

# Transforming Mental Health Policies: Successes and Challenges

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# Two senses of transformation

- 1) We need to transform mental health policies to re-orient systems of care *from* symptom reduction and risk assessment/management *to* the promotion of a full life in the community, even in the face of an on-going mental illness.
- 2) We need to transform the ways in which we design and implement mental health policies to involve persons in recovery and family members as stakeholders who can drive the process of change.

# One thing we have learned

Experience suggests that it is easier to do the former than the latter.

Changing policies is easier than actually changing practices.



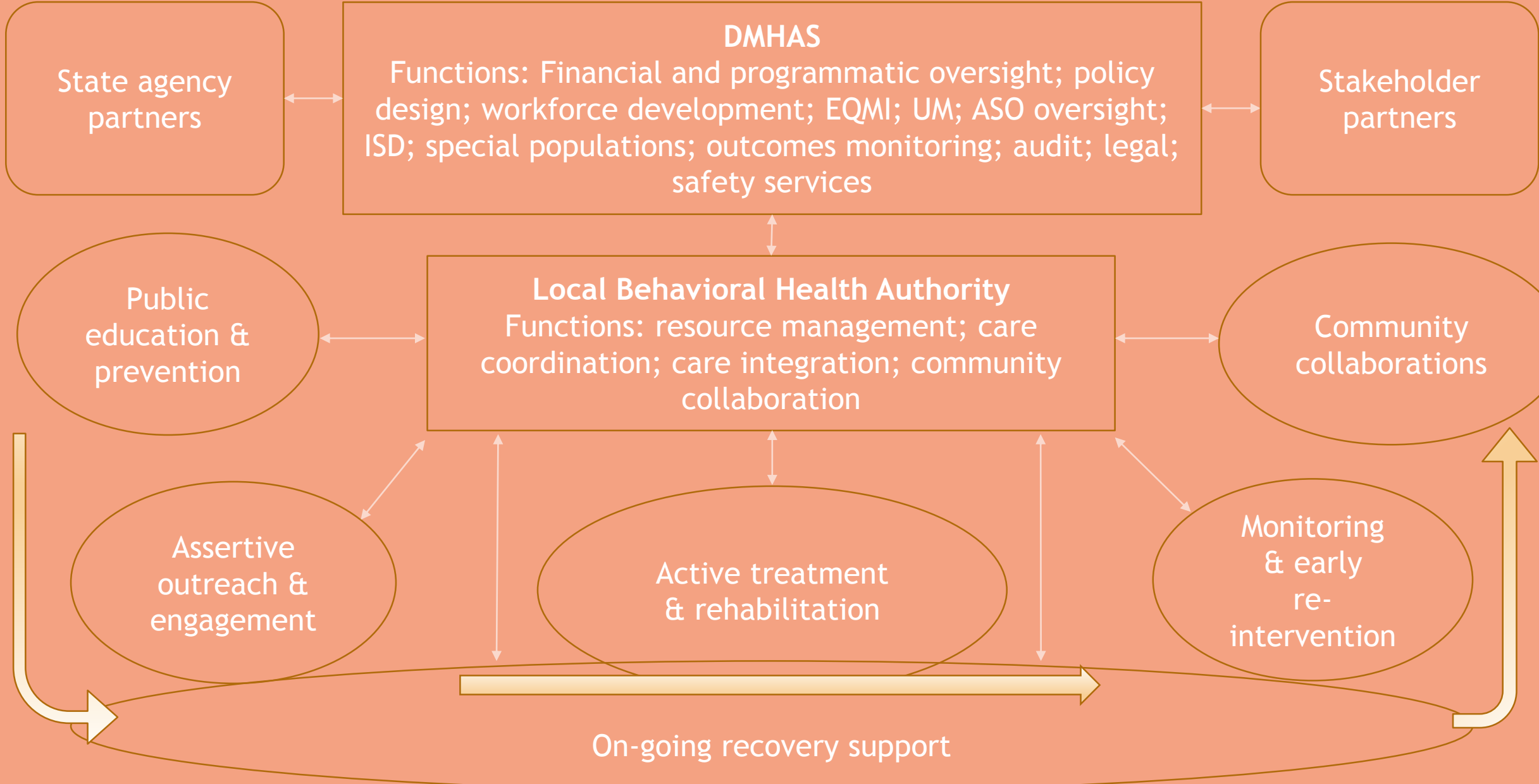
## Changes in policies (1999-2004)

The Department endorses a broad vision of recovery that involves a process of restoring or developing a positive sense of identity and meaningful sense of belonging apart from one's condition while rebuilding a life despite or within the limitations imposed by that condition.

A recovery-oriented system of care identifies and builds upon each person's assets, strengths, and areas of health and competence to support the person in managing his or her condition while regaining a meaningful, constructive sense of membership in the broader community.

## Adoption of “recovery management” model (2005- )

- Shift from acute care model of disconnected episodes of treatment to chronic care/disease management model that emphasizes continuity of care over time and the promotion and exercise of self-care in community settings
- Shift from practitioner as expert in charge to patient- and family-centered practice in which practitioner educates, consults, and provides treatment and other services in support of the patient/family’s values, goals, and vision of a meaningful life





# Example of “clinical stability”

One key principle is that community inclusion provides the foundation for—rather than serves as the reward of—recovery. This is in contrast to the traditional view of get well (recover) first, and then get your life back.

In Hong Kong, there appears to be a practice of reserving recovery-oriented practices/care for people who have achieved “clinical stability.” The result is that recovery is limited to those who have to some degree recovered. But they may need it the least.

# How to transform mental health care to promote recovery among those who most need it?

Some things we can do:

- Decrease stigma, discrimination, and other barriers to access to care and effectiveness of rehabilitation
- Facilitate early identification and ensure timely access to early intervention
- Utilize practices that are effective (i.e., that are evidence-based)
- ???????



# What else there is for us to do:

- We need to rethink relationship of care and cure to recovery as an on-going process
- We need to rethink role of practitioner
- We need to shift focus from what we can't change to what we can
- We need to learn from people in recovery and their loved ones about what outcomes matter the most to them

# Defining transformation to a recovery-oriented system of care

“Revolutions begin when people who are defined as problems achieve the power to redefine the problem.”  
-John McKnight

People who are now seen as ‘burdens’ on a system come to be seen as that system’s greatest assets.



## Two key questions

- Why do we need persons with serious mental illnesses to define the nature of the “problems” to be solved? How could they possibly know?
- How do persons with serious mental illnesses and their families become a valuable asset to a system of care (and the broader society)?



This was not mental illness alone.





# Because this was also mental illness (Consumer/Survivor/Ex-Patient/Service User Movement)





And this is what it looks like now ...





## Otherwise said:

- You can't transform your system alone, any more than you can cure mental illness alone.
- There is no way to create a “user-driven” system without users (i.e., people in recovery) driving it. Like recovery-oriented practice, it requires a collaborative approach based on what people in recovery value, need, and can make use of in living their lives as best as they can.

# People in recovery


- ... are a primary source for identifying strengths and charting a course forward
- ... have the most at stake; the most to gain *and* the most to lose in the process
- ... can be the most effective antidote to stigma and discrimination (putting a positive face on recovery)
- ... have a strong desire to “give back” and have a lot to offer (energy, ideas, support)



# A beginning blueprint for where you might go from here

- Conduct a strengths-based assessment of what is working well in your current system and what areas people in recovery, their loved ones, and other stakeholders would like to see improved first.
- Articulate a shared vision of where you are heading. What implications does the recovery paradigm have specific to Hong Kong? What will it take to afford people “a full life in the community” in your system?
- People can no longer be kept in institutions for prolonged periods against their will. But it is up to each person him or herself (with his or her loved ones) to decide what kind of life he or she wishes to lead in the community. Mental health services support that vision.



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- Identify ways in which existing strengths can be used to build on in taking the next few steps toward this shared vision.
  - Develop an action plan at each level of the system, including local communities, which builds on these strengths, including, importantly, the contributions of the recovery community.
  - Include the recovery community (and family and other allies) in all aspects of transformation, including design, implementation, evaluation, and analysis.

# But how could “our patients” (and families) know what needs to change?

- When it comes to diagnosing and treating illnesses, or assessing and remediating deficits, we have the expertise.
- When it comes to living a meaningful life in the community, each person has the right to determine what kind of life he or she wants to lead—and the “expertise” to know what they need in order to do so.
- When little is expected, little is delivered. When much is expected, people have the tendency to rise to the occasion. When asked (and if they believe you will listen), people have tremendous amounts to offer.



# Distinguishing Technical from Adaptive Challenges\*

	What's the work?	Who does the work?
Technical	Apply current know-how	Authorities
Adaptive	Learn new ways	The people with the problem



\*Heifetz, R.A. & Linsky, M. (2002). *Leadership on the Edge: Staying alive through the dangers of leading*. Boston: Harvard Business School Press.



## Areas of focus

- Address stigma and discrimination in partnership with service users
- Develop and refine services and supports in partnership with service users and loved ones
- Govern, monitor, evaluate, and improve system of care in partnership with service users and loved ones

# Nothing about us, without us!

- Why involve service users and family members in planning, evaluation, and quality improvement?
- How to involve service users and family members in planning, evaluation, and quality improvement.
- What happens when you involve service users and family members in planning, evaluation, and quality improvement?



# Why?

- Because the mental health system exists in order to serve them and they have extensive knowledge of what is helpful, what is not, and how things could be improved.
- Just like with cars or cell phones.
- Health care in general is becoming more and more patient-driven. Behavioral health should be too.

# How?

- Service user and family involvement requires and contributes to significant changes in how the business or providing care is carried out. (ex. of medication errors)
- Having service users and family members “at the table” changes the language used, changes the priorities set, and changes what is selected to be measured and how.
- Through use of community-based, participatory action research methods.



# Example

- State of Connecticut receives federal grant to transform mental health system to a recovery orientation, to change system into one that is service user and family-driven.
- Only way to create a service user and family-driven system is to invite service users and families to play central roles (in partnership with administrators and practitioners) in evaluating the current system and in developing ways to improve the quality of care provided.
- To start, convene a steering committee made up of representatives from family and service user organizations to create a Consumer, Youth, and Family Quality Improvement Collaborative (CYF QuIC).

# CYF QuIC will:


1. Develop quality standards for consumer, youth, and family-driven care
2. Evaluate existing quality review processes against QuIC standards
3. Report findings and recommendations to change current evaluation processes
4. Develop a way to measure the quality of care based on QuIC standards
5. Try out and test measurement tools
6. Generate recommendations based on findings to improve the quality of care



# A Big Challenge for the CYF QuIC

- Usually quality measures evaluate how a mental health provider or program is doing in providing a service
- QuIC's challenge is to shift from what the services do to **what the person wants and needs**
- Shift the focus to measure the **supports that C/Y/F want and need** (e.g. family member support, employment, education)
- Focus on **recovery and resilience** - what the person is able to do for him or herself and achieve in his or her life
- Shift the focus to measure the degree to which **providers/ programs enable people** to do for themselves and achieve their recovery and life goals

# Goals of QuIC

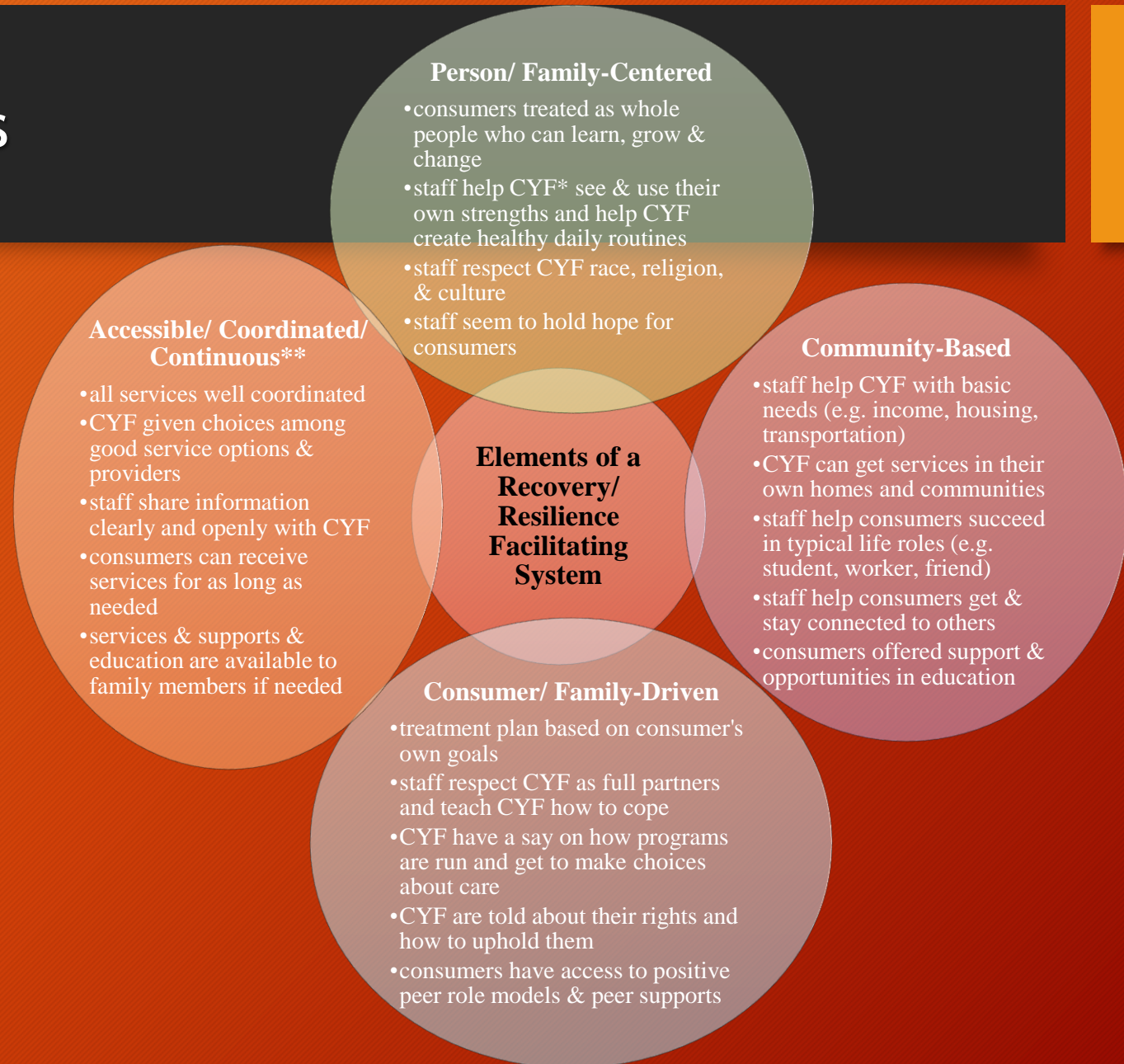
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- The diagram features a central grey oval containing the text "Consumers Youth Families". Surrounding this central oval are five numbered goals, each in a different color (yellow, orange, or red). The goals are arranged in a circular pattern around the central oval.
1. Set the standards for how to evaluate services
  2. Determine how you will evaluate the quality of those services
  3. Evaluate the quality of mental health services you receive
  4. Provide feedback to consumers, youth, families, mental health providers, and promote “informed choice”
  5. Provide feedback to system to improve the quality of services, identify new service needs



# Quality Improvement Collaborative

- Memorandum of Agreement signed by all stakeholders
- 243 Members enrolled
  - 57% Consumers
  - 29% Family Members
  - 15% are Youth/Young Adults
- Transportation, Reimbursement for Childcare, & Translation services ensured people attended
- Feedback:
  - *“I feel so empowered knowing that the idea we share at this table makes a difference statewide and could change the health care system my family and I deal with everyday.”*
  - *“Being able to speak and be heard as a person.”*

# Quality of care as defined by service users and family members





# Characteristics of an Ideal Mental Health System

## An Ideal System ...

1. Is Person Centered
2. Is Family Oriented
3. Is Consumer and Family Driven
4. Upholds Rights and Encourages Advocacy
5. Is Culturally Sensitive/Cultural Competent
6. Meets Basic Needs
7. Provides Recovery Oriented Services
8. Provides Adequate Children and Youth Services
9. Is Community Centered and Promotes A Full Life in the Community
10. Is Well Funded
11. Emphasizes Quality and Accountability

12. Educates Consumers and Families
13. Educates and Involves the Public
14. Is Effective and Outcome Oriented

## In an Ideal System ...

15. Stigma and Discrimination are Reduced or Eliminated
16. Services and Supports are Readily Accessible
17. The System Offers good Crisis Services and Relapse is Prevented
18. Is Comprehensive/Integrated/Well Coordinated
19. The Workforce is Caring and Well-Trained

# Quality Improvement Collaborative

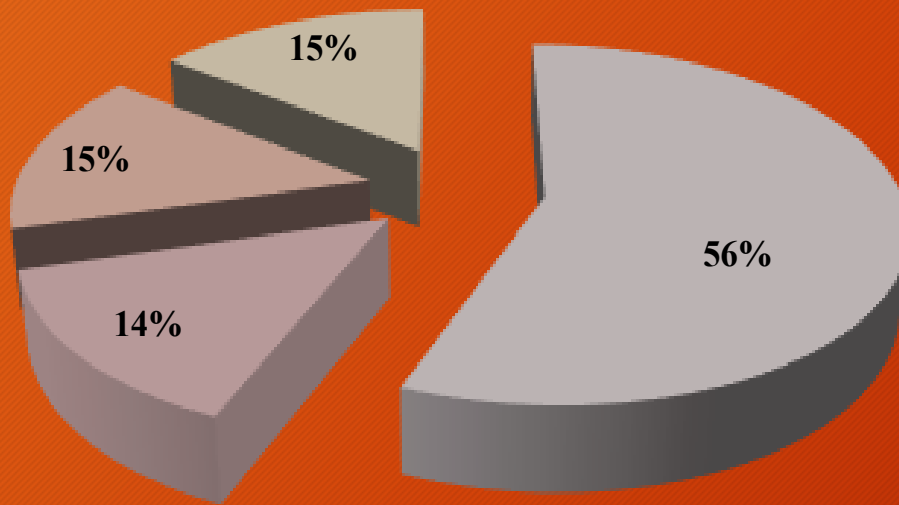
- Quality survey (ERFS) was developed by service users, family members, and researchers to assess quality of care.
- Quality not satisfaction.
- A total of 51 surveyors were trained. Sixty-one percent of the surveyors were White/Caucasian, 25% were West Indian/African American, and 14% were Hispanic/of Hispanic Origin. Five of these surveyors were fluent Spanish speakers and were trained in administering both the English and Spanish versions of the QuIC Survey. The number of service users versus family members trained was fairly balanced, with 17 trained adult service users, 7 young adult service users, 8 adult family members, and 19 child family members.



# Methodology

- 110 agencies involved
- Total of 1,011 valid surveys obtained

**Total Surveys (N= 1011)**



- Adult (n= 568)
- Young Adult (n= 146)
- Adult Family (n= 149)
- Child Family (n= 148)

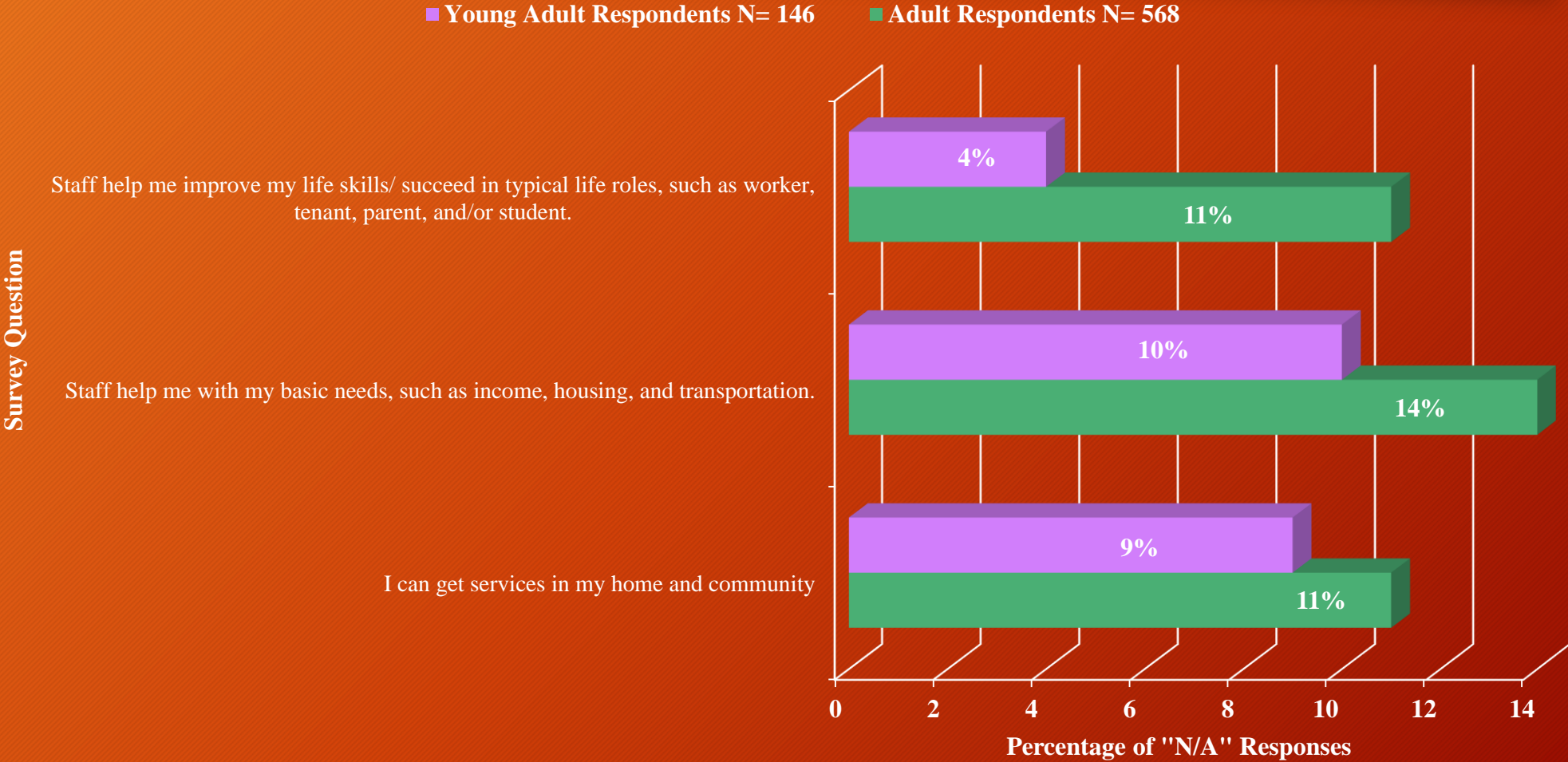
**Table 3. Questions, Mean Scores, and % of ‘Don’t Know’ Responses by Group**

Ratings are on a scale from 1-5, with 5 being best.

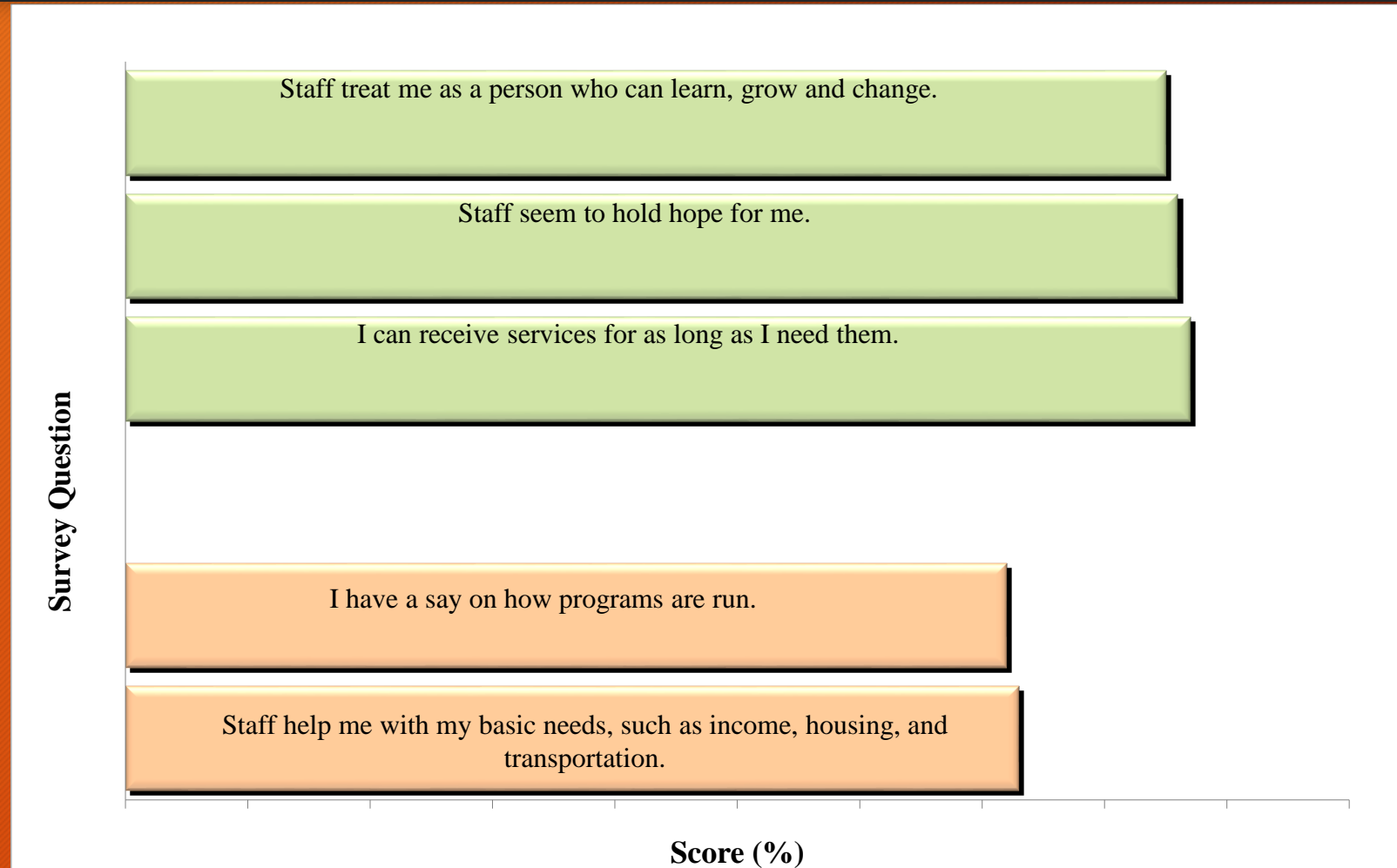
	<b>Consumer (N = 195)</b>	<b>% DK</b>	<b>Family (N = 78)</b>	<b>% DK</b>
1. Providers explain options available at their agency.	3.75		2.60	
2. Providers explain both the positives and negatives about the services and supports available.	3.44		2.61	
3. Providers explain options available outside of their agency.	3.24		2.11	
4. Providers help the person to set his or her own goals.	4.01		2.65	
5. The person/family is involved in making decisions about care.	4.26		3.40	
6. The person/family participates in planning meetings about care.	3.14		2.91	
7. Providers ask if the person/family need transportation or childcare to keep appointments.	2.56		1.42	
8. Providers encourage the person to include family members, friends, and other people in care.	3.28		2.78	
9. The person/family can tell providers what they think about care whenever they want to.	3.89		3.81	
10. The person/family know who to talk with when I have concerns about care or when they want to change providers.	3.17		2.47	
11. Providers have told the person/family how to go about filing a formal grievance if they have serious concerns.	2.68		1.60	
12. When they have expressed concerns about care, the person/family have received a respectful and timely response.	3.89		3.12	
13. The person/family has been assured that they will not suffer any consequences for offering their opinions/feedback.	3.89		2.92	0.97
14. Providers have asked the person/family about their cultural background and how it might impact care.	2.28		1.34	0.94
15. The person/family have been invited to participate in QI activities.	3.12		1.85	1.27
16. Providers have asked the person/family to rate their level of satisfaction with care.	3.22		1.72	1.5
17. When the person/family have been involved in QI activities, their contributions have been taken seriously.	3.41		2.06	1.35
18. When the person/family have been involved in QI activities, they have been paid for their time.	1.84		1.37	0.47
19(I). Providers are aware of and respect the person’s cultural background and its importance.	3.17			
20(I). Providers have talked with the person about writing a Psychiatric Advance Directive.	1.94			



# Items that elicited “I don’t know” or not applicable

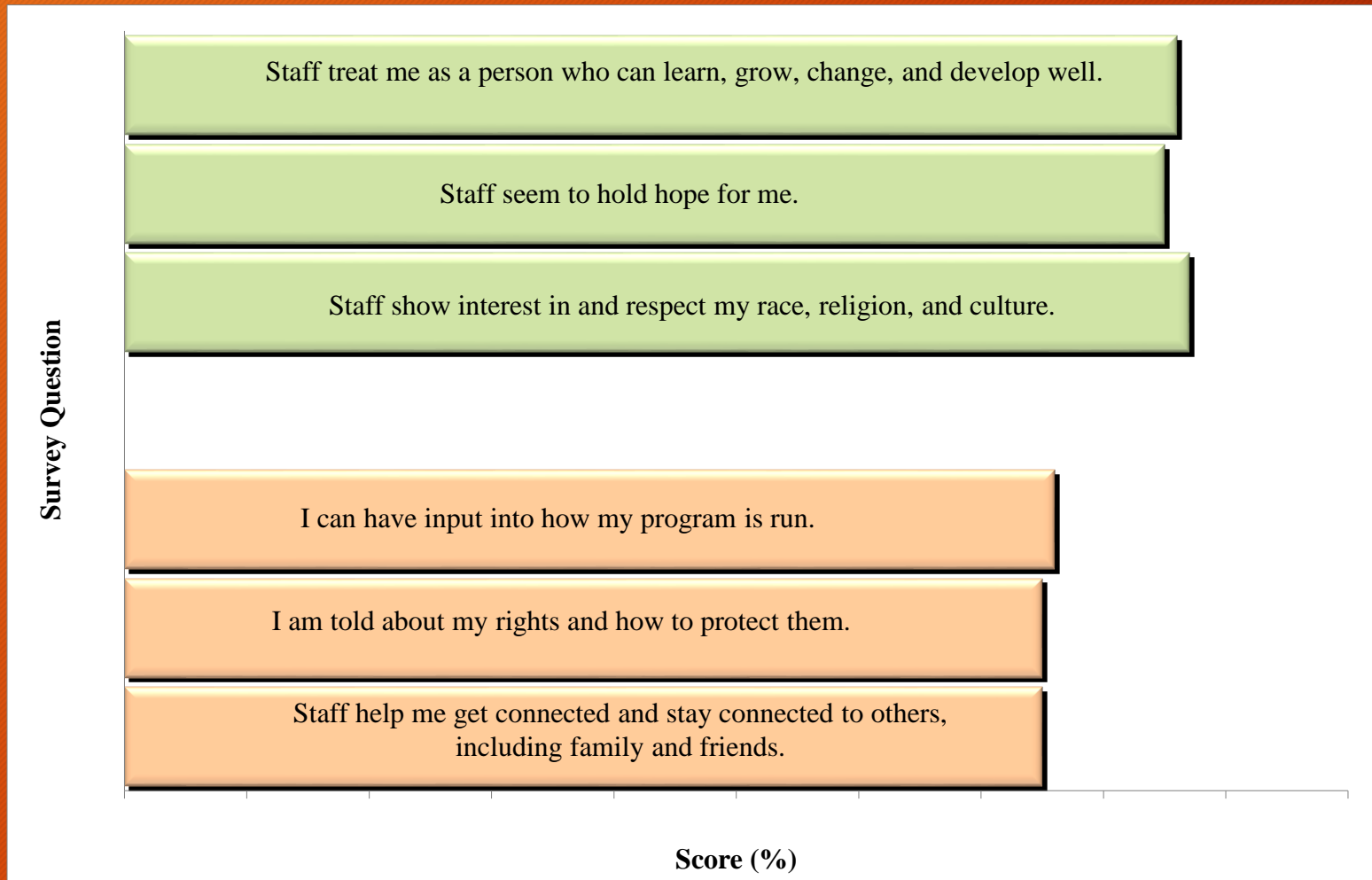


# Highest and Lowest Rated Items by Adults





# Highest and Lowest Rated Items by Youth



# ERFS Report Card

Adult	Score	Grade
Person-Centered	84%	B
Consumer-Driven	80%	B-
Community-Based	76%	C
Accessible/Coordinated/Continuous	81%	B-

Scores provide snapshot of relative quality in different domains



# What to do?

- Recognize that recovery transformation cannot be (just) top down
- Utilize the power that can be activated by viewing service users and families as untapped resources rather than as problems or burdens on the system
- Build trust and respect among staff, service users, and families based on a genuine intent to partner with them

# Use asset-based strategies

- Help recovering service users identify personal assets: interests, strengths, goals, passions, sources of resilience
- Teach and encourage recovering service users to tell personal recovery stories as system change agents
- Teach staff to tell system recovery change stories
- Highlight successes, no matter how small



## How you'll know when its working

“When I am on the job, I do my job. I think everybody is capable of doing something. For many years, I did nothing. I was overmedicated and lay on the couch. That is the way I thought my life would always be. Now, the whole thing of mental health is changing. It's really wonderful to see all these changes. Years ago, you didn't have much to look forward to. I thought I would spend the rest of my life in an institution. Now look at what has happened. I had a lot of people who pushed me along the way. I still have issues with self-esteem but if you have people saying that you can, you can try little things at a time.”

*“There has been a lot of progress in the mental health field. I think that the mental health field has changed. I think it is very pro-client, pro-patient. When I deal with people, I find that they are very concerned. They really want to help you... Staff doesn’t push you to do things that you aren’t able to do. They help you do things that you can do. They help you find goals. I think that the profession has improved a million times.”*





Thank you!