

Utah Work Incentive Initiative

PAR Survey Results

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Introduction

Since the Utah Work Incentive Initiative (UWIN) began in July 2001, evaluation efforts have focused primarily on conceptualizing and implementing the Participatory Action Research (PAR) model in the project work groups. As its name implies, PAR is a participatory, democratic process. It is a model that allows different groups to work together as equal partners in developing solutions to human problems and improving how systems work for the people who use them. The PAR model, as applied to UWIN, calls for each work group to be comprised of three distinct groups that bring their unique knowledge and expertise to the table: (1) consumers of the services under discussion, which, in UWIN's case, includes both those people who have a disability and are seeking employment, as well as potential employers in the field; (2) providers of those services; and (3) researchers/evaluators.

Facilitators for the UWIN work groups were identified and trained in August and September of 2001, and the work groups began meeting in earnest last October. By January 2002, the Outreach and Training Work Group, the largest and most diverse of the project work groups, had encountered some growing pains, as a relatively inexperienced but at least in terms of the PAR process UWIN staff and work group facilitators struggled to pinpoint problems and find solutions to them. During a brainstorming consultation with Dr. Richard Roberts, UWIN staff and evaluators identified a number of strategies for adjusting the PAR process (e.g., dividing work groups into sub groups, providing information to new work group members outside of meeting times) to achieve project goals. These changes have been successfully implemented across all the work groups, moving them into a deeper level of interaction and productivity, as well as commitment to the PAR philosophy and model.

With the work groups now well established and the PAR process running smoothly, UWIN staff and evaluators thought it would be beneficial to hear directly from work group participants how the PAR process was working for them in their work groups. A survey was designed to capture feedback in an anonymous and confidential manner from service providers/professionals and consumers alike for use by the UWIN Management Team and the Grant Oversight and Evaluation (GOE) Work Group.

Methodology

In June 2002, two surveys were prepared, one for consumers (see Appendix A, page 14), another for non-consumers (see Appendix B, page 21), who participate in the UWIN work groups. To facilitate distribution of the surveys, evaluation staff used an online software program called Zoomerang that was made available through the Utah State Office of Education's State Improvement Grant. Work group participants were sent notification of the PAR surveys via e-mail and were able to log on to a predetermined web site address and respond easily online. Because of the initial low response rate to the survey, individuals who had not responded to the first invitation to participate were resent the survey. In total, 21 consumers and 45 non-consumers were invited to participate in the PAR survey. Consumers who were invited to participate were individuals with

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disabilities, i.e., not employers (who, as indicated above, are also considered consumers within the PAR framework). In addition to UWIN project managers and staff, non-consumers invited to participate were primarily representatives of state, federal, or private agencies providing services to individuals with disabilities and their families.

Results

The final PAR survey response rates were 57.1% (n=12) and 64.4% (n=29) for consumers and non-consumers, respectively.

Table 1 shows survey respondents= participation on the UWIN work groups by type of respondent. The most commonly represented work group among consumers was the Ticket to Work sub-group. Non-consumer participation was greatest on the Benefits Planning Assistance and Outreach (BPA&O) sub-group.

Table 1. Respondents= Participation on UWIN Work Groups

Type of UWIN Work Group on which Respondents Participated	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
Employment Supports	33% (4)	31% (9)	32% (13)
Work Incentives Sub-Group: Medicaid Buy-In	41% (5)	17% (5)	24% (10)
Work Incentives Sub-Group: BPA&O	8% (1)	41% (12)	32% (13)
Work Incentives Sub-Group: Ticket to Work	50% (6)	34% (10)	39% (16)
Outreach and Training	17% (2)	17% (5)	17% (7)
Outreach and Training Sub-Group: Brochure	8% (1)	3% (1)	5% (2)
Outreach and Training Sub-Group: Curriculum/Training	0% (0)	10% (3)	7% (3)
Outreach and Training Sub-Group: Matrix/Dissemination	25% (3)	7% (2)	12% (5)

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Table 2. Number of UWIN Work Groups Respondents Participated On

Number of UWIN Work Groups on Which Respondent Participated	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
None	0% (0)	7% (2)	5% (2)
One	50% (6)	55% (16)	54% (22)
Two	25% (3)	24% (7)	24% (10)
Three	17% (2)	7% (2)	10% (4)
Four or more	8% (1)	7% (2)	7% (3)

In Table 2, the number of work groups on which respondents said they participated is displayed. The majority of both consumers and non-consumers (50% and 55%, respectively) reported being on one work group, while less than 10% of respondents in both groups said they were involved in four or more work groups. Interestingly, two non-consumers reported not participating on any UWIN work group.

As can be seen in Table 3 below, the majority (41%) of all PAR survey respondents reported using the UWIN web site once or twice a month. About 25% of consumers and 17% of non-consumers said they did not use the web site at all. Three non-consumers used the web site less frequently than once or twice a month, e.g., As needed, @ Aevery two months, @ or Awhen notified of minutes and meeting updates. @ Two individuals reported having difficulties accessing the UWIN web site. (See Appendix C, page 28, for a complete list of Aother @ responses.)

Table 3. How Often Respondents Use the UWIN Web Site

Frequency of Use	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
Never	25% (3)	17% (5)	20% (8)
Once or twice a month	25% (3)	48% (14)	41% (17)
Once or twice a week	33% (4)	14% (4)	20% (8)
Every day	0% (0)	3% (1)	2% (1)
Other	17% (2)	17% (6)	17% (7)

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What elements of the UWIN web site respondents reported accessing is displayed in Table 4. Consumers most commonly used the web site to look at their work group minutes (50%) and the UWIN activity calendar (50%), while non-consumers said they viewed the UWIN activity calendar (55%) and current information and articles (41%).

Respondents= suggestions of items that might be added to the UWIN web site included (1) links to more Alike@ web sites; (2) a calendar with training events; and (3) the names, addresses, phone numbers of UWIN staff. Other comments respondents reported relevant to using the web site were (1) difficulties downloading documents and (2) difficulties finding work group information and news.

Table 4. What Respondents Use on the UWIN Web Site

Web Site Item	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
UWIN Work Group minutes	50% (6)	34% (10)	39% (16)
UWIN Activity Calendar	50% (6)	55% (16)	54% (22)
UWIN Participant Information	17% (2)	24% (7)	22% (9)
Description and History of the UWIN Project	8% (1)	14% (4)	12% (5)
Participating Agency Links	8% (1)	14% (4)	12% (5)
Current Information and Articles	17% (2)	41% (12)	34% (14)

Because a great deal of time and effort has been and continues to be invested in taking and producing the UWIN work group minutes, UWIN staff were interested in finding out how often work group participants read them. Half (50%) of consumer respondents reported that they Aalways@ read their work group minutes, compared to 17% of non-consumer respondents. The majority (45%) of non-consumers read their work group minutes Amost of the time.@ While no consumers said that Anever@ read the minutes, 14% of non-consumers admitted that they never read them.

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Table 5. Frequency with Which Respondents Read UWIN Work Group Minutes

Frequency	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
Never	0% (0)	14% (4)	10% (4)
Sometimes	25% (3)	24% (7)	24% (10)
Most of the time	25% (3)	45% (13)	39% (16)
Always	50% (6)	17% (5)	27% (11)

Respondents' perceptions of the usefulness of their work group minutes is shown in Table 6. The majority (58%) of consumers found the minutes very useful, compared to 19% of non-consumers. Sixty-one percent (61%) of non-consumers reported they found the minutes useful. A small percentage of both consumer and non-consumer survey respondents (8% and 4%, respectively) said the work group minutes were not at all useful.

Table 6. Usefulness of UWIN Work Group Minutes to Respondents

Usefulness of Work Group Minutes	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
Very useful	58% (7)	19% (5)	32% (12)
Useful	33% (4)	61% (16)	53% (20)
Somewhat useful	0% (0)	15% (4)	10% (4)
Not at all useful	8% (1)	4% (1)	5% (2)

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Table 7. Respondents= Knowledge of the PAR Model

Statement about the PAR Model	Percentage of Respondents Who Answered Correctly:		
	Consumers	Non-Consumers	All Respondents
Under the PAR model, it is important that employers are involved in the UWIN project.	67% (8)	48% (14)	54% (22)
Under the PAR model, UWIN work groups only set short-term goals; the UWIN Executive Board sets all the long-term goals.	92% (11)	97% (28)	95% (39)
Evaluation in the PAR process is left to the experts.	92% (11)	97% (28)	95% (39)
An important idea in the PAR model is that people who are most affected by change are involved in the change process.	83% (10)	72% (21)	76% (31)
Important values in the PAR approach are self-determination and empowerment.	67% (8)	72% (21)	71% (29)
Participants in the PAR process identify important issues, but are not expected to engage in problem-solving.	100% (12)	97% (28)	98% (40)

It is important for the success of the UWIN project overall that all constituencies—consumers, non-consumers, and evaluators—understand the principles and the importance of the PAR process. A question was included in both the consumer and non-consumer surveys about the PAR model. In Table 7, work group participants’ knowledge of the PAR process is shown. Both consumers and non-consumers showed a good understanding of the PAR model. The area of most confusion for both groups was related to the importance of employer involvement in the UWIN project. Overall, only 54% of survey respondents correctly identified that employers should be involved in the project. A possible explanation for this result is that, because the Employer Work Group has not yet begun to meet, work group participants may have the mistaken impression that this element of the project is not critical. This finding also illustrates the importance of regular and thorough communication with all individuals involved in the project.

Table 8 shows PAR survey respondents’ perceptions of how well prepared they were to participate on a UWIN work group. As can be seen in Table 8, no one reported being over prepared. The majority of both consumer and non-consumer work group participants (58% and 59%, respectively) said they felt somewhat prepared for what they encountered in their work groups,

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and approximately one-third of both consumers and non-consumers felt well prepared. Several consumers and non-consumers, when asked that they found most helpful in their preparation to be on a work group, mentioned their own experience, either work or personal, in the disability field.

Table 8. Respondents= Level of Preparation to Participate on a UWIN Work Group

Level of Preparation	Percentage (n)		
	Consumers	Non-Consumers	All Respondents
Over prepared	0% (0)	0% (0)	0% (0)
Well prepared	33% (4)	31% (9)	32% (13)
Somewhat prepared	58% (7)	59% (17)	58% (24)
Not at all prepared	8% (1)	10% (3)	10% (4)

About 10% of both groups reported that they were not at all prepared for their work group involvement. One consumer who felt not at all prepared said individuals [consumers] and family members were invited to participate [on the work groups] to give balance and the right perspective, but that a little explanation was given. This respondent often felt like a token-member to be tolerated. Said a non-consumer who felt not at all prepared: It depends, what do you mean by >prepared=? Do you mean, was I educated about how the PAR process works? Then no, not really. If you mean, was I given any kind of orientation about how the work group and UWIN work? Then, sort of, but I would have liked a little more orientation.

Respondents were also asked what could have been done to prepare them better for their work group participation. One consumer indicated it would have been helpful to have the UWIN guidebook prior to the first meeting. Similarly, another consumer said, You could have given me a little more detail about the work group before I participated. A non-consumer who joined a work group amid-process also felt orientation to [the] process before [the] first meeting would have been helpful. Another non-consumer suggested that at the beginning of each work group meeting an update on all projects be given so we know what's happening and where everyone is in the process. Commented another non-consumer: I feel that the beginning meeting were vague that the leaders knew the expected outcomes of the project and were waiting for the rest of the group to get to that point. I would have been more comfortable with more structure, direction.

The PAR model brings together and gives equal weight to the voices of all constituencies: consumers, service providers, and evaluators. For some UWIN work group participants, this approach is neither new or radical; others, however, are new to the PAR process and, for them, it may feel somewhat unnatural to have consumers or to be a consumer at the table. UWIN staff and

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evaluators thought it was important to assess both consumers= and non-consumers= perspectives of having consumer involvement in UWIN work groups. Consumers were asked to comment on how comfortable they felt participating on their work groups, while non-consumers were asked how effective they perceived consumer participation to be.

As can be seen in Table 9, the majority of consumer respondents (55%) said they felt Avery comfortable@ participating on their work groups, while 27% said they felt Acomfortable.@ No one reported feeling Anot at all comfortable;@ however, one consumer perceived that his/her ideas were thought of as Atrivial@ in his/her work group.

Table 9. Consumers= Level of Comfort in Participating on UWIN Work Groups

Level of Comfort	Percentage (n)
Very comfortable	55% (6)
Comfortable	27% (3)
Somewhat comfortable	18% (2)
Not at all comfortable	0% (0)

On the flip side, Table 10 shows non-consumers= perceptions of the effectiveness of consumer participation on the UWIN work groups. While over half (54%) of non-consumers felt that consumer participation was either Avery effective@ or Aeffective,@ 35% of them rated it only as Asomewhat effective.@ Eleven percent (11%) of non-consumer respondents rated consumer participation as Anot at all effective.@ Only one individualBwho reported being on the BPA&O subgroupBprovided any explanation for this perception, stating that Aconsumers rarely attend meetings.@

Both groups of respondents were asked whether they felt they had contributed to their UWIN work groups. As can be seen in Table 11, the majority (95%) of consumers answered Ayes@ to this question, while only 69% of non-consumers felt they had made a contribution.

In terms of the specific contributions consumers felt they had made to their work groups, one individual said that Abecause I am a client in the system, I believe that I have a unique outlook and firsthand experience on how to look at issues.@ Commented another: AI make them think about things in a different vein. Most of them are professionals in the field doing the same things they have done for years and they seem to have a hard time >getting out of the box.=@ One consumer felt Aknowledge through my own disabilities and the obstacles faced a result@ were what he/she brought to the table.

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Table 10. Non-Consumers= Perceptions of the Effectiveness of Consumer Participation on Work Groups

Level of Effectiveness	Percentage (n)
Very effective	31% (8)
Effective	23% (6)
Somewhat effective	35% (9)
Not at all effective	11% (3)

Table 11. Respondents= Perceptions of Whether They Contributed to Their Work Groups

	Percentage (n) who Answered AYES@:		
	Consumers	Non-Consumers	All Respondents
ADo you think you have contributed to your work group?@	92% (11)	69% (20)	82% (31)

Non-consumers, too, felt their contributions were related to their own knowledge and experience. ATechnical information,@ Aknowledge of programs and resources,@ Aeducation about rural issues and mental health,@ Aexpertise in specific areas,@ and Aissues particular to people with mental illness@ were examples of what non-consumers felt they had contributed to their respective work groups.

Respondents were also asked what contributions they felt their work groups were making to the UWIN project overall. Forty percent (40%) of non-consumers and 92% of consumers responded to this question. While one non-consumer was Aunsure at this time@ what that overall contribution was, most non-consumers linked their work group contributions to the group=s specific area, e.g., Ahelping with work incentive outreach and training,@ Ahelping PAS [Personal Assistance Services] become a reality in the state,@ Aarranging training for BPA&O specialists.@ One saw Amany groups and agencies coming together, even though the beginning of the road was rough. It feels like progress is happening and some of the expectations I believed in are beginning to occur.@ Another non-consumer concluded that Awork groups are vital to the overall process and contribute to the >systems change.=@ A consumer noted that Athe ideas which were put forth [in the work group] are now being incorporated into training, and trial training groups are being held.@ Observed another consumer: AI think we are making progress to streamline the application and evaluation process and to make the process consumer-friendly.@

Finally, work group participants were asked for suggestions for improving the UWIN work

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groups on which they participate. Twenty-five percent (25%) of non-consumers and 50% of consumers responded to this question. One consumer wanted to see more participation in the UWIN process from employers. Another saw the need for a better organization and purpose in work group meetings, as well as more follow-through after meetings. Along these same lines, a non-consumer saw the need for a better preparation and planning prior to the [work group] meeting. Commented another non-consumer: It would serve the goals of UWIC more effectively if persons who attended meetings did not digress and parties followed an agenda. And if the...work group decided the time/location of the next meeting and put it in the notes, I would be able to have time to reserve my calendar. One non-consumer put things in perspective as follows: We have had our rocky moments, but with the direction and help from staff for the group, we have moved ahead. It is difficult to schedule one more meeting into a person's schedule, but the dedication of the group has been impressive.

Summary and Recommendations

In spite of some initial rough going, which is perhaps best viewed as not-unexpected growing pains, the PAR process appears to have taken hold in the various UWIN work groups and to be running smoothly. As indicated by their responses to this survey, work group participants—consumers and non-consumers alike—seem to grasp the theory and logic behind the PAR process and to support its application to UWIN. Most importantly, consumers are bringing their perspectives, experience, and expertise to the table, which is a major goal not only of the PAR process, but of the UWIN project overall.

Consumer Participation

Somewhat disconcerting, however, is the perception of some non-consumers of the effectiveness of consumer participation on the UWIN work groups. As noted above, 35% of non-consumers (nine individuals) rated consumer participation as somewhat effective, while 11% (three individuals) rated it as not at all effective. Further investigation revealed one of the three individuals who rated consumer involvement as not at all effective did not indicate the work group to which he or she belonged. Of the two respondents who did list their work groups, one was a member of the BPA&O Sub-Group and the other a member of the Ticket to Work Sub-Group.

Of the nine individuals who rated consumer participation as somewhat effective, three were members of the Employment Supports Work Group, two were members of the BPA&O Sub-Group, one was a member of the Medicaid Buy-In Sub-Group, one indicated membership on both the BPA&O and Medicaid Buy-In Sub-Groups, and one indicated membership on both the BPA&O and Ticket Sub-Groups. (One of the nine respondents did not list his or her work group.)

Thus, the most frequently mentioned group where consumer participation was rated either somewhat effective or not at all effective was the BPA&O Sub-Group (five mentions), followed by the Employment Supports Work Group (three mentions) and the Medicaid Buy-In and Ticket Sub-Groups (two mentions each). UWIN staff should explore the situation with each of these

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work groups and determine if the unfavorable ratings of consumer participation might be the result of the *level* of consumer participation. For example, someone may be rating consumer participation as *Asomewhat effective@* or *Anot at all effective@* because few, if any, consumers are attending those particular work group meetings. Regardless of the perceptions non-consumers have of the effectiveness of consumer participation, it is worth noting that 92% of consumers surveyed perceived that they had contributed to their work groups, while only 69% of non-consumers felt that they had made contributions.

Work Group Functioning

Recommendations for improving the functioning of UWIN work groups can be gleaned from survey responses to open-ended questions relating to work group minutes, to preparation received prior to serving on a work group, and to specific suggestions survey respondents made for work group improvement. Based on this survey information, UWIN staff should consider the following:

- B** Preparing new work group members more thoroughly prior to their actual participation. This could be accomplished by sending new members, in advance of their first meeting, an abbreviated UWIN orientation *Apacket@* tailored to that particular work group. The new member could also be encouraged to visit the UWIN website prior to his or her first meeting.

The orientation packet should include a work group *Acharter@* that states the mission of the work group and places the work group in the context of the larger UWIN project. (These documents were drafted for several work groups early on but should be revisited to ensure all work groups are covered.)

- B** Working with work group co-facilitators to develop agendas for each work group meeting and having written agendas available for distribution at each work group meeting. If feasible, the agenda could be sent out to work group members in advance of the meeting.
- B** Sending notices or reminders of all major work group meetings at least two weeks in advance of meetings. It should be kept in mind that some meeting dates are set at the last meeting, so people who weren't there will not have it scheduled. These individuals should be notified of the next meeting date and time as soon as possible.
- B** Reviewing all work group attendance records to date, then contacting the habitual *Anon-attenders@* to gauge their continued interest in serving on their particular work group(s). This attendance review would also serve to assure that adequate representation of all three PAR participant groups is maintained (i.e., consumers, providers, evaluators). If any of these three groups is *not* represented, whether through non-attendance or attrition, then the proper balance will need to be restored to ensure that the PAR process is being honored.

UWIN Website

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Thirty-nine percent of all respondents indicated using the UWIN website to view work group minutes, and more than half of all respondents (54%) said they used the website to view the UWIN activity calendar. Forty-one percent of non-consumers said they used the website to access current information and articles. While this usage is encouraging, there remains a large group of individuals who do not access the UWIN website all that frequently. Twenty percent of all respondents said they never used the website, and 41% said they used it just once or twice a month. Given these findings, UWIN staff should:

- B Continue to improve the website in an effort to make it more accessible to work group participants.
- B Update the site continually with current information so that those individuals who are accessing it on a regular basis will continue to do so.
- B Use upcoming work group meetings to determine who is having difficulty accessing the website and record the nature of those difficulties. This will allow UWIN staff to provide technical assistance as necessary to those who wish to access UWIN information via the website but are having problems doing so.

Employer Involvement

As noted in the introduction to this report, under the PAR model, employers are considered to be consumers and, thus, are expected to participate on the various UWIN work groups. However, most work groups do not address issues that are directly relevant to employers, the exceptions being the Outreach and Training Sub-Group dealing with the UWIN media campaign and the Employment Supports Work Group (to the extent that the latter deals with such things as work site supports and reasonable accommodations). To uphold the PAR process, these two work groups should involve employers. Moreover, once the last UWIN work group, Employer Involvement, is formed, it should include, in keeping with the PAR process both consumers (i.e., individuals with disabilities) and an evaluator.

Conclusion

On the whole, PAR survey results affirm the choice made to adopt the PAR model for the design, implementation, and evaluation of the various UWIN interventions. The PAR process is working, and consumers and non-consumers feel they are making important contributions to the UWIN effort. It would be beneficial, nearly a year into the PAR process, to have work groups take the time in an upcoming meeting to assess and celebrate their accomplishments and effectiveness to date. A brief overview of the PAR survey results could be given, and work group members, especially those who did not respond to the survey, could be given the opportunity to suggest specific improvements they would like to see in their individual work groups. This exercise, which revisits the first step in the PAR process, taking stock, can provide valuable additional input for consideration by UWIN staff.

Appendix A.

Survey of UWIN Work Group Participants (Non-Consumers)

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Survey of UWIN Group Participants (Non-consumers)

1. Please tell us which UWIN work group(s) and sub-groups you are on. Choose all that apply.

- Employment Supports
- Work Incentives Sub-group: Medicaid Buy-In
- Work Incentives Sub-group: BPA&O
- Work Incentives Sub-group: Ticket to Work
- Outreach and Training
- Outreach and Training Sub-group: Brochure
- Outreach and Training Sub-group: Curriculum/Training
- Outreach and Training Sub-group: Matrix/Dissemination

2. How often do you log on to the UWIN web site?

- Never
 - Once or twice a month
 - Once or twice a week
 - Every day
 - Other, Please Specify
-

3. What do you usually use the Web site for? Choose all that apply.

- UWIN Work Group Minutes
 - UWIN Activity Calendar
 - UWIN Participant Information
 - Description and History of the UWIN Project
 - Participating Agency Links
 - Current Information and Articles
 - Other, Please Specify
-

4. Is there anything else that should be added to the web site?

5. Do you read your work group minutes?

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- Never
- Sometimes
- Most of the time
- Always

6. If you answered “Never” to question # 5, please explain.

7. How useful do you find your work group minutes?

- Very Useful
- Useful
- Somewhat useful
- Not at all useful

8. If you answered “Not at all useful” to question # 7, please explain.

9. The UWIN work groups are set up under the Participatory Action Research (PAR) model. Which of the following statements are true about the PAR process? Check all that apply.

Under the PAR model, it is important that employers are involved in the UWIN project.

Under the PAR model, UWIN work groups only set short-term goals only; the UWIN Executive Boards sets all the long-term goals.

Evaluation in the PAR process is left to the experts.

An important idea in the PAR model is that people who are most affected by change are involved in the change process.

Important values in the PAR approach are self-determination and empowerment.

Participants in the PAR process identify important issues, but are not

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expected to engage in problem-solving.

10. How well prepared were you to participate on a UWIN Work Group?

- Over prepared
- Well Prepared
- Somewhat prepared
- Not at all Prepared

11. If you answered "Not at all prepared" to question #10, please explain.

12. What did you find most helpful in your preparation to be on a work group?

13. What could we have done to prepare you better for your work group?

14. How effective do you feel consumer participation has been on your work group(s)?

- Very effective
- Effective
- Somewhat effective
- Not at all effective

15. If you answered "Not at all effective" to question #14, please explain.

16. Do you think you have contributed anything to your work group?

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_____ YES _____ NO

17. If you answered “yes” to question #16, please explain.

18. What contribution(s) do you see your work group(s) making to UWIN overall?

19. Do you have any suggestions for improving the UWIN work Group(s) you participate on?

Appendix B.

Survey of UWIN Work Group Participation (Consumers)

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Survey of UWIN Work Group Participants (Consumers)

1. Please tell us which UWIN work group(s) and sub-groups you are on. Choose all that apply.

- Employment Supports
- Work Incentives Sub-group: Medicaid Buy-In
- Work Incentives Sub-group: BPA&O
- Work Incentives Sub-group: Ticket to Work
- Outreach and Training
- Outreach and Training Sub-group: Brochure
- Outreach and Training Sub-group: Curriculum/Training
- Outreach and Training Sub-group: Matrix/Dissemination

2. How often do you log on to the UWIN web site?

- Never
 - Once or twice a month
 - Once or twice a week
 - Every day
 - Other, Please Specify
-

3. What do you usually use the Web site for? Choose all that apply.

- UWIN Work Group Minutes
 - UWIN Activity Calendar
 - UWIN Participant Information
 - Description and History of the UWIN Project
 - Participating Agency Links
 - Current Information and Articles
 - Other, Please Specify
-

4. Is there anything else that should be added to the web site?

5. Do you read your work group minutes?

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- Never
- Sometimes
- Most of the time
- Always

6. If you answered “Never” to question # 5, please explain.

7. How useful do you find your work group minutes?

- Very Useful
- Useful
- Somewhat useful
- Not at all useful

8. If you answered “Not at all useful” to question # 7, please explain.

9. The UWIN work groups are set up under the Participatory Action Research (PAR) model. Check the following statements that are TRUE.

Under the PAR model, it is important that employers are involved in the UWIN project.

Under the PAR model, UWIN work groups only set short-term goals only; the UWIN Executive Boards sets all the long-term goals.

Evaluation in the PAR process is left to the experts.

An important idea in the PAR model is that people who are most affected by change are involved in the change process.

Important values in the PAR approach are self-determination and empowerment.

Participants in the PAR process identify important issues, but are not

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expected to engage in problem-solving.

10. How well prepared were you to participate on a UWIN Work Group?

- Over prepared
- Well Prepared
- Somewhat prepared
- Not at all Prepared

11. If you answered "Not at all prepared" to question #10, please explain.

12. What did you find most helpful in your preparation to be on a work group?

13. What could we have done to prepare you better for your work group?

14. How comfortable do you feel speaking in your work group(s)?

- Very comfortable
- Comfortable
- Somewhat comfortable
- Not at all comfortable

15. If you answered "Not at all comfortable" to question #14, please explain.

16. Do you think you have contributed anything to your work group?

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_____ YES _____ NO

17. If you answered “yes” to question #16, please explain.

18. What contribution(s) do you see your work group(s) making to UWIN overall?

19. Do you have any suggestions for improving the UWIN work Group(s) you participate on?

Appendix C.

Responses to Open-Ended Survey Questions

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ID Q4. Is there anything else that should be added to the web site?

NON-CONSUMERS (n=6):

- 6 Links to more Alike@ web sites.
- 8 Last time I looked, I couldn't find names, addresses, phone numbers of staff but that was many weeks ago.
- 9 Not yet used the site.
- 13 Not at this time.
- 15 Calendar with training events.
- 16 I think that it would be most helpful if it was clearer where an individual could go for work group information and news. A better separation of purpose.

CONSUMERS (n=3):

- 34 Not that I can think of.
- 36 Often unable to download attachments.
- 41 Current.

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ID Q6. Please explain why you never read the meeting minutes.

NON-CONSUMERS (n=6):

- 4 If the minutes from the meeting before are sitting on the table when I come in for the next month=s meeting, I will read them then. But I never go to the website to read the minutes.
- 7 I don=t think I get them.
- 8 I did not know until the last meeting that they would be posted on the site. If the list serv messages that come every other week saying Areminder@ provided a notice that minutes were posted, this would be helpful reminder.
- 9 Not a regular participant.
- 13 Not at this time.
- 17 Have never seen them.

CONSUMERS (n=1):

- 34 I look.

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ID Q8. Please explain why you do not find the minutes useful.

NON-CONSUMERS (n=1):

9 Never received any minutes to review.

CONSUMERS (n=1):

37 Time spent in other volunteer activities.

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ID Q11. Please explain why you answered A not at all prepared@ to Q10.

NON-CONSUMERS (n=5):

- 5 It depends, what do you mean by Aprepared@? Do you mean, was I educated about how the PAR process works? Then, no, not really. If you mean, was I given any kind of orientation about how the work group and UWIN work? Then, sort of, but I would have liked a little more orientation. If you mean, did I come into the work group with the education and training necessary to be a contributing member? Then, mostly, although I learned along the way.
- 10 N/A.
- 20 My knowledge level of the issues, PAR process, purpose(s) of the project, expected outcomes were at a very low level. I wasn't sure why I was invited to participate, other than as a representative of a particular group.
- 25 Have had frequent conflicts with meeting schedule, e-mail requests for information are not responded to.
- 27 I have not been available due to work load to participate as often as I would like at meetings so I do not feel that I am very helpful or even part of the group.

CONSUMERS (n=1):

- 40 To give balance and the right perspective, individuals and family members were invited and little explanation was given. Often felt like a 'token' member to be tolerated.

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ID Q12. What did you find most helpful in your preparation to be on a work group?

NON-CONSUMERS (n=16):

- 2 Work experience.
- 4 Asking about how the process worked and asking where everything fit in.
- 6 Handouts and information that I can take back to the office.
- 8 General background on UWIN, previous large group meetings providing context.
- 9 N/A
- 10 The documents provided to give me an understanding of the project and the group=s role in that process.
- 11 The notebook and orientation.
- 12 Learning the history of UWIN and the vision for the future then using that information to determine where I could contribute best.
- 13 Communication with other members and leaders.
- 14 Work experience.
- 15 The opportunity to hear issues and concerns from other individuals who saw it differently.
- 18 OverviewBbig picture.
- 19 BPA&O workgroup retreatBI finally figured out what our task is.
- 20 Minutes and training groups.
- 27 Reviewing the prior notes.
- 29 Experience in employment issues.

CONSUMERS (n=9):

- 30 The respect given to each participant as they gave input. Consumers are given even status to professionals. All are important.
- 31 Past experience.
- 34 Having info on how to be.
- 35 Prior work experience.
- 36 Some background in disability field.
- 37 Being awareBthrough experienceBof obstacles of employment.
- 39 My knowledge gained from my personal experiences and my ability to work with all types of personalities.
- 40 To be to the meetings and ask questions anyway.
- 41 Thinking.

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ID Q13. What could we have done to prepare you better for your work group?

NON-CONSUMERS (n=16):

- 2 Explain all agencies= involvement.
- 4 Provide me with more orientation on how the process works, how everything fits together, what to expect from a meeting, etc.
- 6 At the beginning of each meeting give an update on all projects so we know what happening and where everyone is in the process.
- 8 I need to learn a lot more about Medicaid.
- 9 N/A.
- 11 While in the subgroups, go over more of the history or details for that particular subgroup.
- 13 I think more written materials written by specialist in the area.
- 14 More understanding about the purpose and goals of the group.
- 15 Nothing.
- 18 Clearer expectations.
- 19 I feel that the beginning meetings were vagueBthat the leaders knew the expected outcomes of the project and were waiting for the rest of the group to get to that point. I would have been more comfortable with more structure, direction.
- 20 More guidance/structure.
- 24 Orientation to process before first meeting (I joined mid-process).
- 26 Know the time commitment expectations to be able to attend and be a part.
- 27 The last meeting I attended, the people did not discuss anything except what UWIN/UWIC were so we didn=t get very far.
- 29 A better overall description of the issue.

CONSUMERS (n=6):

- 30 A little more pre-knowledge about what the program was about and what was hoped to be accomplished.
- 35 Provided 'Guide for work group members' before first meeting.
- 37 Make sure all participants are able to hear the discussion.
- 39 You could have given me a little more detail about the work group before I participated.
- 40 Spent time in a smaller group explaining the background and purpose for the group, where it came from, its duration, etc.
- 41 More information.

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ID Q15. Please explain why you feel that consumer participation has been ANot at all effective.@

NON-CONSUMERS (n=3):

9 N/A.

19 Consumers rarely attend meetings. Perhaps they feel as Aout of the loop@ as I have felt.

27 My busy schedule often is filled before I know when the next meeting is. I=ve missed several meetings.

ID Q15. Please explain why you have felt ANot at all comfortable@ in your work group(s).

CONSUMERS (n=1):

33 Sometimes I feel like my ideas are thought of as trivial.

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ID Q17. Please explain what you feel you have contributed to your work group(s).

NON-CONSUMERS (n=18):

- 2 Technical information.
- 3 I offer a link to the agency that has been missing, providing accurate information for input.
- 4 Well, I suppose that on occasion I have made sure we addressed significant issues that may have been neglected. I have tried to make comments that would increase the amount of value we could get out of the meeting.
- 5 Knowledge of programs and resources.
- 6 I think that if you're not at these meetings your Division and the people that you represent may be overlooked. Some people seem to have their own ideas about how this should all work out so it is good to have a forum to talk about different ideas. We need to make sure that people feel comfortable in talking and sharing ideas.
- 9 N/A.
- 10 Explored the impact of PAS for those with a mental illness.
- 11 I feel everyone needs to understand the issue and be willing to put some work into the issue since there is limited funding.
- 12 Education about rural issues and mental health.
- 13 My ideas and visions of consumer-sensitive services and programs.
- 14 I feel that my work experience has been of value to the groups.
- 16 I try and be prepared to help the program as best as I can at each meeting, because of that I feel that I have received many duties and responsibilities.
- 18 Expertise in specific areas.
- 19 Life does not begin at 22, when students leave the education system. It seems that agency representatives frequently forget that. I feel that I serve as a reminder that Ayoung@ adults will be clients of these agencies in the near future, and consideration should be given to their needs and interests.
- 20 The voice of an advocate has been heard.
- 21 A ton.
- 22 My knowledge of resources and of the work incentives offered.
- 29 Issues particular to people with mental illness.

CONSUMERS (n=11):

- 30 I was able to give input from both consumer and IL aspects. Ideas were always given thought to. Some were adopted, some rejected, but never without group discussion.
- 31 A consumer=s perspective.
- 32 I have tried to bring the concept of Independent Living philosophy into all discussions.
- 33 Some good ideas.
- 34 Some of my comments help.
- 36 Represent advocate/family view point.
- 37 Knowledge through my own disabilities and the obstacles faced as a result.
- 38 I feel able to add insight, report from the advocacy side as well as consumer advocate with

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- very close daily contact.
- 39 Because I am a client in the system I believe that I have a unique outlook and firsthand experience on how to look at issues.
- 40 I make them think about things in a different vein. Most of them are professionals in the field doing the same things they have done for years and they seem to have a hard time 'getting out of the box'.
- 41 Significant impact on group directions, conceptions, and implementation.

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ID Q18. What contribution do you see your work group(s) making to UWIN overall?

NON-CONSUMERS (n=15):

- 2 Helping with work incentive outreach and training.
- 3 Assuring accurate, consistent information is being circulated.
- 6 We are working out some ideas about BPA&O. I hope people are saying what they think during the meeting.
- 9 N/A.
- 10 Helping PAS become a reality in the state.
- 12 Arranging training for BPA&O specialists which, in turn, will offer clients multiple choices in career planning and how that planning will support future career goals.
- 13 We are beginning to build a unified structure.
- 14 Providing far-reaching information and recognizing where the training needs are. Developing a standard for BPA&O.
- 15 Individuals with disabilities, executive directors, and staff at all levels have had opportunity to have input...doing together and not Ato.@
- 16 I see many groups and agencies coming together, even though the beginning of the road was rough. It feels like progress is happening and some of the expectations I believed in are beginning to occur.
- 18 Work groups are vital to the overall process and contribute to the A systems change.@
- 19 Perceived loss of benefits can be a major barrier to an individual (or his/her family) considering employment. Hopefully this work group will be instrumental in developing a system to enable more prospective employees to learn about work incentives.
- 20 Guidance from advocates.
- 26 Unsure at this time.
- 29 Personal assistance reimbursement model that will meet the needs of all disabled people.

CONSUMERS (n=10):

- 30 The ideas which were put forth are now being incorporated into training and trial training groups are being held.
- 31 Enhanced services.
- 32 I think we are making progress to streamline the application and evaluation process and to make the process consumer friendly.
- 34 Input that will be effective.
- 35 Part of the whole.
- 37 Understanding areas of eligibility for those who need services.
- 38 Data collection, advocacy at legislative as well as grassroots level.
- 39 Together we can divide and conquer the world.
- 40 ?
- 41 Keeping rooted in mission.

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ID Q19. Do you have any suggestions for improving the UWIN work group(s) you participate on?

NON-CONSUMERS (n=11):

- 4 Better facilitating, prepared agendas, more effective use of time as a result of better preparation and planning prior to the meeting.
- 6 Send the minutes via e-mail a few days before the meeting to the members of the committee.
- 8 I need guidance on what we should accomplish then it will be possible to figure out how to make some useful contribution.
- 9 Not at the present time.
- 10 We have had our rocky moments but with the direction and help from staff for the group, we have moved ahead. It is difficult to schedule one more meeting into a person's schedule but the dedication of the group has been impressive.
- 12 Meet monthly for a longer period of time. Requires a lot of travel twice a month for out of town participants.
- 13 Pre-planned agendas.
- 18 Possible using audioconferences more frequently.
- 19 Give me a specific task to complete!! I am much happier when I am busy.
- 20 Regular updates.
- 27 It would serve the goals of UWIC more effectively if persons who attended meetings did not digress and parties followed an agenda. And if the meeting work group decided the time/location of the next meeting and put it in the notes I would be able to have time to reserve my calendar.

CONSUMERS (n=6):

- 31 Continued open discussions.
- 34 No.
- 35 Not at this point.
- 37 More participation by those individuals who are employers.
- 40 Better organization and purpose in meetings and follow through.
- 41 More information for participants. Helping participants realize they can have a significant impact.