

Building Consumer Consensus on Independent Living Using the Concerns Report

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People with mental retardation, brain injury, and psychiatric disabilities constitute fewer than 5% of all consumers receiving services from Independent Living Centers (Jones, Petty, Boles & Mathews, 1986). The focus of this project was to ask these underserved people to identify their independent living needs. The needs identified by these potential Independent Living Center (ILC) consumers will be used to develop interventions and accommodations that will result in increased and improved services.

Consumers were recruited from Community Mental Retardation Centers, Kansas Head Injury Survivors Councils, and Psychiatric Self-Advocacy groups throughout the state of Kansas. Each group received a letter requesting assistance in the recruitment of persons who were either living independently or in the process of learning to live independently. The criteria for nomination of a consumer to be a participant was that the person was in the process of becoming independent, would be able to talk about challenges or barriers to their independence, and would be able to participate in group discussions. Consequently, we were asking for experts on independent living and it should be noted that the consumers were considered consultants because of their level of expertise about the needs of their underserved population. This initial request resulted in the nomination of many more consumers than could be accommodated, therefore, a second letter was sent and a follow-up phone call was made requesting that each group select and nominate a primary representative and an alternate representative. Thus, 121 participants across the three populations were identified and enrolled in the survey portions of their respective conferences (N=52 MR; N=32 BI; N=37 PD). Thus, 121 surveys were sent and 83 were completed and returned for a 69% response rate. The total attendance at the three subsequent conferences was 111 (N=38 MR; N=36 BI; N=37 PD). Each conference participant was considered an expert consultant on this project and reimbursed for their time and travel expenses.

To identify needs, the Concerns Report Method (Fawcett, Suarez de Balcazar, Johnson, Whang-Ramos, Seekins, & Bradford, 1987) was used to identify community strengths and specific consumer needs. The Concerns Report Method (CRM) has been used extensively and successfully for this purpose in the past. As of 1989, this method has been used by more than 17,000 persons with disabilities in urban, inner-city, suburban, and rural communities in 17 different states across the country. The method involves the participation of representative members of a community, who report their concerns about specific issues in their community. These issues are listed in a survey format and then sent to other community members requesting that each person rate each concern on two dimensions. Using a five point, Likert-type rating scale for each dimension, community members report: (1) their estimate of the importance of the issue and, (2) their satisfaction with the community's response to the issue. The rating scales range from not important (a score of 0 pt.) to very important (a score of 4 pt.) and not satisfied (a

score of 0 pt.) to very satisfied (a score of 4 pt.). After the surveys have been circulated, completed, and collected, the point values for each issue are calculated. The point value for each issue is a combined score of relative importance and relative satisfaction. Depending on the point value for an issue, it will fall into one of three categories: (1) a non-important issue, (2) an issue of high importance and high satisfaction, also known as community strength, or (3) an issue of high importance and low satisfaction, considered to be a community need.

This study used three focus groups consisting of consumer-consultants to review the Concerns Report Index of needs (298 issues) for independent living services. The focus groups of consumer-consultants independently reviewed, identified, and selected issues relevant to their lives and their communities. These issues were then compiled, rank ordered, duplicates removed, and incorporated into three survey forms. Thus, a Concerns Report Survey was constructed for each underserved group from the index of issues. These separate surveys were then sent to each consumer-representative according to their membership in each of the participating groups throughout Kansas. The surveys included instructions necessary to score items on the dimensions of perceived importance and estimated satisfaction with their community's responsiveness to each issue. In addition to the written instructions, telephone calls were made to respondents to answer any questions or further explain the scoring procedure. The completed surveys were then analyzed according to the relative importance and satisfaction ratings for each issue.

Once all the surveys were received and analyzed, the consumer consensus conferences were conducted and the survey information was presented to all participants. The Concerns Report Method presents the survey information in a forum designed to promote discussion, consensus, and problem-solving of issues with the participation of all consumers. The conference agendas started with the presentation of community strengths, identified by participants, which established a positive atmosphere and an enthusiastic tone for the meeting.

Concerns Report Survey Community Strengths

The issues that the groups identified as strengths (e.g., high importance and high satisfaction) on the Concerns Report Survey were as follows (due to space limits only the top 6 issues are presented):

Consumers with mental retardation (N=52)

1. I can obtain services for my needs on my own.
2. Landlords respect my privacy and property.
3. Store clerks are friendly and helpful to me.
4. I feel safe from physical harm by others.
5. I can get emergency personal care services, if needed.
6. The physical design of my place allows me to be independent.

Consumers with brain injury (N=32)

1. My family encourages me to be independent.
2. I can successfully speak for my own needs.
3. My family does not isolate me from the community.
4. Handicapped parking is available in shopping areas.
5. I receive social support from my family.
6. Healthcare providers treat me with dignity and respect.

Consumers with psychiatric disabilities (N=37)

1. I feel safe in my home.
2. My treatment has been helpful to me.

3. I have access to local news, happenings, and activities.
4. My mental healthcare providers will answer any questions about my disability or its treatment.
5. Good mental health services are available to me.
6. Independent living centers respect the needs of people from different cultural backgrounds.

These strengths were discussed at each of the conferences in detail and, in most cases, qualifying information about each strength was obtained. As an example, persons with mental retardation stated, "I can obtain services for my needs on my own." as their highest ranked strength. However, through discussion it was found that preliminary steps – consulting with a trusted friend to find the right person to ask about a service, contacting that person, presenting the request, asking for assistance, and enlisting their help – were all part of the process.

Concerns Report Survey Community Needs

The issues that the groups identified as needs (e.g., high importance and low satisfaction) on the Concerns Report Survey were as follows (space allows only the top 6 issues to be presented):

Consumers with mental retardation (N=52).

1. Financial assistance is not available for assistive devices not paid for by Medicare or Medicaid
2. Transportation is not adequate nor available at night.
3. Adequate employment opportunities are not available.
4. Reasonably priced assistive devices (e.g., wheelchairs, braces, hearing aids etc.) are not available to purchase.
5. Transportation to and from events is not available on weekends or holidays.
6. Schools do not teach all students to be sensitive and respect persons with disabilities.

Consumers with brain injury (N=32).

1. Adequate employment opportunities are not available.
2. Adequate career counseling is not available to people with brain injuries.
3. Accessible housing is not available at an affordable cost.
4. Affordable legal help is not available in cases of discrimination or social security appeals.
5. People with recent brain injury need more information about services and programs available to them.
6. Accessible and affordable emergency transportation is not available to persons with brain injuries.

Consumers with psychiatric disability (N=37).

1. A person cannot earn enough money at a job to make up for the loss of disability benefits.
2. Schools do not teach all students to be sensitive and respect persons with disabilities.
3. The media (radio, TV, movies, newspaper) do not portray persons with psychiatric disabilities in realistic ways.
4. Transportation to shopping, medical, and recreation centers is not available when needed (especially at night and on weekends).
5. Most community members do not understand the needs of persons with psychiatric disabilities.
6. School personnel are not sensitive to the needs of students with psychiatric disabilities.

These specific needs were discussed in greater detail during each of the respective conferences, as were the strengths. The top rated concern of all groups involved financial issues. Persons with brain injuries expanded upon the issue of inadequate job opportunities by noting a general lack of support for maintaining a job. Persons with psychiatric disabilities noted that many jobs rarely included prescription benefits and some medications cost more per month than they could afford on their earnings.

Following the identification of community strengths and weaknesses through the use of the Concerns Report Method the study participants were asked to review the issues that the President's Committee on Employment of People with Disabilities had found in 1993. The participants were given the list of 12 issues that the President's Committee had generated and were asked to rank each issue. The following table contains the President's Committee rankings compared with those of consumers participating in these conferences.

Table 1. Rank order of Priorities of the President's Committee on Employment of People with Disabilities Teleconference compared to persons with either mental retardation, brain injury, or psychiatric disabilities.

President's Committee	Persons with m.r.	Persons with b.i.	Persons with p.d.
1. ADA Enforcement & Implementation	2	7	10
2. Health Care	3,4,5	4	1
3. Empowerment & Advocacy	3,4,5	3	5
4. Employment	1	2	4
5. Education	7-12	1	8
6. Personal Assistance	7-12	12	11
7. Transportation	7-12	5	9
8. Housing	6	6	3
9. Mental Health	7-12	9	2
10. Attitudes about disability	7-12	8	7
11. Work Disincentives	7-12	10	6
12. Assistive Equipment	3,4,5	11	12
N = 1200	N = 52	N = 32	N = 37

The President's Committee contacted over 1,200 respondents by teleconference; however, the respondents were not consumers of services. The respondents were mostly administrators of service agencies or advocacy organizations representing a broad spectrum of particular disability groups. Comparing priorities across the groups there are obvious similarities and differences. The similarities among the groups were reflected in the general agreement on issues and the relative importance attributed to them. Of the top six priority issues of President's Committee, five were shared by persons with mental retardation, four by persons with brain injury, and three by persons with psychiatric disabilities. These issues in order of priority for the combined sample were employment, health care, empowerment and advocacy, education, and ADA enforcement and implementation.

The differences between the groups are many. The President's Committee members were heterogeneous in their advocacy areas, representing particular disability groups, but homogeneous in their desire to increase funding for the consumers they serve. As can be seen in Table 1, the President's Committee ranked ADA enforcement and implementation as their number one priority, whereas persons with disabilities selected jobs. The diversity of opinion between these groups may reflect different perspective on the same issue. For example, the enforcement of the ADA will influence employment practices, job availability, and influence community attitudes about persons with disabilities as taxpaying community members.

Another difference between the consumers and the President's Committee was their point of view. Consumers focused on their day-to-day experiences versus the President's Committee, which may have reflected a more issue driven agenda. These differences probably reflect the contingencies in the respondent's environments and how important they are for survival. This finding, differential ranking by group inclusion or social position, will be interesting to explore and might prompt the question, should consumers' high priorities be shared by service staff and administrators?

Conference Resolution and Conclusions

After the Concerns Report results were discussed and the President's Committee issues were ranked, the groups were asked to summarize all of the issues discussed during the conferences. The overall consensus was the following top six issues that people in Kansas want were:

1. Jobs with good pay, meaningful work, and good benefits.
2. Health Care that pays for medical, dental, and prescription services.
3. ADA Laws that support consumers to get and keep jobs and live independently.
4. Schools that prepare people for real jobs and teach other students to respect and treat people with dignity regardless of disability.
5. Housing in safe neighborhoods that is accessible and affordable.
6. Community education which accurately portrays people with disabilities and eliminates stereotypes and stigma.

The Needs Conferences for Underserved Consumers with disabilities using the Concerns Report Method were found to be effective means of: (1) identifying major concerns, (2) prioritizing concerns according to importance and satisfaction, and (3) providing a forum to discuss and explore specific situations which provided a context for the concerns.

While the Concerns Report Method worked, there is need to add items to the CRM Index to better represent the needs of persons from underserved and culturally diverse backgrounds. Secondly, wording of the items in the CRM Index needs to be simplified. A third revision might include alternate forms of the rating scale to be easier to use for more diverse populations. The RTC/IL for Underserved Populations is studying these changes and their validation as a part of its future research agenda. Because consumers identified, discussed, and prioritized key needs and concerns, this information should be valuable for service providers, state planning commissions, and policy makers. Ideally, service providers and advocates will attend to consumer input like business attends to market research. Governmental regulating

agencies or professional accrediting organizations might incorporate consumer participation, evaluation, and satisfaction in certification or accreditation surveys. The RTC/IL is studying these and other ways that the results of the Concerns Report Method can be disseminated and used to resolve community needs.

References

- (1987). *Handbook of the disabled citizens' concerns report method*. The Research and Training Center on Independent Living, and the Institute for Public Policy and Business Research at the University of Kansas.
- (1986). *Independent living: a survey of program and service needs*. *Rehabilitation Counseling Bulletin*, 29(4),278-283.
- (1993). The President's Committee on Employment of the Disabled. Washington, DC: Author.

I. Concerns Report Method --Key Informant Phase
Comprehensive Working Index
(18 Categories N =298)

1. Community integration. N = 18
2. Community safety and accessibility. N=11
3. Community healthcare. N =27
4. Community schools. N = 18
5. Community Employment. N = 22
6. Public transportation. N = 18
7. Community housing. N = 23
8. Community social services. N = 29
9. Personal assistance services. N = 10
10. Counseling services. N =23
11. Community support for families. N=11
12. Accessibility and accommodations provided by retail merchants. N = 17
13. Accessibility and accommodations provided by restaurants. N = 7
14. Accessible communications and News media. N = 15
15. Recreational opportunities and facilities. N = 9
16. Vocational education/rehabilitation services. N = 10
17. Assistive devices. N = 16
18. Consumer advocacy. N = 14

Independent Living

CONCERNS WORKING LIST OF ALL ITEMS

Category	Item	Text
1	1.	You are offered the same opportunity as other citizens to participate in your community.
1	2.	Support and help are available from community members.
1	3.	Your local government responds to your needs in the community.
1	4.	Community members understand the needs of disabled residents.
1	5.	Persons with disabilities are effective in advocating for services, programs, and policies that might benefit them.
1	6.	Resources are provided so that you are offered the same opportunity as other citizens to participate in your community.
1	7.	You are not socially isolated from the community because of your disability.
1	8.	Disabled people in the community communicate with each other.
1	9.	Adequate opportunities are available to interact with other people in your community.
1	10.	Churches are barrier free.
1	11.	Churches are sensitive to the needs of members who have a disability.
1	12.	Public services are provided on an equal basis to persons with a disability and those who are nondisabled.
1	13.	The community understands the needs of persons of short stature.
1	14.	In general, your community is a good place for a person with a disability to live.
1	15.	Persons with disabilities are encouraged and assisted to register to vote.
1	16.	Your VR agency is responsive to the needs of persons with disabilities.
1	17.	Poling places are accessible.
1	18.	People with disabilities can easily cast their vote by absentee ballot when necessary.
2	1.	Your community is a safe place to live.

INDEPENDENT LIVING CONFERENCE QUESTIONNAIRE

For Persons with mental retardation

1. You are offered the same opportunity as other citizens to participate in your community.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

2. You are not socially isolated from the community because of your disability.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

3. You feel safe from physical harm by others.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

4. Affordable health care is available to you.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

5. Dentists, doctors, and general practitioners are educated to work with people with severe disabilities.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

6. Public schools meet the needs of students with disabilities.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

INDEPENDENT LIVING CONFERENCE QUESTIONNAIRE

For Persons with head injuries

7. People with head injuries in the community communicate with each other.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

8. Persons with head injuries are encouraged and assisted to register to vote.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

9. Your VR agency is responsive to the needs of persons with head injuries.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

10. City/county buildings and offices are accessible to citizens with head injuries.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

11. Public buildings are accessible.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

12. Good medical care is available.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

INDEPENDENT LIVING CONFERENCE QUESTIONNAIRE

For Persons with psychiatric disabilities

1. Community members understand the needs of persons with psychiatric disabilities.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

2. Persons with psychiatric disabilities are effective in advocating for services, programs, and policies that might benefit them.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

3. Persons with psychiatric disabilities living in the community communicate with each other.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

4. Your community is a safe place for people with psychiatric disabilities to live.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

5. You feel safe in your home.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

6. You are treated fairly by the police and court officials.

Please circle the number that tells how you feel about the statement above.

0	1	2	3	4	0	1	2	3	4
not				very	not				very
important				important	satisfied				satisfied

II. Concerns Report Method – Survey & Conference Phase Consumers with mental retardation (N = 52)

Community Strengths (e.g., high importance and high satisfaction)

1. I can obtain services for my needs on my own.
2. Landlords respect my privacy and property.
3. Store clerks are friendly and helpful to me.
4. I feel safe from physical harm by others.
5. I can get emergency personal care services, if needed.
6. The physical design of my place allows me to be independent.

Community Needs (e.g., high importance and low satisfaction)

1. Financial assistance is not available for assistive devices not paid for by Medicare or Medicaid.
2. Transportation is not adequate nor available at night.
3. Adequate employment opportunities are not available.
4. Reasonably priced assistive devices (e.g., wheelchairs, braces, hearing aids etc.) are not available to purchase.
5. Transportation to and from events is not available on weekends or holidays.
6. Schools do not teach all students to be sensitive and respect persons with disabilities.

II. Concerns Report Method – Survey & Conference Phase Consumers with brain injury (N = 32)

Community strengths (e.g., high importance and high satisfaction)

1. My family encourages me to be independent.
2. I can successfully speak for my own needs.
3. My family does not isolate me from the community.
4. Handicapped parking is available in shopping areas.
5. I receive social support from my family.
6. Healthcare providers treat me with dignity and respect.

Community Needs

1. Adequate employment opportunities are not available.
2. Adequate career counseling is not available to people with brain injuries.
3. Accessible housing is not available at an affordable cost.
4. Affordable legal help is not available in cases of discrimination or social security appeals.
5. People with recent brain injury need more information about services and programs available to them.
6. Accessible and affordable emergency transportation is not available to persons with brain injuries.

II. Concerns Report Method – Survey & Conference Phase Consumers with psychiatric disabilities (N = 37)

Community Strengths (e.g., high importance and high satisfaction)

1. I feel safe in my home.
2. My treatment has been helpful to me.
3. I have access to local news, happenings, and activities.
4. My mental healthcare providers answer my questions about my disability or RX.
5. Good mental health services are available to me.
6. Independent living centers respect people from different cultural backgrounds.

Community Needs (e.g., high importance and low satisfaction)

1. You cannot earn enough money at a job to make up for the loss of disability benefits.
2. Schools do not teach all students to be sensitive and respect persons with disabilities.
3. The media (radio, TV, movies, newspaper) do not portray persons with psychiatric disabilities in realistic ways.
4. Transportation to shopping, medical, and recreation centers is not available when needed (especially at night and on weekends).
5. Most community members do not understand the needs of persons with psychiatric disabilities.
6. School personnel are not sensitive to the needs of students with psychiatric disabilities.

Table 1. Priorities of the President's Committee on Employment of People with Disabilities Teleconference compared to consumer ranking.

President's Committee	Persons with mental retardation	Persons with brain injury	Persons with psychiatric disabilities
Rankings:			
1. ADA Enforcement & Implementation	2	7	10
2. Health Care	3,4,5	4	1
3. Empowerment & Advocacy	3,4,5	3	5
4. Employment	1	2	4
5. Education	7-12	1	8
6. Personal Assistance	7-12	12	11
7. Transportation	7-12	5	9
8. Housing	6	6	3
9. Mental Health	7-12	9	2
10. Community Attitudes about disability	7-12	8	7
11. Work Disincentives	7-12	10	6
12. Assistive Equipment	3,4,5	11	12
N = 1200	N=52	N=32	N=37

III. Concerns Report Method – Community Action Phase

1. Consumers with mental retardation are in the process of:
 - a. Forming self-advocacy groups on a county by county basis.
 - b. In rural Kansas, some counties are merging their efforts to support "People First" chapters that represent regions such as: southeast, south-central, and northwest Kansas.
 - c. The immediate goal is to send a group of local leaders to a leadership training conference in Rapid City South Dakota in September, 1995.
 - d. The longer term goal is to send a Kansas delegation to the national Self Advocacy Convention, scheduled for July 1996, in Tulsa, Oklahoma.

III. Concerns Report Method – Community Action Phase

2. The Consumers with head injuries decided to:

a. Educate service providers about their experience of independent living through the HCBS waiver program. They attended the Kansas Head Injury Associations State conference and presented their views and action agenda.

b. Address the need for community education about head injury. They have formed a task force and an editorial board which is soliciting anecdotes, poems, cartoons, and art work from members of the Kansas Head Injury Survivors Council for a book about everyday life after a head injury. The main theme is one of hope, optimism, and humor. The RTC/IL will assist with this book as a materials development project.

III. Concerns Report Method – Community Action Phase

3. The Consumers with psychiatric disabilities decided to:

a. Appear and give testimony on behalf of a community shelter program that was brought before the Lawrence City Commission with threat of closure. Consumers advocated for the continuance of the program and eventually prevailed with the program funding reinstated.

b. Consumers have decided to launch a media watch campaign and provide feedback to local newspapers, television, and radio stations regarding the accuracy of depictions of persons with disabilities.

c. Consumers, in conjunction with the media watch campaign, are interested in producing some public education announcements for various media. These spots may appear in newspapers, local theaters, on local cable television channels, and radio announcements.