time is precious with learning disabilities
- Teachers and parents – team effort
- Student self-advocacy
- Regular contact with teacher, parent, young person
- Public school – limited communication
- Students need to get to a place of understanding
- Public schools don't acknowledge learning differences – assembly line education

Statement 3: Young adults are confident and do not view their learning disability as a liability.
   Stakeholder Response -
- Use of the term "liability" is a negative – negative content, connotation but may be easier for people to understand
- View as a liability – will never change – will be a part of life
- Life long issue, cope with strategies but it is always there
- Don't view as liability
- Liability feels like a stoppage, barrier
- Community should not view as a liability either
- Liability – hindrance
- View as a plus

THE PETER AND ELIZABETH C. TOWER FOUNDATION

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
    Stakeholder Response -
- Need to know their needs and how they learn best – strategies
- Result Statement #2 is necessary for result statements #3 and #4 (combine)
- Understand how to manipulate their dyslexia
- Strengths in my difference – advantage
- College, law school – policy supports and accommodation

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
Stakeholder Response -
- No changes

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Early identification of signs (parents, teachers, students as well)
- Demystify "dyslexia" – use as umbrella term
- Trial and error on learning styles is critical
- Need strategies, try them out, continued availability of supports, continuity and consistency in systems
- Training program for college students/graduate students
- Teacher coursework – focus on identification, analysis, adaptation
- 10% of population – need universal screening
- De-stigmatize – use correct language – make it okay to get help
- Community awareness – signs, support
- Variations in intellectual differences understood

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
- Kurzweil
- Speech to text programs
- Textbooks online – can read to you, highlight, dictionary
- Standardized testing – available reader
- Reasonable homework but avoid creating differences
- Accommodations – policy support
- More strategies…. better equipped
- Trial and error
- Self-advocacy
- Advisors to help with strategies
- Executive function programming – organization, interact with reading, flashcards, teach and use application

Statement 3: Young adults are confident and do not view their learning disability as a liability.
- 4-color pen – color, visually appealing, code
- Example problems should be the hardest problems
- Situational education – sports, recreation, testing situations
- Team effort
- Confidence building activities – sports, arts, music, drama, full gamut
- Peer mentors – people to look up to for supports

2351 North Forest Road   716 689-0370
Getzville, NY 14068-1225   (fax)   716 689-3716
www.thetowerfoundation.org   [141]   info@thetowerfoundation.org

- Teaming support/someone like you – not alone
- Get together, support, social
- Interest and enjoyment

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
- College counseling
- Public schools – limited accommodations
- Equip with skills
- Time management, discipline, study skills

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
- Available resources for parental needs
- Parents are experts of child's condition as well as the child
- Help with strategies, advocates
- Realize that it is real – not just that the child is not working hard enough
- Family should not make children feel any differently than other children or their peers
- Kids scholarship fund – financial support

2351 North Forest Road
Getzville, NY 14068-1225
www.thetowerfoundation.org

[142]

716 689-0370
(fax)   716 689-3716
info@thetowerfoundation.org

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-04-25
FOCUS GROUP | Parents
Host: The Gow School for Dyslexia and Learning Disabilities (Erie County, New York)

<u>**Review of Result Original Statements**</u>

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
　　Stakeholder Response -
* Children with learning differences – phrased negatively
* Not a disability
* Early – as soon as possible
* Individual needs and abilities
* Language based should be included somewhere
* Availability of services is limited
* Concern around use of psychological in definition
* May not be diagnosed until 8 or 9 years of age (3rd, 6th, 9th grade are common for diagnosis)
* No services available in the public schools
* Individualized Education Plan (IEP) – language was not included on it – need to address it but there are high costs associated with remediating – don't want to use the terms
* Avoidance of terms
* Disconnect – they identified issue and didn't discuss resources available including the Gow School
* Private schools don't have resources – concerned about their pockets ($)
* Earlier intervention = better chance of success
* Milder the case, harder to identify
* Students cover themselves – smart
* Reassessment is critical

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
　　Stakeholder Response -
* Youth with learning "differences"
* Should be connected to result statement #1
* Don't want to be different
* May not understand the challenge
* Don't want to have to go to special resource center
* De-stigmatizing
* Parent-teacher-child interaction

Statement 3: Young adults are confident and do not view their learning disability as a liability.
　　Stakeholder Response -
* Liability is negative
* Learning difference as an asset
* Liability may be too stark
* Learning difference is a state of fact
* Liability – translation – barriers?
* Skill set translates to success

- Gow School youth are confident
- Need to develop comfort in themselves

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
Stakeholder Response -
- Good goal for all adults
- Inter-discipline – autonomy (mind, body, soul)
- Need to have skills to function without parents as young adults
- Transitions are challenging

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
Stakeholder Response -
- Higher priority – list first
- Result statements #5 and #1 are interconnected; interwoven – early intervention
- Unfortunately, early intervention can be too expensive

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
- Education – childcare professionals, parents, pre-school, caregivers, teachers, pediatricians (especially with other interventions, linkage to other needed supports, awareness and signs)
- Parent information/education
- Community/marketing awareness – signs and concerns
- Documentation – measurement, diagnosis
- Advocacy component – mediation
- Pathway needs variation based on child's needs
- School accountability mechanisms – share test results with parents so they know what is going on
- Home and school connection
- Universal testing, screening
- Social policy to ensure available universal screening
- Reassessment and determine need for additional services and opportunities

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
- Advocacy, self-advocacy (confidence to remove barriers to asking for support)
- Education about learning differences (balance)
- Understand availability of resources
- Parent education of learning differences
- Community awareness
- Cultural change in schools, administration, education training
- Child has a problem is not a problem
- Provision of educational environments where children are taught in different modalities

Statement 3: Young adults are confident and do not view their learning disability as a liability.
- Support to build confidence, self worth
- Spheres of growth/opportunities
- Skills set – development
- Afterschool supports
- Counseling services
- Positive adult and peer mentors
- Reinforcement/available supports
- Holistic services
- Big Brother – upperclassman support, culture of caring
- Public Awareness – PSAs
- Community level goals
- Discipline

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
- Vocational supports
- Life skills
- Technology as resources – not all tech all the time
- Kurzweil technology
- Text to speech technology
- Colleges, support use of technology
- Academic tutoring/note taking
- Support for accommodation/policy
- Testing pre-admission

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
- Informed on available resources
- Simple resource guides – "Dummies Books" – hit the important points
- Middle ground between parents and educators
- Child comes first
- Parent to parent support (comfort)
- Change culture of schools
- Availability of neuropath evaluations – trained individuals
- Costs

THE PETER AND ELIZABETH C. TOWER FOUNDATION

2012-06-04
FOCUS GROUP| School District Special Education Directors
Host: Orleans/Niagara Board of Cooperative Educational Services (BOCES) (Niagara County, New York)

<u>**Review of Original Result Statements**</u>

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
   Stakeholder Response -
- What do you mean by services – in school or wider variety
- Diagnosed – assessed may be better
- "Early enough" based on pre-intervention, early is relative term, appropriate and not premature identification
- Early is vague, depending on objective
- Diagnosed – loaded term, medical connotation, maybe identified is better
- Learning disabilities – learning "concerns"
- Learning Disability – aligned with Tower's definition
- Be careful with term "dyslexia"

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
   Stakeholder Response -
- The schools could have more resources, especially in face of budget crunch
- Demystification
- Talk about areas of strength/work on strengths
- Not something we do well; needs more focus
- Progress monitoring
- Professional development around how kids learn
- Schools Attuned – Mel Levine
- Not "receive" resources but use/seek access to strategies

Statement 3: Young people are confident and do not view their learning disabilities as a liability.
   Stakeholder Response -
- Liability – does have punch
- Self-determination may be better or self actualization
- Not a limit or inhibitor to what they want to do
- Hard to measure confidence
- How does learning disability affect learning; how do you identify strategies to accommodate – "self determination" better than "confident"
- Focus on positive and effective ways to succeed
- View learning disability as naturally occurring part of life – deal with as such

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits.
   Stakeholder Response -
- Equipped – prepared or well-prepared
- Needs self-advocacy dimension – apply strategies
- Opportunities to experience work and college settings to make decisions about the future

---

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
   Stakeholder Response -
   - Identify – locate, find?
   - Should be families and young adults
   - Informed – need more, need "understanding"

Statement 6: Consider a Community Result Statement
   Stakeholder Response -
   - Educate community so they are more comfortable with young people with learning disabilities
   - Employer accommodations

Strategies Associated with Original Results Statements

Statement 1: Children with learning disabilities are properly identified early, diagnosed and connected to services that meet their individual needs.
   - Educate wider range of evidence-based practice interventions in schools

Statement 2: Youth with learning disabilities understand how they learn and receive resources that support them accordingly.
   Stakeholder Response -
   - Progress monitoring
   - Professional development around the notion of "attuning" students

Statement 3: Young people are confident and do not view their learning disabilities as a liability.
   - Surveys

Statement 4: Young adults are equipped for the workplace and/or their educational pursuits
   - Expose to work on college settings
   - Learn to build portfolios and resumes
   - Look at college and career readiness standards (as early as kindergarten)

Statement 5: Families are informed about learning disabilities and are able to identify and navigate available services.
   - Community education
   - Surveys