



TRIAD

Treatment/Recovery Information
and Advocacy Database

Update

May, 2003



TRIAD

Treatment/Recovery Information
and Advocacy Database

Steering Group: Rick Birkel, Phil Leaf, Mike Fitzpatrick,
Ron Honberg, Joel Miller, and Steve Buck

Advisory Group: Listed in brochure

Colleagues and Staff: Abigail Graf, Patrick Corrigan, Aspen
Systems Corporation, NAMI members around the country



TRIAD

Treatment/Recovery Information
and Advocacy Database

Why Information and Data?

- **Administration**
- **Planning**
- **Quality Improvement**
- **Research**
- **Accreditation**



TRIAD

Treatment/Recovery Information
and Advocacy Database

Why Information and Data?

MHSIP mission: to foster and enhance the quality and scope of information for decisions that will improve the quality of life and recovery of people with mental illness.



TRIAD

Treatment/Recovery Information
and Advocacy Database

Why Information and Data?

Information and data are central to advocacy.



TRIAD

Treatment/Recovery Information
and Advocacy Database

Advocacy, Information, and Data

Data are needed to convincingly communicate an issue to policy-makers and the public, so as to change policy or practice.

- Convincingly: sound and relevant information that makes a strong case
- Communicate: intelligible
- Change: produces results



TRIAD

Treatment/Recovery Information
and Advocacy Database

Why TRIAD? Why NAMII?

A project to convincingly
communicate data to produce change:
improved treatment and recovery for
consumers with severe mental
illnesses.



TRIAD

Treatment/Recovery Information
and Advocacy Database

What TRIAD is and is not

TRIAD is not:

- yet another report card, measurement system, or research project
- a ranking or rating of states
- NAMI going it alone

TRIAD is:

- a translation of relevant data collected by others
- Projects to collect data that do not exist or that NAMI has a unique role in developing
- Aimed at advocacy
- collaborative



TRIAD

Treatment/Recovery Information
and Advocacy Database

Timely, equitable, high-quality, evidence-based, safe interventions

- Medication
- Inpatient Care
- ACT Programs
- General Medical Care
- Integrated Services for Dual Diagnosis
- Family Psychoeducation and Support
- Peer-provided Services
- Supported Employment
- Affordable and Appropriate Housing and Supports
- Jail Diversion Programs



TRIAD

Treatment/Recovery Information
and Advocacy Database

Other Indicators of Interest:

- Investments
- Stigma and Discrimination
- Consumer Outcomes



TRIAD

Treatment/Recovery Information
and Advocacy Database

Current Projects:

- NAMI Consumer/Family Survey
- Examination of Media/Legislative Stigma/Discrimination
- Mental Health System Fact Sheets
- Web-based, interactive guide to schizophrenia treatment



TRIAD

Treatment/Recovery Information
and Advocacy Database

Consumer/Family Member Survey

- nationally representative sample survey of more than 3,000 NAMI members
- representative sample of NAMI members from each state/region
- survey pre-tested among NAMI members around the country and in local drop-in center
- mailed survey, with pre- and post-survey post-card; follow-up calls to non-respondents



TRIAD

Treatment/Recovery Information
and Advocacy Database

This question asks about services and treatments received **in the last year**. Circle the number next to each service and treatment that you or your loved one with a serious mental disorder has used. Please rate the services and treatments that were used according to the following:

Access: Did you or your loved one know where and how to get the service or treatment?

Timeliness: Was the service or treatment received in a reasonable amount of time?

Quality: Were you or your loved one satisfied that the service or treatment met your expectations and was helpful in meeting your needs?

Safety: Did you or your loved one feel confident that the service or treatment did not put you or your family member at risk of harm?



TRIAD

Treatment/Recovery Information
and Advocacy Database

1	Medication
2	Inpatient care/ hospitalization
3	ACT services (Assertive Community Treatment services, also known as PACT—Program of Assertive Community Treatment—or intensive case management provided by a team of providers 24 hours a day, 7 days a week, as needed)
4	Supported employment services
5	Crisis intervention (such as going to an emergency room or crisis intervention clinic)
6	Individual or group psychotherapy
7	Treatment of substance abuse problem
8	Peer or other consumer-run programs/services/support (such as drop-in center or peer-provided job coaching)



TRIAD

Treatment/Recovery Information
and Advocacy Database

Do you or your loved one with a serious mental disorder currently work at a job for pay?

1	Yes, full time (35 hours a week or more)
2	Yes, part time (less than 35 hours a week)
3	No
4	Unsure



TRIAD

Treatment/Recovery Information
and Advocacy Database

- What barriers (if any) to employment do you feel you or your loved one with a serious mental disorder has experienced? (*Circle **ALL** that apply.*)

1	None
2	Lack of jobs in the community
3	Stigma and discrimination against people with mental disorders
4	Lack of vocational services
5	Fear of losing health or disability income benefits
6	Inadequate treatment of mental health condition
7	Lack of transportation to job/employment services
8	Other (<i>Please specify</i>): _____
9	Unsure



TRIAD

Treatment/Recovery Information
and Advocacy Database

5. If you or your loved one with a serious mental disorder do not enjoy the most appropriate living arrangement, what barriers contribute to the problem? (*Circle **All that apply.***)
- 1 Housing costs are too expensive
 - 2 Appropriate housing is limited due to stigma against people with mental illness
 - 3 Independent living is difficult because there are not good supports for consumers in the community to help them maintain an independent living arrangement
 - 4 More structured residential care is not available
 - 5 There is no financial assistance from the government to pay for housing and support
 - 6 Family does not support living independently
 - 7 Other (*Please specify*):
-
- 8 Unsure



TRIAD

Treatment/Recovery Information
and Advocacy Database

Do you or your loved one with a serious mental disorder also have a serious non-mental health condition (such as diabetes, asthma, heart disease, hypertension, HIV/AIDS)?

1	Yes	
2	No	(Go to Question 7)
3	Unsure	(Go to Question 7)



TRIAD

Treatment/Recovery Information
and Advocacy Database

Preliminary Results

- 2994 respondents
- 16% consumers/83% family members
- 49.3% responses reflect individual with diagnosis of schizophrenia; 60% had multiple mental health diagnoses; 31% had co-morbid health condition other than mental health; 47% 25 to 44 years of age; 81% unmarried; 65% unemployed; 55% have approximate total annual income of less than \$10,000
- Biggest barriers to preferred housing were costs and lack of supports in the community
- Biggest barriers to employment were stigma/discrimination and fear of losing health/income benefits



TRIAD

Treatment/Recovery Information
and Advocacy Database

State Legislative Analysis

- Systematic identification of all bills/legislation in each state and characterize whether they improve things or not for individuals with mental illnesses
- State profiles
- National trends
- Evaluate usefulness of approach for ongoing monitoring project



TRIAD

Treatment/Recovery Information
and Advocacy Database

State Media Analysis

- Systematic identification of mental illness articles in major newspapers in all states
- Characterize coverage trends by individual reporters; editors; newspapers; states; and nationally



TRIAD

Treatment/Recovery Information
and Advocacy Database

State Profiles

- **gather data on mental health service system in each state**
 - national data sources (e.g., NRI, CMHS, CMS, SSA, DOJ)
 - state data sources
- **products**
 - one-page fact sheets on various aspects of the state system
 - 8 to 10 page report profiling overall state system
 - national analyses identifying trends
 - national website listing data and sources for others to use



TRIAD

Treatment/Recovery Information
and Advocacy Database

State Profile Foci in 2003:

- Number of adults with severe mental illnesses and proportion receiving care, homeless, in jail/prison, unemployed
- Expenditures: state expenditures on the public mental health system
- State system overview
- Implementation of Evidence-Based Practice
- Housing



TRIAD

Treatment/Recovery Information
and Advocacy Database

About You

[Home](#) >

[About You](#) >

[Appropriate Care](#) >

[Education and Teamwork](#)

Welcome to Compare Your Care! We appreciate your taking the time to participate in this pilot study. It will take you about 10 or 15 minutes to answer the questions. Your answers and comments about this website will help us make a website that is easy to use and that will ask the right questions. Thank you!

Please enter your study ID number:

Are you:

Male

Female

What is your age?

years

Please select one:

I have been diagnosed with schizophrenia

Someone in my family or a friend has schizophrenia



TRIAD

Treatment/Recovery Information
and Advocacy Database

Health Insurance

[Home](#) > [About You](#) > [Appropriate Care](#) > [Education and Teamwork](#)

The questions that follow are about your relative who has schizophrenia.

Does your relative now have any of these kinds of insurance? (*Check all that apply*)

Medicare

Medicaid

VA, CHAMPUS or CHAMPVA

Private health insurance

No insurance

None of the above

I don't know



TRIAD

Treatment/Recovery Information
and Advocacy Database

Family Education

[Home](#) >

[About You](#) >

[Appropriate Care](#) >

Education and Teamwork

Has anyone in your family ever received information about your relative's illness or treatment, or did they get advice or support about how to be helpful to him or her?

No

Yes

Don't know

Has anyone in your family ever attended any kind of educational or support program about schizophrenia and its treatment?

No

Yes

Don't know



TRIAD

Treatment/Recovery Information
and Advocacy Database

Treatment and Service

[Home](#) > [About You](#) > [Appropriate Care](#) > [Education and Teamwork](#) > [Feedback](#) >
[Day-to-Day Living](#)

Has your relative ever been hospitalized for schizophrenia?

No

Yes

In the past year, since January 2002, how many times did he or she go to an emergency room or crisis center because of schizophrenia?

times

In the past year, since January 2002, has he or she participated in a consumer-run program like a support group or drop-in center?

No

Yes



TRIAD

Treatment/Recovery Information
and Advocacy Database

Medications

[Home](#) > [About You](#) > [Appropriate Care](#) > [Education and Teamwork](#) >
[Feedback](#) > [Day-to-Day Living](#)

Please list up to three medicines prescribed by a doctor that your relative is currently taking for mental health problems. Do not include medicines that can be bought without a prescription.

If the medicine bottles are handy, use them to select the drug names and enter the dosage information.

My relative doesn't take any medications

I don't know the names of the medications my relative takes

My relative takes the following medications:**Drug 1:** Name, starting with A-O Name, starting with P-Z

Drug 1: How much your relative takes each time he or she takes it

Drug 1: How often your relative takes it ___ times

Drug 2: Name, starting with A-O Name, starting with P-Z

Drug 2: How much your relative takes each time he or she takes it

Drug 2: How often your relative takes it ___ times



TRIAD

Treatment/Recovery Information
and Advocacy Database

Medication Side Effects

[Home](#) > [About You](#) > [Appropriate Care](#) > [Education and Teamwork](#) >
[Feedback](#) > [Day-to-Day Living](#)

How often does your relative's medication cause these problems:

a. Restless or jittery inside

Most of the time Some of the time None of the time

b. Slowed down or like a "zombie"

Most of the time Some of the time None of the time

c. Shaking or interference with use of hands, arms or legs

Most of the time Some of the time None of the time

d. Weight gain

Most of the time Some of the time None of the time



TRIAD

Treatment/Recovery Information
and Advocacy Database

Daily Living

[Home](#) >

[About You](#) >

[Feedback](#) >

[Appropriate Care](#) >

Day-to-Day Living

[Education and Teamwork](#) >

During a usual week, what does your relative do most of the time?

Work at a job for pay

Go to a structured day program

Go to school

Do volunteer work

Keep house

Nothing much

Something else



TRIAD

Treatment/Recovery Information
and Advocacy Database

Your Care Guide

[Home](#) > [About You](#) > [Appropriate Care](#) > [Education and Teamwork](#) > [Feedback](#) > [Day-to-Day Living](#) > [Feedback](#) > **Your Care Guide**

[Print this and take it to your doctor](#)

Survey Questions

[Your survey answers](#)

Your Feedback

Ratings you gave your doctor and your personalized feedback

[Overall rating of your doctor](#)

[Medications](#)

[Medication Side Effects](#)

[Taking Medications](#)

[Therapy and Support Programs](#)

Survey Questions

[Your survey answers](#)

Your Feedback

Ratings you gave your doctor and your personalized feedback

[Overall rating of your doctor](#)

[Family Support Programs](#)

[Family Support Programs](#)