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THE DATA NEEDS OF COMMUNITY-BASED PEER SUPPORT PROGRAMS

Preliminary Report of the Findings of a National Survey conducted by the Missouri Institute of Mental Health under subcontract to UIC National Research and Training Center of Psychiatric Disability

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Executive Summary

Without a management information system infrastructure appropriate for the needs of community-based peer support programs, it is highly unlikely that such programs will be included in the networks of provider agencies within managed behavioral healthcare plans. To survive the radical restructuring of the mental health delivery system, peer support programs will require not only the technological hardware to facilitate the collection and processing of data, but will also need the development of appropriate data collection instruments and other key data related components in order to track, monitor, and report system and person-based outcomes. On the other hand, the development of management information systems within the delivery of peer support services could destroy the casual, informal mode of peer support services developed within these consumer organizations, and could also create a barrier to service utilization due to member fear of lack of confidentiality protections. The burden of collecting data could also tax the resources of an organization without providing much benefit to members.

The following descriptive results of a national survey of data needs of community-based peer support programs conducted by the Missouri Institute of Mental Health are being used to assist in the development of an outcomes protocol for community-based peer support programs as part of the Community-Based Peer Support Outcomes Protocol Project, a three year research and demonstration project funded under a subcontract from the UIC National Research and Training Center on Psychiatric Disability. The survey was designed to assess the desire, capacity, data infrastructure, and concerns of peer support programs to collect program outcome data.

Staff from the project developed the 44 item questionnaire, and administered it by telephone interviews and/or collection of paper and pencil responses returned by facsimile. Since the total number of mental health consumer-run peer programs nationwide is relatively small, a convenient sample of 30 organizations was drawn from the *National Directory of Mental Health Consumer and Ex-Patient Organizations and Resources* (SC SHARE, 1995). Respondents to the survey were generally Executive Directors of consumer-run peer support agencies with membership ranging from six in a locally affiliated support group to 2000 in a nationally affiliated group.

In general, it was found that most peer organizations surveyed offer drop-in and socialization programs (50%), conduct advocacy (80%), provide mutual support (73%), and distribute information and make referrals (73%). The key goals were identified as education and empowerment (80%), rehabilitation and recovery support (57%), providing a forum where consumers can share mental health experiences (63%), prevention of hospitalization (53%), and as an alternative to traditional mental health services (77%).

While 90% of those organizations surveyed reported that they use computers, with the majority having three or less computers available, 40% did not data collection using computers. Preparation of reports (80%), correspondence (80%), and bookkeeping were the most frequent uses.

Eighty-three percent collected or kept data on the members/recipients or services. However, data collection was generally limited to demographic information (age=53%, race=47%, sex=53%, telephone number=50%, address=53%, housing=43%, and income=23%), or membership census (63%). Only 20% conducted member assessments, with the exception of tracking hospitalizations which rose to 30% of the peer organizations. Forty-three percent of the respondent organizations reported they conducted program evaluations or satisfaction surveys, but less than a quarter collected outcomes information.

Most data was collected for reporting requirements (63%) or to justify program budget (53%). Forty-three percent also used the data collected for advocacy purposes, but only forty percent used the information for quality improvement, and twenty-three percent for consumer education. The limited use of data is probably due to the type of data that is generally collected (i.e., census data and member demographic information).

It is important to note that almost forty percent of the programs surveyed indicated that they thought that data collection on members would discourage people from using services, and forty-three percent felt that data collection and evaluation would be a burden to the organization.

The findings suggest that while data collection is recognized as an important activity for community-based peer support programs by over half of the survey respondents, there are considerable concerns that need to be evaluated in the field-testing of the outcomes protocol, including confidentiality protections, program burden, and effect on service utilization. Further, the lack of familiarity with data collection beyond keeping a count of members indicates that the use of an outcomes protocol will depend on availability of both training seminars and materials. Further, the beneficial uses of data will have to be demonstrated. It is encouraging to note that most of the programs that were surveyed did have sufficient computers to manage data electronically.

Jean Campbell, Ph.D.
Principal Investigator

STUDY FINDINGS

Question #1
How would you describe what your organization does? **(Please check all that apply)**

Programming	Freq.
Mutual Support	25
Living Skills/Daily Activities	13
Case Management	10
Employment Support	6
Information Referral	22
Mentoring	9
Peer Support Res. Program	8
Advocacy	25
Arts	1
Crisis	9
Hotline	3
Drop-in/Social	15

Question #2
Is your organization part of a larger organization or a group of organizations?

Yes	21
No	9

Question #3
If Yes, is your organization part of a.......?

Local organization	10
State organization	8
National organization	3
NA	9

Question #4
How many members/participants does your organization have?

No. Members/Participants	Frequency
0-25	8
26- 100	3
101- 200	4
201- 500	6
501+	8
Missing	1

Question #5
What sort of model would you say describe the day to day programming?
Is it a clubhouse model, a drop-in, more structured.....?

Type of Model Reported	Frequency
Drop-in	8
Clubhouse	2
Advocacy	3
Other (Structured, Mixed, Community Support)	9

Question #6
Is your organization consumer run?

Response	Frequency
Partially	10
entirely	18
not at all	2

Question #7
When was the organization formed?

Decade formed	Fequency
1990's	11
1980's	15
1970's	2
missing	2

The oldest was formed in 1971.......

Question #8

Is this when you began providing services?

Yes	23
No	7

Question #9

Who utilizes the services or your organization? (**Check all that apply**)

Consumers	30
Family	9
Consumers/survivors of Substance Abuse	18
Substance Abuse Only	0
Survivors of Family Violence	4

Question #10

Do you have a mission statement? If yes, what is it?

Yes	21
No	1
Missing	8

Question #11

In general, what do you see as your organizations key goals? (**Check all that apply**)?

Alternative to traditional mental health services	23
Prevention of hospitalization	16
Meeting basic needs	13
Alternative to professionally run programs	17
Providing a forum in which to share mental health experiences	19
Rehabilitation and recovery support	17
Education and Empowerment	24
Coping skills	10
Crisis support	1
Case Management	5
Vocational training	0

Question #12
How many people make up your staff and administration?

Responses: 1 minimum - 40 maximum …..Average of 11.2 persons

Question #13
Do you use full-time, part-time, and/or volunteer staff? **(Check all that apply)**

Full-time	23
Part-time	21
Volunteer	26

Question #14
What are your staff job-titles? **(Check all that apply)**

Title	Frequency
Administrator	17
Case Manager	4
Peer Educator	14
Facilitator	12
Advisor	3
ResourcePerson	5
Clerical Person	14
Researcher	4
Couselor	2
Evaluator	2
Coordinator	3

Question #15
Do you distinguish between professionals/consumers/survivors?

YES	11
No	18
DK	1

Question #16

If yes, please indicate which of the positions listed below are professional or
consumer/survivor positions with the following:

P= Professional only
C= Consumer only
PC= Professional and Consumer

Question #17

Where do you get your funding?

Public	
Local	6
State	26
Federal	6
Private	3
Membership Dues	5
Fundraisers	3
Donations	5
Non-Profit	14
Foundations	4
Parent Organization	6
Grants	8

Question #18

Are there any other significant sources of funding which your organization utilizes?

Response	Frequency
FEMA	1

Question #19

How would you describe the stability and duration of your funding?

Very Unstable	2
Unstable	6
Tenuous	9
Stable	12
No Answer	1

Question #20
Please describe what you have planned in the near future regarding funding?

Phone Drives	3
Grant Apps.	22
Phil. Requests	4
Other	1

Question #21
Has your organization considered approaching a managed care organization for support, referral, or reimbursement for services?

YES	17
NO	9
Don't Know	4

Question #22
 If yes, please specify type of support: (Check all that apply)

Organizational Support	4
Referral	11
Reimbursement	12
Other	0

Question #23
Do your organization use computers?

YES	27
No	3

Question #24
How many do you have?

ranges from 1-15 with the majority having 3 or less

Question #25
What do you use these computers for?

Bookkeeping	19
Membership Information	18
Correspondence	24
Reports	24
Data Collection	18
Desktop Publishing	17
Vocational Training	3

Question #26
Is there a specific person assigned to handle your computer work?

Yes	12
No	18

Question #27
What is his/her job title?

Title	Frequency
Secretary/Clerical	4
Coordinator	3
Executive or Assistant Directors	3
Contracted Consultant	1
HUD Specialist	1

Question #28
Is that person paid, volunteer? (Check all that apply)

Status	Frequency
Paid	11
Volunteer	1
Paid in-kind	0
Full-time	5
Part-time	5
Don't Know	0

Question #29
Are you online?

Yes	9
No	19
Don't Know	2

Question #30
Do you collect or keep data on the members/ service recipients?

YES	25
No	5

Question #31
If yes, please indicate type of data your organization collects. **(Check all that apply)**

MEMBERSHIP INFORMATION	Freq.
Age	16
Race	14
Sex	16
Phone	15
Address	16
Housing	13
Income	7
SERVICE DATA	**Freq.**
Census of Members	19
Service use by members (total)	19
Service use by members (indiv.)	14
Drop-in/Drop-out	6
Other service data	4
MEMBER ASSESSMENT	**Freq.**
Quality Of Life assessments	6
Hospitalizations	9
Functional Skills assessment	6
Employment tenure	6
OUTCOMES	**Freq.**
Empowerment	7
Recovery	3
Independence	6
Well-being	2
Community Integration	4
Physical. Health	2
Program evaluation/satisfaction	13

Question #32

If you collect data, who does the analysis of data in your organization?

> Director and general staff account for all but three. The other three list "all", "outside monitor", and "HUD Staff".

Question #33

Do you collect data on an ongoing basis or only around specific services or needs?

Ongoing	10
Specific	7
Don't know	1
No answer	12

Question #34

How do you use any data you collect? **(Check all that apply)**

Quality improvement	12
Consumer education	7
Grant applications	10
Budget justification	16
Cost containment	6
Advocacy	13
Required reporting	19
Other	1

Question #35

In general, how frequently do you collect this data?

Weekly	5
Monthly	9
Annually	1
Snapshot	2
Continuously	6

Question #36

Do you do this data collection on computers or paper or both?

Computers	4
Paper	7
Both	13
NA	6

Question #37

Do you keep a Masterlist using clients names or do you assign numbers using Unique ID's?

Masterlists	10
Unique ID's	3
Other	3
Both	4
No identifying info.	4
NA	6

Question #38

Do you collect data on everyone or do you select a sample of members?

Everyone	17
Sample	4
Both	3
NA	6

Question #39

Do you have any rules you follow regarding issues of confidentiality in data collection?

Strict confidentiality	18
Try to ensure confidentiality	6
No rules in place	1
No answer	5

Question #40

Has your organization had any training regarding issues of confidentiality in data collection?

YES	19
NO	11

Question #41

What sort of data would you collect if you had the resources?

Responses:

- needs assessment
- little as possible
- service useage
- QOL impact of services
- Population needs assessment
- Outcomes comparison to traditional treatment
- consumer opinion
- less, if possible
- vocational info
- managed care info.
- Subs.Ab. vs. MI vs. Dual Dx info
- MI dx vs. Dual dx
- more on hospitalization
- funding possibilities
- demographic info on clients
- demographic info and funding info

Question #42

Do you think data collection on program members or evaluation activities would discourage people from seeking your services?

YES	11
No	13
Don't know	6

Question #43

Do you think data collection and evaluation is a burden for your organization?

YES	13
NO	16
Don't know	1

Peer Program Data Needs Survey

We have received a three-year grant from the National Institute for Disability Rehabilitation Research (NIDRR) to develop a data collection instrument for community based peer support programs and would like your help by answering a few questions. This project is directed by Jean Campbell, a consumer/survivor researcher at the Missouri Institute of Mental Health. Mental health consumers will participate in all phases of the project. Our goal is to provide community-based peer support programs such as yours with an information system appropriate to your needs and capacities. Ideally, this will enable you to establish the effectiveness of your programs and to meet data collection requirements for funding or service reimbursement. We believe that such an information system is essential to ensure the survival of peer support programs under a system quickly moving towards managed care. Your responses are very important to the success of our project. For your help in answering a few questions, we will send you the data collection instrument, support and training documents, and have technical assistance available when the project is completed.

Please return this fax ASAP to MIMH at (573) 499-0660
Thank you for your help.

Name   _____

Organization   _____

Title/Position   _____

Phone   _____

Address   _____

                  _____

PEER PROGRAM DATA NEEDS SURVEY

1) How would you describe what your organization does? **(Please check all that apply)**

○ Mutual Support ○ Advocacy

○ Living Skills/Daily Activities ○ Arts and Theater

○ Case Management ○ Crisis Counseling

○ Employment Support ○ Hotline

○ Information and Referral ○ Drop-in/ Socialization Prog's

○ Mentoring ○ Other_____

○ Peer Run Residential Prog.s

2) Is your organization part of a larger organization or a group of organizations?

○ No (Unaffiliated) ○ Yes (specify)_____ ○ Don't know

3) If Yes, is your organization part of a.......?

○ local organization

○ state organization

○ national organization

4) How many members/participants does your organization have? _____

5) What sort of model would you say describe the day to day programming? Is it a clubhouse model, a drop-in, more structured.....?

_____

_____

6) Is your organization consumer run?

○partially   ○entirely   ○ Not at all **(stop here)**

7) When was the organization formed? _____

8) Is this when you began providing services?   ○yes   ○no   ○don't know
      if no, when did you begin? _____

9) Who utilizes the services of your organization? **(Check all that apply)**

○Consumer/Survivors

○Family Members of Consumers/Survivors

○Consumer/Survivors with substance abuse problems

○Substance Abuse Clients <u>only</u>

○Survivors of Family Violence

10) Do you have a mission statement? If yes, what is it?

_____

_____

_____

_____

11) In general, what do you see as your organizations key goals? (**Check all that apply**)

○Providing an alternative or supplement to traditional mental health services

○Preventing hospitalization of members

○Meeting basic needs of members

○Providing an alternative to professionally run support groups

○Providing a forum in which to share mental health experiences/mutual support

○Providing rehabilitation/recovery support

○Educating/Empowering clients/survivors

○The development of coping skills

○Crisis support

○Case management

○Vocational training

○Other_____

12) How many people make up your staff and administration? _____

13) Do you utilize full-time, part-time, and/or volunteer staff? (**Check all that apply**)

○full time   ○part time   ○volunteer

14) What are your staff job-titles? (**Check all that apply**)

○Administrators   ○Case Managers   ○Executive Director ○Facilitators

○Advisors   ○Resource Person   ○Clerical   ○Researcher

○Peer Specialist   ○Counselor   ○Evaluator   ○Other_____

15) Do you distinguish between professionals/consumers/survivors?

◯Yes　　　◯No　　　◯Don't know

16) If yes, please indicate which of the positions listed below are professional or consumer/survivor positions with the following:

P= Professional only
C= Consumer only
PC= Professional and Consumer

__Administrators　　__Case Managers　　__Executive Director __Facilitators

__Advisors　　　　__Resource Person　__Clerical　　__Researcher

__Peer Specialist　__Counselor　　　　__Evaluator　__Other

17) Where do you get your funding?**(Check all that apply)**

◯Publicly funded　◯Privately funded　　　◯Non-Profit

◯Local　　　　　　　◯Membership Dues　　◯Foundations

◯State　　　　◯Fundraisers　　　　◯Parent Organization

◯Federal　　　◯Donations　　　　◯Grants

Other (specify) _____

18) Are there any other significant sources of funding which your organization utilizes?

_____

19) How do you evaluate the stability and duration of your program funding?

○ very unstable

○ unstable

○ tenuous

○ stable

20) Please describe what you have planned in the near future regarding funding?

○ phone drives

○ grant applications

○ philanthropic requests

○ other

21) Has your organization considered approaching a managed care organization for support, referral, or reimbursement for services?

○ Yes   ○ No   ○ Don't know

22) If yes, please specify type of support: (Check those which apply)

○ Organizational support

○ Referral

○ Reimbursement per service

○ Other

23) Does your organization use computers?   ○ yes   ○ no

24) How many do you have?_____

25) What do you use these computers for?

O bookkeeping

O membership information

O correspondence

O reports

O data collection

O desktop publishing (newsletter, etc.)

O vocational training

26) Is there a specific person assigned to handle your computer work?

O yes   O no   O don't know

27) What is his/her job title? _____

28) Is that person.......? (Check all that apply)

O paid

O volunteer

O paid in-kind

O full-time

O part-time

O don't know

29) Are you online?   O yes   O no   O don't know

   Online Address; _____

30) Do you collect or keep data on the members/ service recipients?

◯Yes   ◯No   ◯Don't know

31) If yes, please indicate type of data your organization collects. **(Check all that apply)**

Membership information

◯age

◯race

◯sex

◯phone

◯address

◯housing

◯income

◯other_____

Service information

◯overall member census

◯member service use (total)

◯member service use (by individual)

◯drop-out

◯other_____

Member Assessment

○quality of life assessments

○hospitalizations

○functional skills assessments

○employment tenure

Outcomes

○empowerment

○recovery

○independence

○well-being

○community integration

○physical health

○program evaluation/satisfaction

○other_____

32) If you collect data, who does the analysis of data in your organization?

○Director

○Staff

○Member (s)

○Outside Person

○Don't know

33) Do you collect data on an ongoing basis or only around specific services or needs?

❍Ongoing

❍Specific services and needs

❍Don't know

34) How do you use any data you collect? **(Check all that apply)**

❍Quality improvement   ❍Cost containment

❍Consumer education   ❍Advocacy

❍Grant application   ❍Required reporting

❍Budget justification   ❍Other _____

35) In general, how frequently do you collect data?

❍Weekly

❍Monthly

❍Annually

❍snapshot

❍continuously

36) Is data collection done with computers or on paper?

❍Computers

❍Paper

❍Both

❍Don't know

37) Do you keep a Masterlist using clients names or do you assign numbers using Unique ID's?

○Masterlists

○UniqueID's

○Both

○Other

○No identifying information

○Don't know

38) Do you collect data on everyone or do you select a sample of members?

○everyone

○sample of members

○both

○don't know

39) Do you have any rules you follow regarding issues of confidentiality in data collection?

○strict confidentiality protocols

○try to ensure confidentiality through supervision

○no rules in place

○don't know

40) Has your organization had any training regarding issues of confidentiality in data collection?

○yes   ○no   ○don't know

41) What sort of data would you collect if you had the resources?

_____

_____

_____

_____

42) Do you think data collection on program members or evaluation activities would discourage people from seeking your services?

◯yes   ◯no   ◯don't know

43) Do you think data collection and evaluation is a burden for your organization?

◯yes   ◯no   ◯don't know

44) From what other organizations, groups, or agencies do you receive data that you use in your program?

_____

_____

_____

Thank you for completing this survey. A copy of the final results will be mailed to you. Would you fax/send us a copy of any data collection tools or instruments your organization uses?
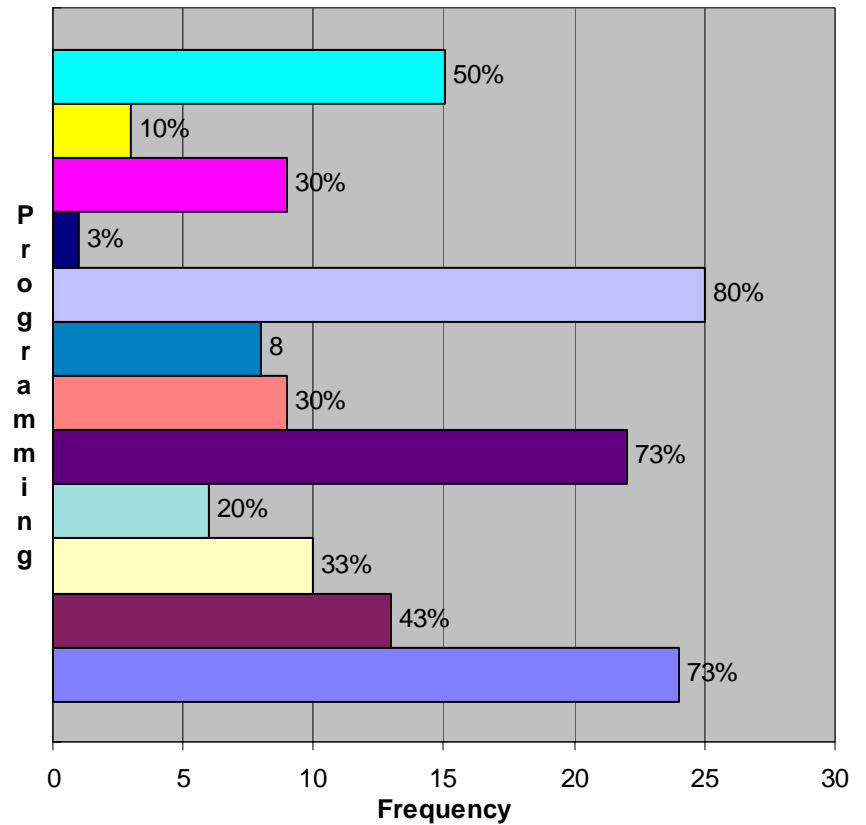
Send instruments to:

Phil Daniels c/o MIMH
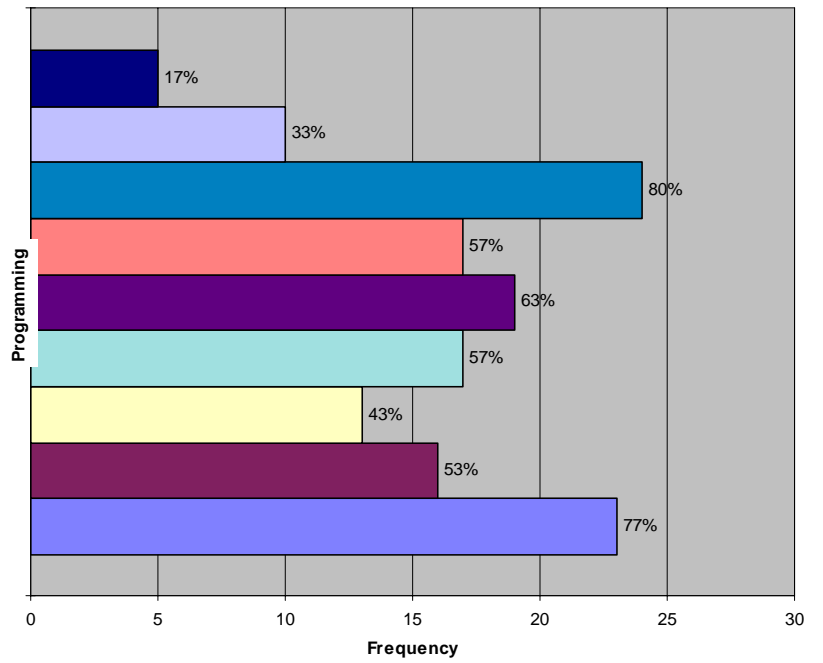*Fax # (314) 644-7934*

SELECTED GRAPHS:

Question #1: How would you describe what your organization does?

Legend:
- Drop-in/Social
- Hotline
- Crisis
- Arts
- Advocacy
- Peer Support Res. Program
- Mentoring
- Information Referral
- Employment Support
- Case Management
- Living Skills/Daily Activities
- Mutual Support

Bar values (Frequency, %):
- Drop-in/Social: 50%
- Hotline: 10%
- Crisis: 30%
- Arts: 3%
- Advocacy: 80%
- Peer Support Res. Program: 8
- Mentoring: 30%
- Information Referral: 73%
- Employment Support: 20%
- Case Management: 33%
- Living Skills/Daily Activities: 43%
- Mutual Support: 73%

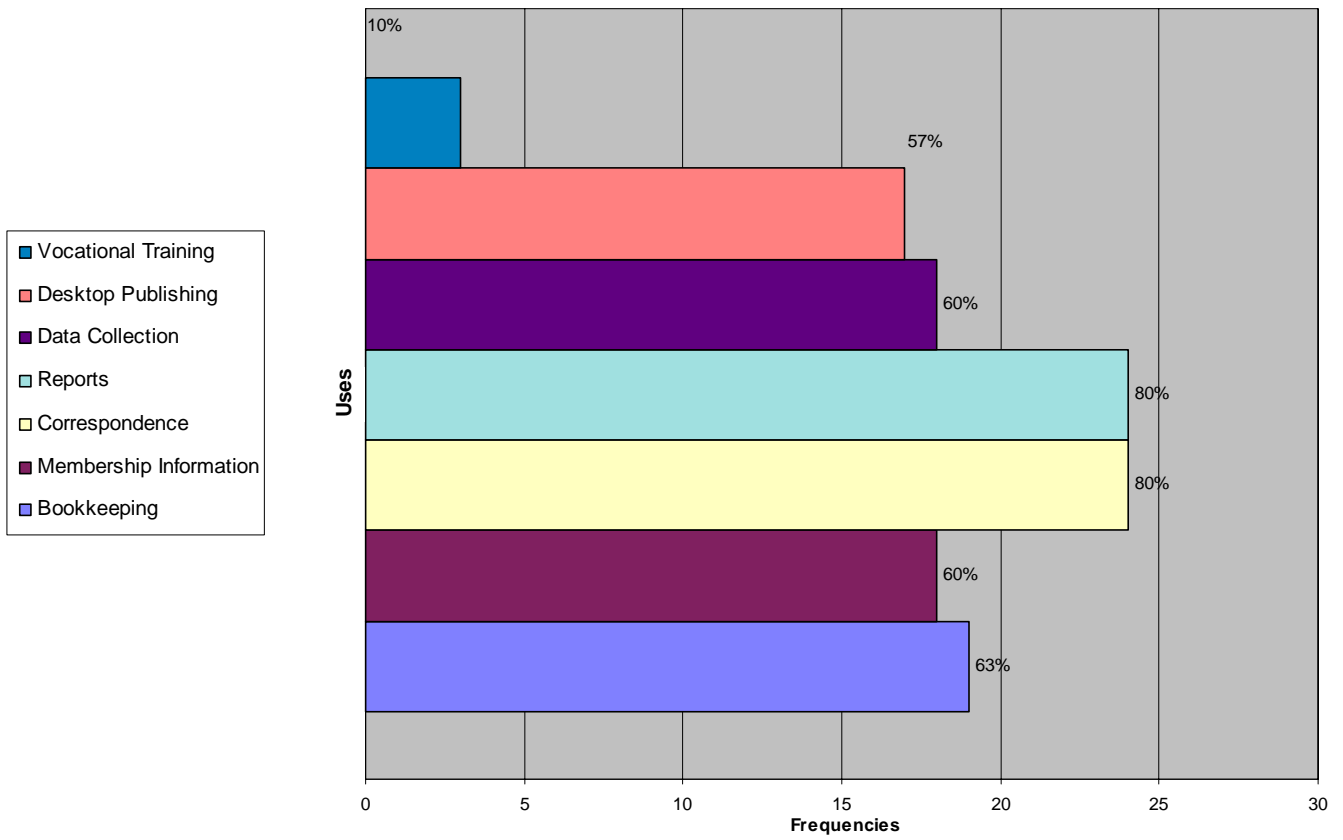Y-axis label: Programming
X-axis label: Frequency

Question #11: What do you see as the key goals of your organization?
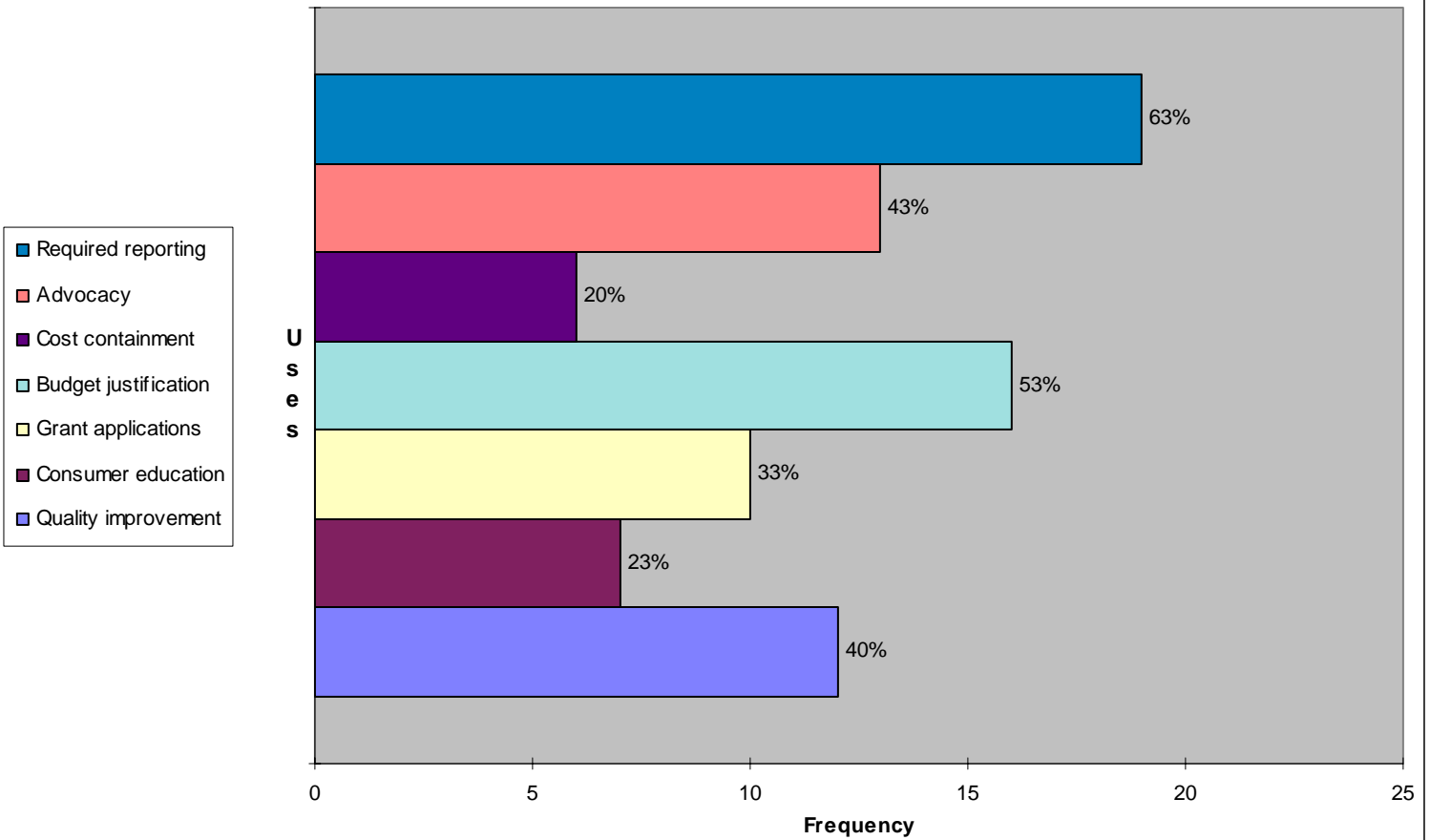
Legend:
- ■ Crisis management
- □ Coping skills
- ■ Education and Empowerment
- ■ Rehabilitation and recovery support
- ■ Providing a forum in which to share mental health experiences
- □ Alternative to professionally run programs
- □ Meeting basic needs
- ■ Prevention of hospitalization
- ■ Alternative to traditional mental health services

Chart (Frequency vs Programming):

- Crisis management: 17%
- Coping skills: 33%
- Education and Empowerment: 80%
- Rehabilitation and recovery support: 57%
- Providing a forum in which to share mental health experiences: 63%
- Alternative to professionally run programs: 57%
- Meeting basic needs: 43%
- Prevention of hospitalization: 53%
- Alternative to traditional mental health services: 77%

X-axis: Frequency (0, 5, 10, 15, 20, 25, 30)
Y-axis: Programming

Question #25: How do you use your computers?

Legend:
- Vocational Training
- Desktop Publishing
- Data Collection
- Reports
- Correspondence
- Membership Information
- Bookkeeping

Data labels:
- 10%
- 57%
- 60%
- 80%
- 80%
- 60%
- 63%

Y-axis: Uses
X-axis: Frequencies (0, 5, 10, 15, 20, 25, 30)

Question #34: How do you use the data you collect?

Legend:
- Required reporting
- Advocacy
- Cost containment
- Budget justification
- Grant applications
- Consumer education
- Quality improvement

Y-axis: Uses
X-axis: Frequency

Values:
- Required reporting: 63%
- Advocacy: 43%
- Cost containment: 20%
- Budget justification: 53%
- Grant applications: 33%
- Consumer education: 23%
- Quality improvement: 40%

Question #42: Do you think data collection on members would discourage people from using your services?

Yes 37%

No 43%

Don't Know 20%

Question #43: Do you think data collection and evaluation is a burden for your organization

Don't Know
3%

Yes
44%

No
53%