

2004 COMMUNITY PRACTICE REVIEW

NORTHWEST REGION REVIEW- FINDINGS

Jackson v. Ft. Stanton

Thank You!

I owe and extend my appreciation and gratitude to the Jackson Class Members, their families, guardians, friends, case managers and providers/staff who support them for their willingness to participate and provide information. All of the reviewers were extremely grateful for your openness and generous sharing of your time.

I would like to extend a special thank you to Crystal Wright, Northwest (NW) Regional Program Manager, Mike Renaud, Shirl Roper-Hardman, Dennis O'Keefe, Edna Ashley and Louise Thomas who assisted in preparing, carrying out and following up on the NW Review. They also did a masterful job of arranging the 65+ interviews.

I want to extend my sincere appreciation and gratitude to the reviewers and their managers from DHI and LTSD. Each of these individuals worked hard to be fair, accurate and thoughtful during the review interviews, scoring and write-up. I look forward to working with all of you again.

Donna Storey, DHI, Pat Syme, LTSD, Paul Schwalje, LTSD and Keytha Jones, Community Monitor's Office, faithfully joined me in participating in and learning from the regional provider meetings. Thanks to Pat and Paul some lingering unresolved issues got resolved. Donna chaired these meetings and followed up with providers on questions regarding the Community Practice Review Protocol as well as questions regarding standards or regulations. Keytha joined with Regional Office staff, providers and Paul to attempt to resolve the immediate and special needs issues. Thanks to all of you for attempting to get people the things they need.

Edna Ortiz was and continues to be an invaluable asset in the review of data. Her unwavering willingness to reflect on past "rationale for scoring" and to explain the data analysis and reasoning of the past to ensure continuity with today was and is invaluable.


Lyn-Rucker, Community Monitor

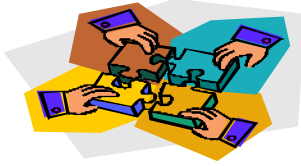


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I. INTRODUCTION AND REVIEW OF METHODOLOGY

The 2004 Community Practice Review of the Northwest (NW) Region consisted of four phases. Each phase and its focus are outlined below.

Phase I	Sample Selection, Review Preparation	April 19, 2004 to May 6, 2004
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During this time, generally, the following activities took place:

- The Regional Office provided a current list of Jackson Class Members to the Community Monitor.
- The Community Monitor and Regional Program Manager reconciled the regional list with the LTSD (Santa Fe) list of Class Members and where they live.
- The Community Monitor selected the sample.
- Once the sample was selected, the Regional Office began to gather documents required for the review. They did this in concert with local independent case managers.
- Crystal Wright, her staff and the Community Monitor assigned reviewers and case judges to individual class members.
- The Regional Office mailed documents to reviewers seven days in advance of the on site review start date.

The reconciled total number of class members served in the NW Region was 29. The total number of class members selected for the review was thirteen or 45% of class members served.

More about Sample Selection

In an effort to ensure that the selection of the sample, in general, was done in a way that mirrors, to the extent possible, the selection methodology of the past, the Community Monitor:

1. Spoke with the previous Community Monitor, Linda Glenn, and asked her to describe the methodology used;
2. Consulted with DHI (Donna Storey) and LTSD (Christine Wester) staff who are knowledgeable and/or were involved in the actual selection of previous samples; and
3. Reviewed some previous audit reports to identify the number of class members typically reviewed in the NW Region.

Based on this information the number of class members to be reviewed was set at 13 individuals. Then an Excel spreadsheet was developed which listed, by class member, the following information:

- Name, social security number, region; and

- Name of the day, case management and residential providers supporting each person.

Again, as in the past, at least one class member from each residential agency was represented in the sample. In addition, an effort was made to include at least one person from each of the day and case management agencies serving class members and to equitably choose the proportion of class members selected from a given agency. That is, if Agency “X” served 25% of the class members in the NW Region, then an effort was made to select 25% of the total sample from that agency.

A random table of numbers was used to determine the people selected to be in the sample. If number “7” was picked from the random table of numbers, every 7th person would be selected to be in the review from Agency “X” until the number needed from that agency was reached.

Assignment of Reviewers and Case Judges

With the exception of the Community Monitor, all reviewers in the NW Region were either Long Term Services Division or Department of Health Improvement staff. The only restrictive “criteria” for reviewers, other than they had to be trained, was that LTSD staff could not review individuals within their own region.

Case judges were frequently assigned based on the needs of the class member. For example, if a class member was on the aspiration list, had a mealtime plan or positioning challenges, the case judge who is an Occupational Therapist was assigned. If a class member had mental health/behavioral challenges a case judges with that background was assigned and so on.

Reviewers included:

Deb Donovan, LTSD
 Deb Russell, DHI
 Donna Storey, DHI

Susan Leonis, LTSD
 Marti Madrid, DHI
 Lyn Rucker, Community Monitor
 Valerie Valdez, DHI

Case judges included Lyn Rucker, the Community Monitor, and the following consultants to the Community Monitor:

Wanda Black
 Keytha Jones

Carly Crawford

Phase II On Site Information Gathering June 7 to June 10, 2004

Thirteen individual class members were visited during the review. These thirteen people receive services from:

- three Independent Case Management Agencies (Excel, Innovative and Peak);

- five day service providers (Disability Services, Mosaic, PMS/Shield, ResCare, and Zuni); and
- five residential providers (Disability Services, Mentor/High Desert Family Services, Mosaic, ResCare and Zuni).

There were approximately 65 individuals interviewed during this review. The protocol calls for interviews with:

- individual class members;
- each class member's guardian, if there is one;
- independent case managers;
- supported employment/direct support staff from day habilitation;
- residential direct support staff; and
- others as needed (nurses, therapists, etc.).

Documentation was requested and reviewed.

For each class member, reviewers filled out the 97 pages of the protocol book and scored 147 questions. This information was then reviewed and reconciled with a case judge. In an effort to ensure that the interpretation of the question, the criteria applied and the scoring of the answer was the same as previous years, regular consultation took place between reviewers, case judges, and the Community Monitor. As in past years, Ruby Moore, Supported Employment Consultant, reviewed and reconciled with reviewers/case judges the scores of all class members in the Supported Employment area.

Due to President Reagan's funeral, the summation with the regional office took place on Thursday June 10th instead of Friday. During the summation, the reviewers, Regional Program Manager and the Community Monitor met to discuss preliminary findings. At the conclusion of the on site review the protocol books were sent back to DHI for data entry.

More about the Protocol Used

The 2002 Protocol Book was used to develop the 2004 Protocol Book. While there were format changes (from vertical to a horizontal platform), there were no changes made to the questions asked from one year (2002) to the next (2004).

There were no "note"¹ content changes made to the written guide(lines) for reviewers, with one exception. Question #97 ("What is the level of participation of the legal guardian in this person's life and service planning?") of the 2002 Protocol Book offered no criteria against which to measure the answer. The 2004 Protocol Book defines 'limited' (less than 12 times per year); 'moderate' (one or more times per month) and 'active' (3 or more times per month). Otherwise, the 2002

¹ Some questions in the 2004 Protocol Book have "notes" to be used as guides for reviewers when scoring. These "notes" came from the instructions outlined in the 2002 Protocol Book.

Community Systems Review Protocol Book is the same as the 2004 Community Practice Review Protocol Book.

In addition to maintaining the same protocol book, the past Community Systems Review Coordinators for LTSD and DHI coordinated and trained over 35 people in the requirements of the 2004 Community Practice Review. All requirements from previous years were incorporated into this training and required of trainees. As a part of this training, reviewers were required to conduct an actual review including interviews, completing all of the protocol books and having protocol books case judged. Case judges were required to meet with reviewers and case judge their books. All first time reviewers were mentored or 'shadowed' by an experienced reviewer. All case judges and reviewers were evaluated at the conclusion of the "mock review". Reviewers that were found to need additional training and support were scheduled to be "shadowed" by a mentor for their first "real" review. All new case judges were required to participate in an additional day of training geared specifically to the regulations, requirements and practice expectations of the New Mexico developmental disabilities service system. In addition, case judges met before, during and after the training session with Christina Crowe, the LTSD and DHI Training Coordinators, the Supported Employment Consultant and the Community Monitor to identify and clarify questions.

Phase III Information Review, Clarification, Data Entry and Analysis June 2004 to November 2004

The individual summaries found in Attachment A were reviewed and edited multiple times to ensure clarity, accuracy and reasonableness. A brief description of each review follows:

- Review #1: Each reviewer wrote individual summaries, findings and recommendations. These individual summaries were reviewed and edited by the reviewer in conjunction with his/her case judge during the review week.
- Review #2: These summaries went to DHI at the conclusion of the review week. DHI typed/edited the individual summaries and sent them to the Community Monitor.
- Review #3: The Community Monitor conducted further editing and then sent the summaries, findings and recommendations to the Northwest Regional Office and LTSD.
- Review #4: The Regional Program Manager and NW Regional Office staff reviewed the individual findings and made recommended edits to the Community Monitor.
- Review #5: The Community Monitor made agreed upon changes and sent the revised individual findings to the NW Regional Office.
- Review #6: For one individual in the review, objections were raised regarding the findings. Given the serious nature of this individual's health status, the Community Monitor asked Carly Crawford, MS,

each person's situation were given to Regional Office staff during the review week. Highlights of the issues are in the individual write-ups in Attachment A.

B. INDIVIDUALS "NEEDING SPECIAL ATTENTION"

Four individuals (30.7%) of the thirteen individuals reviewed were identified as needing "special attention". Individuals identified as "**needing special attention**" are individuals for whom issues have been identified that are or may, if not addressed, affect the person's health, safety and welfare. The Community Monitor requested follow-up/intervention and feedback take place on identified items as quickly as possible but in no instance to exceed 60 days. Details of each person's situation were given to Regional Office staff during the review week. Highlights of the issues are in the individual write-ups in Attachment A.

Thus, an unduplicated total of seven individuals (54% of sample) were identified as needing "immediate" or "special" attention during this review.

Case Management Agencies Supporting People with Immediate or Special Needs

	Immediate Need	Special Attention	Total
Excel	2	2	4
IHAH	1	2	3
Peak	0	0	0
Total	3	4	7

Provider Agencies Supporting People with Immediate or Special Needs

	Immediate Need	Special Attention	Total
Disability Services	0	1	1
High Desert	1	0	1
Mosaic	0	3	3
PMS/Shield	1	0	1
ResCare	1	1	2
Zuni	1	0	1

C. INDIVIDUAL FINDINGS AND RECOMMENDATIONS

For items not identified as requiring either immediate or special attention, the expectation is that follow-up and resolution will occur within 90 days on all of the recommendations made in the individual write-ups. The individual findings are contained in Attachment A.

III. QUALITY AND OVERALL SATISFACTION

While a significant portion of the review is focused on the degree to which various organizations and/or individuals have fulfilled their responsibilities in line with the Joint Stipulation, the heart of this review is the person. Determining how class members are treated, to what extent each person is receiving services that are needed, the degree to which each person is living his/her preferred life . . . this is where we must start and this is where we must repeatedly return as we make judgments about the quality and adequacy of what is being provided.

The following chart summarizes some of the quality of life information gathered during the review. As is evident, providers are making significant efforts to accommodate people's cultural preferences. Evidence of this effort frequently included serving preferred ethnic foods, providing appropriately bilingual staff, the regular inclusion of preferred music, and enabling the person to attend special celebrations.

Providers are making significant efforts to accommodate cultural preferences.

Many class members are not enabled to make personal choices about things like where and with whom to live and spend time.

However, personal quality of life limitations remain. Significant numbers of class members are not enabled to make personal choices such as where and with whom to live, and how or with whom to spend time. These rights that so many Americans take for granted have not become integrated into the fabric of life for many the class members reviewed.

CND = Can not determine

QUALITY OF LIFE	Response
Person is offered a range of opportunities for participation in each of the life areas. (2 CND)	4 Yes 5 Partial 2 No
Does the person have the opportunity to make informed choices? (3 CND)	5 Yes 4 Partial 1 No
<ul style="list-style-type: none"> ▪ About where and with whom to live? (4 CND) 	4 Yes 1 Partial 4 No
<ul style="list-style-type: none"> ▪ About where and with whom to work/spend his/her day? (5 CND) 	4 Yes 2 Partial 2 No
<ul style="list-style-type: none"> ▪ About where and with whom to socialize/spend leisure time? (6 CND) 	3 Yes 3 Partial 1 No
Providers do not prevent the person from pursuing relationships and are respecting the rights of this person? (1 CND)	10 Yes 2 Partial
Does the person have daily choices/appropriate autonomy over his/her life?	6 Yes 6 Partial 1 No
Have the person's cultural preferences been accommodated? (1 CND, 1 N/A)	10 Yes 1 Partial

QUALITY OF LIFE	Response
Is the person treated with dignity and respect?	5 Yes 8 Partial

Individuals who were able and willing to answer questions regarding their level of satisfaction with services provided the following information.

CND = Can not determine

SATISFACTION	Response
Overall, is the person satisfied with the current services? (6 CND)	4 Yes 3 Partial
Does the person get along with the case manager? (11 CND)	2 Yes
Does the person find the case manager helpful? (12 CND)	1 Yes
Does the legal guardian find the case manager helpful? (5 CND)	7 Yes 1 Partial
Does the person have adequate food and drink available? (1 CND)	12 Yes
Does the person have adequate transportation to meet his/her needs? (1 CND)	9 Yes 3 Partial
Does the person have sufficient personal money? (2 CND)	9 Yes 2 Partial
Does the person get along with their day program/employment staff? (5 CND)	7 Yes 1 Partial
Does the person get along with the residential provider staff? (4 CND)	8 Yes 1 Partial

Level of satisfaction and quality of care is frequently influenced by the longevity, knowledge and trust developed between the individual and his/her family with those providing direct services. During the review we learned that:

- Generally providers have done a good job of attempting to stabilize and maintain competent, kind and knowledgeable staff. Over half of those reviewed are supported by some staff who were identified as being very involved and positive. These staff know the person well and have developed a caring and supportive relationship.

62% of day staff "know" the person well.
83% of home staff "know" the person well.
- Eight people were identified as getting along well with their residential support staff. (4 CND)
- Seven people were identified as getting along well with their day/employment staff. (5 CND)

- For five of the people reviewed, there was evidence that they have achieved progress in the past year. (3 CND)
- Two people are involved in supported employment!
- Five people are adequately integrated into the community.
- Nine people were identified as having access to adequate transportation. (1 CND)

38% of class members reviewed show evidence of progress in the past year.

15% were involved in Sup. Employment.

38% are adequately integrated into the community.

75% have adequate transportation.

82% have sufficient personal money.

- Nine were identified as having sufficient personal money. (2 CND)

Generally, people were found to be supported by informed staff who care for and work well with the individual. People who could express themselves, in most cases, got along well with their staff and found them to be helpful. Satisfaction was higher when staff went out of their way to accommodate individual preferences consistently, thoughtfully and creatively throughout the day. Being able to get around in the home at will), being able to influence daily activities, having equipment that works and is accessible across environments, having staff who speak your preferred language and staff who know your family and cultural preferences all contributed to a sense of respect and well being on the part of the class member and his/her family/guardian.

The lack of overwhelming satisfaction with services was influenced by numerous things: incompatibility with housemates, having housemates moved into the home without prior consultation or consent, lack of consistent follow through or communication between people, or preferences not being honored; etc.

IV. EFFECTIVENESS OF PERSONAL SAFEGUARDS

A. GUARDIANSHIP

All thirteen individuals reported as a part of this review have guardians. Five of these individuals have guardians who are actively involved with them, four have moderately involved guardians and four have guardians who are involved in only a limited way.

38% have active participation of guardians;
31% have moderate participation; and
31% have limited participation.

There are a number of guardians who are unable or unwilling to be actively involved.

Generally, the vast majority of guardians care very deeply about the person for whom they are advocating. In the case of family members, they love and have a lifetime of memories and history with the person. For corporate guardians, the majority are active and involved advocates.

Guardians are intended to play a key and active role in the person's life and as such serve as a personal safeguard and champion. When this safeguard is missing, the already vulnerable person finds him/herself more at risk of being friendless and family-less; of receiving poor health care monitoring and support; of neglect or life wasting; or of becoming someone who is 'maintained' but not nourished and respected. This review shows that there are multiple reasons for lack of active guardian involvement, including:

- The guardian is experiencing increasing health problems;
- Lack of personal knowledge about the individual by a corporate guardian;
- Difficulty participating because of distances; and/or
- Inability to consistently attend meetings, like ISP's.

Changing, transferring or eliminating guardianship is a complex and delicate issue. In some cases co-guardianship might be appealing and effective. In other cases, guardianship may need to be transferred to another family member or friend. In still others, a corporate guardian may need to be pursued or changed. In the meantime, the individual needs support and personal attention, consequently, two people were seen as needing a friend-advocate or someone unrelated to service provision to fill in for this missing safeguard.

2 people were seen as needing a friend-advocate.

B. CASE MANAGEMENT (CM)

"Case Management services are intended to support the individual in pursuing their desired life outcomes

by facilitating access to supports and services.

... Case Management services are intended to assist the individual to enhance (not replace) their natural supports and other available resources with DD Waiver services.

The case manager is an advocate for the individual." . . .

New Mexico DD Waiver Service Standards,
March 2003

Before you can advocate for an individual, you must first get to know him/her. Eight of the case managers were rated as "knowing the person". Reviewers interviewed and received confirming testimony of case managers who knew many of the details of an individual's current life/services as well as some details from past personal history.

In addition to "knowing" the individual, there was evidence of long-term relationships and reports of proactive advocacy. There were compliments given to case managers who understood his/her role and job (9 case managers) and who initiated quick follow-up to avoid gaps in service or lack of diligent and swift intervention.

62% of the cm knew the person.
69% of the cm understood the role/job.
69% were seen as available to the person.

Presence is an essential component of “getting to know” and “being aware” enough to initiate informed action on behalf of an individual. Nine individuals have case managers seen as “being available” to the person. This “availability” is, in part, a result of the requirement that case managers spend at least one cumulative hour each month with the person in a minimum of two different settings or on different days of each month.

<p>31% have documentation that the cm is monitoring and tracking the delivery of services as outlined in the ISP.</p>	<p>Given these numbers, the expectation would be that the majority of case managers would be seen as taking appropriate and needed action on behalf of the individuals for whom they work. While evidence documented that some certainly do (for 4 people), too frequently the case manager does not appear to have adequate knowledge and information to facilitate the development of a comprehensive ISP or is not tracking, monitoring or reporting the implementation or lack of implementation of ISP's.</p>
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cm = case manager/case management

CND: Can not Determine

N/A Not Applicable

Question	Response	% Yes
Was the cm able to describe the person's health related needs?	6 Yes 7 Partial	46%
Does the cm record contain documentation that the case manager is monitoring and tracking the delivery of services as outlined in the ISP?	4 Yes 9 Partial	31%
Does the cm provide cm services at the level needed by this person?	4 Yes 9 Partial	31%
Does the legal guardian find the cm helpful? (5 CND)	7 Yes 1 Partial	88%

Expectations create the boundaries for individuals supported. The field of developmental disabilities learned long ago about the importance of the 'self fulfilling prophecy'; that is, if the person is seen as 'able' then it is more likely that he/she will be supported to 'be able'. Conversely, if the person is seen as 'un-able' to grow, develop and progress, maintenance – or worse, regression – can become the outcome. Consequently, it is extremely important that each person be seen as 'able' to grow, develop and progress. It is essential that each person be seen as capable, respectable, accomplished and competent in order to first have, and then successfully pursue, his/her desired life outcomes. It is hard to over-emphasize the importance of working with case managers and team members so that they are continually elevating their expectations regarding individuals whom they support.

<p>Only 38% of the case managers were seen as having “an appropriate expectation of growth” for the person they are supporting.</p>

V. ADEQUACY OF PLANNING AND IMPLEMENTATION

A. ASSESSMENTS

Assessment refers to the process of identifying an individual's specific strengths, developmental needs and need for services. This should include identification of the individual's present developmental level and health status and where possible, the cause of the disability; the expressed needs and desires of the individual and his or her family; and the environmental conditions that would facilitate or impede the individual's growth, development and performance. (CMS W196 ²)

The purpose of assessments and special consultations is to obtain information that will assist Individual Service Plan (ISP) team members to establish goals, to identify the individual's capabilities and areas of need relative to those goals, and to identify the strategies and supports that are the least restrictive and most likely to be effective in assisting the individual to attain his or her goals.

Typically teams should be trained to be sure that:

- ✓ Each person's needs and strengths have been accurately assessed and relevant input has been obtained from team members.
- ✓ Assessments identify needs, strengths and preferences.
- ✓ Assessments identify presenting disabilities and, if possible, causes.
- ✓ Recommendations made as a part of assessments are made and implemented or, if not, there is team consensus on why not.

Assessments are foundational. If the foundation is not well done the entire plan will be weak and poorly constructed. Assessments, as the numbers below illustrate, were extremely weak overall. Teams only considered assessments during the planning process 15% of the time. Only one person's team obtained the needed assessments in order to do adequate planning. Assessments that were obtained were seen as "adequate" for planning for only one person and were clearly used to influence planning for only two people.

Question	Response	% Yes
Did the team consider what assessments the person needs and would be relevant to the team's planning efforts?	6 Yes 7 Partial	46%
Did the team arrange for and obtain the needed, relevant assessments?	1 Yes 12 Partial	8%
Are the assessments adequate for planning?	1 Yes 12 Partial	8%
Were the recommendations from assessments used in planning?	2 Yes 10 Partial 1 No	15%

² CFR Active Treatment Requirements, these are the corresponding "Tag Numbers".

B. THE PLANNING TEAM

During the review, the “planning team” is examined in several ways, including expectations and membership.

Successful support planning requires the greatest possible involvement of the individual, his or her family, guardian, case manager, providers of supports as well as specialists as indicated by the needs of the person. Each participant - individual, family, professional, paraprofessional and non-professional - is expected to work together and to demonstrate a continuing commitment to learn about the individual and about his or her current vision, goals and circumstances, and to support the individual in particular ways to realize those aspirations.

The team had appropriate expectations for growth for 3 (23%) of those reviewed.	One of the important predictors of ISP ‘appropriateness’ and ‘rigor’ is embodied in the question, “Overall, does the team have an appropriate expectation of growth for this person?” The answer was “yes” for only three people of those reviewed. We’ve all learned that what we believe can happen dramatically influences our drive and accomplishments. This is also true of our expectations of others. As mentioned earlier, teams should receive the support they need to be sure that they are continually elevating their expectations regarding individuals whom they support.
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Team ‘**membership**’, like assessments, is a foundation essential for the development of an effective ISP. For the people we reviewed, five people had an “appropriately constituted team”. People typically missing were therapists, direct support staff and nurses. In only five cases (one case of 13 was N/A) was there evidence of consistent involvement of team members not physically present at the team meetings in the development of the ISP. It is important to note that New Mexico requires therapists (BT’s, OT’s, PT’s, ST’s) to attend ISP meetings in person, via videoconference or by telephone, yet they are not consistently complying.

5 people (38%) had an “appropriately constituted team”. Only 5 people (42%) who had ‘missing’ team members had these members participating in development of the ISP.
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62% (8) of the day staff knew the person well but only 46% (6) had adequate input into the person’s ISP. 83% (10) of residential staff knew the person well but only 67% (8) had adequate input into the person’s ISP.	Direct Support Staff play a key, central and daily role in support of the individual. They are the staff that work with the person the most and therefore should be the most knowledgeable about the person’s needs, responses, preferences and expectations. As such, they should be actively involved in the planning process for the individuals whom they support. During this review we found that residential staff were more likely to have adequate input into the person’s ISP than the day staff.
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C. THE INDIVIDUAL SERVICE PLAN (ISP)

The general requirements regarding the Individual Service Plan, nationally, are articulated in multiple documents including Centers on Medicare and Medicaid, CARF standards and The Council Outcome Measures. In New Mexico they are outlined in 7 NMAC 26.5. There is general agreement in terms of ISP and team requirements and expectations. The team is expected to prepare:

- ✓ *an ISP*
- ✓ *based on assessed needs and strengths; which*
- ✓ *includes opportunities for individual choice and self management and identifies:*
 - ✓ *The relevant interventions to support the individual toward independence;*
 - ✓ *the discrete, measurable, criteria based objectives the individual is to achieve; and*
 - ✓ *the specific individualized program of specialized and generic strategies, supports and techniques to be employed.*

The ISP should:

- ✓ *be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible; and*
- ✓ *prevent or decelerate regression or loss of current optimal functional status.*

As needed, the person must be furnished with, have maintained in good repair, and taught to use and make informed choices about the use of dentures, eyeglasses, hearing and other communication aids, braces and other devices identified by the team.

All of the individuals in the review had an ISP. Nine (69%) of those ISP's addressed living, learning/working and social/leisure in a way that correlates with the person's desires and capabilities.

But the overall findings regarding the quality of the ISP and its component parts were quite disappointing. Generally, the ISP's appeared to be much the same from year to year to year. It appears that many ISP's are duplicated word for word from year to year with little or no change in the content in spite of the person's evolution. In some cases, much more was going on in an individual's life than was reflected in the ISP. In others, the person appeared to be in a holding pattern that reflected no new challenges, expectations or experiences. As the numbers indicate, there is an urgent need to review, revise and rethink the expectations around the ISP.

	Met Paper Expectation	Content Adequate
▪ There is a document called an ISP	(13) 100%	
▪ Long-term vision is adequate?		(2) 15%
▪ Goals include criteria by which the team can determine when the goal(s) have been achieved?		(0) 0%
▪ ISP goals related to achieving the person's long-term vision?		(6) 46%
▪ ISP goals address the person's major needs?		(2) 15%

	Met Paper Expectation	Content Adequate
▪ The recommendations and/or objectives of ancillary providers are integrated into the goals, objectives and strategies of the ISP?		(1) 8%
▪ Does the ISP reflect how the person will get to work/day activities, shopping, and social activities?		(9) 69%
▪ Does the ISP contain a specific crisis plan that meets the person's needs?		(3) 23%
▪ Does the ISP contain specific arrangements for primary health care?		(8) 62%
▪ Does the ISP reflect how the person will obtain prescribed medications?		(8) 62%
▪ Does the ISP contain a list of adaptive equipment needed and who will provide it? (1 N/A not included in the denominator)		(6) 50%

The **Functional Supports Assessment**, which is also required, was

▪ found in only 5 cases to offer adequate guidance to achieving the person's long-term vision; and	(5) 38%
▪ used as the basis for goal development for only 5 people.	(5) 38%

D. ISP TEAM MEMBER AND PROCESS EXPECTATIONS

In addition to the paper and content requirements surrounding the ISP, there are also team member and team process expectations. Each member of the team is expected to carry out responsibilities as assigned and articulated in the ISP. As the following summary will illustrate, many of the teams are meeting the "six month review" requirement, however, the majority of teams are not convening when the individual is experiencing a change in circumstances and/or needs. Transition and/or discharge planning, which is a part of the planning that is needed when an individual's circumstances change, was rarely seen. As the individual write-ups will verify, the lack of prior planning can be unnecessarily distressing for everyone involved.

	Response	Met Process or Outcome Expectations
Was the person provided the assistance and support needed to participate meaningfully in the planning process? (1 CND)	8 Yes 3 Partial 1 No	62% Yes
Is there evidence that the ISP was reviewed by the team within the last 6 months? (3 N/A not included in denominator)	10 Yes	100% Yes
Do records or facts exist to indicate that the team convened meetings as needed due to changed circumstances and/or needs?	7 Yes 6 No	54% Yes

	Response	Met Process or Outcome Expectations
Has the person changed residential/day services in the last year?	4 Yes 9 No	31% Yes
▪ Was this change planned by the team? (9 N/A)	1 Yes 1 Partial 2 No	25% Yes
▪ Was this change appropriate to meet the person's needs? (9 N/A)	1 Yes 2 Partial 1 No	25% Yes

Teams supporting two individuals were recommended for additional Team Process Training.

E. IMPLEMENTATION OF THE ISP

In order to facilitate growth, limit regression and move towards the individual's vision, the ISP goals, objectives and strategies need to be consistently implemented in all relevant settings both formally and informally as the need arises or opportunities present themselves. In order for consistent implementation to take place, you would expect that those who work with and support the person to achieve his/her goals:

- ✓ Know what the person's goals are across settings;
- ✓ Implement goals, objectives and strategies as outlined in the ISP; and
- ✓ Follow agreed upon (by the team in the ISP) intervention/ reinforcement strategies.

The following demonstrates that these expectations are not being met.

	Response	Met Process or Outcome Expectations
Are the individual members of the team following up on their responsibilities?	3 Yes 9 Partial 1 No	23%
If there is evidence of team conflict, in the reviewer's opinion, has the team made efforts to build consensus? (9 N/A)	2 Yes 2 Partial	50%
Is there adequate communication among team members between meetings to ensure the person's program can be/is being implemented?	5 Yes 7 Partial 1 No	38%

	Response	Met Process or Outcome Expectations
Is there evidence or documentation of physical regression in the last year? (2 CND)	3 Yes 8 No	27%
Is there evidence or documentation of behavioral or functional regression in the last year? (2 CND)	2 Yes 9 No	18%
If there is evidence of regression, is/has the team adequately addressing the regression? (9 N/A)	0 Yes 2 Partial 2 No	0%
Has the team process been adequate for assessing, planning, implementing and monitoring of services for this person?	2 Yes 9 Partial 2 No	15%
Overall, is the ISP adequate to meet the person's needs?	0 Yes 11 Partial 2 No	0%
Is the program of the level of intensity adequate to meet this person's needs?	1 Yes 11 Partial 1 No	8%

F. ADAPTIVE EQUIPMENT AND AUGMENTATIVE COMMUNICATION

During the review, questions are asked to determine whether individuals have the equipment they need, whether it is in working order and whether they have access to needed equipment throughout their day in all environments. The challenges observed included: devices needing to be updated, device not available to the person at all times across environments, devices missing, staff unable or unwilling to assist the individual to use the devices, devices not appropriate to the individuals, and devices not used by the individual in all places.

Historical Scoring: Adaptive Equipment/Augmentative Communication

Question	2000	2001	2002	2003	2004
Has the person received all adaptive equipment needed?	60%	70%	73%		45%
Has the person received all assistive technology needed?	44%	60%	57%		64%
Has the person received all communication assessments and services needed?	55%	36%	42%		17%

G. OVERALL ADEQUACY/INTENSITY OF THE ISP

Overall, the ISP is in desperate condition. Generally, it is not an effective planning and coordination tool and it does not serve as a positive motivator for change.

Historical Scoring: Overall Adequacy/Intensity of ISP

Question	2000	2001	2002	2003	2004
Does the person have an ISP that addresses living, learning/working and social/leisure that correlates with the person's desires and capabilities, in accordance with DOH regulations?	82%	82%	75%		69%
Does the person have an ISP that contains a functional supports assessment based on a long-term view?	100%	100%	92%		54%
Does the person receive services and supports recommended in the ISP?	55%	73%	67%		38%
Does the person have adequate access to and use of generic services and natural supports?	45%	82%	83%		23%
Is the person adequately integrated into the community?	45%	82%	67%		38%

VI. COMMUNITY INTEGRATION AND MEMBERSHIP

Community integration and membership, like individual interests, varies depending on the preferences, interactions, and experiences of the person. It may also vary depending on what is available in the local and surrounding community and how easily one can access those activities/resources. It is important, then, that the individual knows what is available, regularly experiences ordinary life and people in the community, experiments to find new things of interest, exercises choice about what s/he wishes to do and has control over personal resources.

There are things that can be considered "components of" or that "result" from community integration, membership and involvement. Some of those things are highlighted below.

A. VALUED ROLES, FRIENDS AND NATURAL SUPPORTS

Belonging is a key 'result' of integration and membership. "People experience different ways of belonging to each other. They speak of others as kin, as friends, as co-workers, as neighbors, as belonging to the same association or congregation, as sharing a common interest, as being "regulars" (like a regular customer in a tavern or regular visit to the park). Shaped by culture and personal history, each of these different relationships implies privileges and obligations specific to its participants. Most everyone identified someone as a friend, but each friendship takes its own

shape and meaning. For each person, these different kinds of belonging form the context of social support. People excluded from membership risk loneliness, isolation, and powerlessness.”³

During the review, questions are asked and observations take place that enable reviewers to probe what’s actually happening in the lives of class members. Are people belonging: experiencing valued roles, friends and natural supports? Some of the “indicators of good practice” found during the review are identified below.

The indicator statements followed by an asterisk are directly related to questions in the protocol. Thus, for those indicators, the number preceding the statement represents the actual number of persons in the sample that are supported by the identified good practice. Indicator statements without asterisks represent anecdotal evidence of good practice that became evident as a result of the total review process: interviews, documentation review and observation. While these numbers are frequently low, the indicators stand as beacons, demonstrating the presence of good practice in the region and providing the models for replication which would allow all persons to be supported with the identified good practice.

People play valued roles in their community

2 people participate in supported employment.*

3 people total have some community employment.*

People are a part of and integrated into their communities

5 people were seen as adequately integrated into the community.*

10 people have their cultural preferences accommodated.*

People have individual interests and hobbies that are supported.

3 people participate in church/have interest in religion.

1 person is very interested in basketball, baseball and softball.

2 people are building relationships around having coffee with others.

2 people are “regulars”, known and expected.

People have friends (non-paid – and personally selected)

3 people were identified as really liking their housemates.

5 people were identified as having friends or familiar acquaintances.

³ John O'Brien and Connie Lyle O'Brien, Members of Each Other, Responsive Systems Associates, 1991.

People have natural supports

5 people enjoy consistent, positive involvement of family.

4 people were identified as having natural supports (barber, grocery, church, restaurants).

People have their own homes and neighborhoods

5 people or members of their team identified homes that were really suited for the person.

People show evidence of progress

5 people have gained skills and shown improvement.*

1 person is learning sign language.

2 people had medication reduced or eliminated.

6 people have and are using devices which enable more self control and personal interactions.

B. WORK/DAY SUPPORTS AND SERVICES

Interviews with day/employment support staff gave reviewers the opportunity to speak directly with the person's direct support staff. The following summarizes some of the information received.

	Response	% Yes
Did the direct service staff receive training on implementing this person's ISP?	6 Yes 5 Partial 2 No	46%
Was the direct service staff able to describe his/her responsibilities in providing daily care/supports to the person?	9 Yes 4 Partial	69%
Did the direct service staff have training in the ISP process?	8 Yes 2 Partial 3 No	62%
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	5 Yes 8 Partial	38%
Does the direct service staff have an appropriate expectation of growth for this person?	6 Yes 7 Partial	46%
Is the day/employment environment generally clean, free of safety hazards and conducive to the work/activity intended? (3 CND; 1 N/A)	5 Yes 4 Partial	56%

C. SUPPORTED EMPLOYMENT

It has long been recognized that having a job contributes to a person’s self esteem and how society defines an individual’s worth. People with disabilities are the most unemployed and under-employed group of Americans. Most people with disabilities want to work and to be as economically self-sufficient as possible. With appropriate training, job opportunities and supports, people with developmental disabilities are often model employees, miss fewer workdays than other employees, and change jobs less frequently. Given the importance of work, questions were asked regarding employment during the review process. The results are highlighted below.

Historical Scoring: Supported Employment

Question	2000	2001	2002	2003	2004
Need an employment assessment?	45%	91%	17%		62%
Need supported employment?	45%	27%	8%		46%
Receive supported employment assessment?	100%	100%	100%		75%
Assessment conforms to DOH Regs?	100%	100%	100%		13%
Has a Career Development Plan?	100%	100%	100%		0%
Is supported work in line with requirements?	80%	33%	100%		33%

D. HOME

Interviews at home gave reviewers the opportunity to speak directly with the person’s daily direct support staff. The following summarizes some of the information received from these interviews.

	Response	% Yes
Did the direct service staff receive training on implementing this person’s ISP?	6 Yes 3 Partial 3 No	50%
Is the home safe for individuals? (void of hazards?)	9 Yes 3 No	75%
Was the direct service staff able to describe his/her responsibilities in providing daily care/supports to the person?	9 Yes 3 Partial	75%
Did the direct service staff have training in the ISP process?	4 Yes 4 Partial 4 No	33%

	Response	% Yes
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	2 Yes 8 Partial 2 No	17%
Does the direct service staff have an appropriate expectation of growth for this person?	6 Yes 6 Partial	50%
Does the person's home offer a minimal level of quality of life?	8 Yes 4 Partial	67 %

VII. WELLNESS

Just as individualized supports and services are essential to one's success in the community, good health and wellness are essential when attempting to ensure safety, stability, acceptance, integration and the person's overall well being.

Most Jackson Class members have been in the community for ten years or longer. It would be expected, and it was found to be frequently true, that each person has by now established a long-standing relationship with needed physical and mental health care clinicians.

The health and wellness challenges that emerged from this review seemed to cluster in the following areas:

- Needed **health care assessments are frequently not acquired**. Those that are acquired are often **not maintained and/or the results are not conveyed** to staff who "need to know".
 - 6 people (46%) needed assessments/procedures that could not be confirmed as having been done.
 - 6 people were identified as having health/safety issues that do not appear to have been addressed.
 - 5 people have health related issues that those who support them appear to be unaware of and/or are not trained to support properly.
- There is a **lack of follow-up on recommendations made by health care professionals**.
 - 3 people (23%) had recommendations made but follow through could not be verified.
- Some **therapies are not provided consistently and across all environments**. Many of the therapist work for the public schools so they are not available for therapy, oversight, consultation or training of staff during the day, weekend and summers.
 - 4 people were not receiving SLP services in line with needs.
 - 1 person had staff not following PT's recommendations.
 - 4 people were not receiving OT services in line with needs.
 - 2 people were missing reports from therapists so involvement and status was unclear.

- For some people (2) taking (e.g., psychotropic) **medication, expectations for monitoring, reporting and testing** appear to be unclear or the reason for or efficacy of the medication is not known.
- When there is **inconsistent participation in team meetings, lack of diligent and informed oversight and supervision, and poor documentation**, people are in jeopardy of receiving poor, inaccurate or ineffective interventions.
- When there **is no single person designated as the health care coordinator** with responsibility for exchanging information with the multiple health care professionals, multiple providers and multiple related specialists, continuity and quality of health care services and interventions are typically compromised and the welfare of the class member is jeopardized.
- The **region does not have a nurse or staff with responsibility for providing health care oversight and technical assistance**, thus making it impossible for LTSD to provide such important oversight and support.
- Regionally and **statewide the roles and responsibilities for agency nurses have not been made clear**. Guidelines for nurses have not been developed or provided. Requirements for nursing oversight and supervision have not been made clear.
- LTSD has not articulated or distinguished **what functions a Registered Nurse (RN) can perform** and distinguish these functions from **what a Certified Nursing Assistant (CNA) is allowed to do**.
- **Dental services** were highlighted as an issue. While annual checkups might occur, follow-up as needed frequently does not take place.
- It was reported that **emergency room services cannot be relied on** to provide timely and needed interventions. Technical assistance is needed.

A. HEALTH AND MEDICAL

	Response	% Yes
Was the employment/day direct service staff able to describe this person's health-related needs?	5 Yes 7 Partial 1 No	38%
Was the residential direct service staff able to describe this person's health-related needs? ⁴	6 Yes 6 Partial	50%
Overall, were the team members interviewed able to describe the person's health-related needs?	3 Yes 10 Partial	23%

⁴ The total number accounted for in this instance is 12, not the usual 13. The reviewer was unable to visit one individual at home and as a result this question could not be scored.

	Response	% Yes
Is there evidence that the team discussed the person's health-related issues?	6 Yes 7 Partial	46%
In the opinion of the reviewer, are the person's health supports/needs being adequately addressed?	1 Yes 8 Partial 4 No	8%

B. BEHAVIORAL SUPPORTS

Historical Scoring: Behavioral

Question	2000	2001	2002	2003	2004
Does the person need behavioral services?	45%	45%	33%		38%
Have adequate behavioral assessments been completed?	60%	80%	75%		60%
Does the person have behavior support plan developed out of the behavior assessments that meet the person's needs?	60%	80%	75%		75%
Have the staff been trained on the behavior support plan?	40%	100%	75%		50%
Does the person receive behavioral services consistent with his/her needs?	80%	80%	50%		60%
Are behavioral support services integrated into the ISP?	20%	40%	75%		40%