

2004 COMMUNITY PRACTICE REVIEW

SOUTHWEST 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. Everyone was extremely grateful for your openness and generous sharing of your time.

I would like to extend a special thank you to Scott Doan, Southwest Regional Program Manager and all of the Regional Office Staff who assisted in preparing, carrying out and following up on the Southwest Audit: Randy Cahall, Dora Stewart, Cheryl Frazine, Judy Sangster, Rebecca Keefe and Cheryl Dunphy. I owe a special thank you to everyone who helped schedule over 75 interviews, copied hundreds of pages of files, to Jena Caruthers for organizing the provider meetings and to Michelle Patterson and Kerry Palma for agreeing to be the leads in follow-up on recommendations.

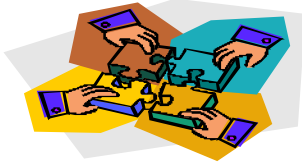
I want to extend my appreciation and gratitude to the reviewers and their managers from DHI and LTSD. Each of these individuals worked hard to be fair, accurate and thoughtful during the review interviews, scoring and write-up. I look forward to working with all of you again.

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 as we reviewed the data time and again, made changes and reviewed it again to ensure its accuracy and fairness. 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.

A handwritten signature in black ink that reads "Lyn Rucker". The signature is written in a cursive, flowing style with a long horizontal line extending to the right.

Lyn Rucker, Community Monitor



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I. INTRODUCTION AND REVIEW OF METHODOLOGY

The 2004 Community Practice Review of the Southwest (SW) Region consisted of four phases. Each phase and its focus is outlined below.

Phase I	Sample Selection, Review Preparation	January 30, 2003 to February 20, 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.
- Regional Program Manager 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 total number of class members served in the Southwest Region was reported to be 55. The total number of class members selected for the review was fifteen. Two more class members were selected as alternates but were not needed.

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 previous audit reports to identify the number of class members typically reviewed in each region.

Based on this information the number of class members to be reviewed in the Southwest region was set at 15. Then an Excel spreadsheet was developed which listed, by class member, the following information:

- Name, social security number, region; and
- Name of day, case management and residential providers.

Again, as in the past, at least one class member from each residential agency would be represented in the sample. In addition, at least one person from each of the day and case management agencies serving class members would be selected. An effort was made 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 Southwest region, then as close as possible to 25% of the sample would be from that agency.

A random table of numbers was used to determine the person 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

All reviewers in the SW Region were either Long Term Services Division, Department of Health Improvement staff or consultants to the Community Monitor (CCM). The only restrictive "criteria" for reviewers, other than that they had to be trained, was that LTSD staff could not review in their own region.

Case judges were 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 judge with that background was assigned and so on.

Reviewers included:

Sandra Clamp, CCM	Carly Crawford, CCM
Christina Crowe, CCM	Gina DeAgüero, DHI
David Espinosa, LTSD	Marti Madrid, DHI
Deb Russell, DHI	Donna Storey, DHI
Valerie Valdez, DHI	Christine Wester, LTSD

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

Sandra Clamp	Carly Crawford
Christina Crowe	

Phase II

On Site Information Gathering

March 1 to March 5, 2004

Fifteen individual class members were visited during the review. These 15 people receive services from:

- 4 independent case management agencies (DSLML, SCCM, Peak, and NMQCM); and
- 7 residential/day provider agencies (Alliance, Life Quest, Opportunity Center, Progressive, ResCare, Tresco and WNG).

There were approximately 75 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, the Community Monitor and Christina Crowe. Christina has been both a case judge and reviewer on many previous audits throughout the years. In addition, two of the reviewers (one LTSD and one DHI) used to work full time coordinating and participating as reviewers in previous audits so their guidance and clarification was sought frequently. Occasionally, Linda Glenn was also consulted. 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.

On Friday morning of the review week the reviewers, case judges and the Community Monitor met to give a status report and to discuss preliminary findings with regional office staff and representatives from LTSD and the Plan of Action Office. While this meeting was intended to be a dialogue, Regional Staff had been instructed to "just listen", not to ask questions or provide information. In spite of this unacceptable restriction, individual issues were reviewed in detail so that the regional office and provider follow-up/correction could begin immediately where needed.

At the conclusion of this status report, protocol books are 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?”) in the 2002 Protocol Book offered no criteria against which to measure the answers. 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 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 complete with interviews, completing all of the protocol books and being case judged. Case judges were required to meet with reviewers and case judge their books. All first time reviewers were mentored or shadowed by experienced reviewers. 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 March 8 to May 27, 2004

The individual summaries found in Attachment A were reviewed and edited multiple times to ensure clarity, accuracy and reasonableness.

Review #1: Each reviewer wrote the 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.

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.

- 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 Southwest Regional Office and LTSD.
- Review #4: The Regional Office Bureau Chief, Regional Program Manager and representatives from the regional office reviewed the individual findings and reviewed their recommended changes with the Community Monitor.
- Review #5: The Community Monitor made agreed upon changes and sent the revised individual findings to the SW Regional Office.
- Review #6: The Community Monitor met with the Regional Office staff, reviewed each individual's findings/recommendations. Where clarification was needed, it was added. Where measurability for monitoring and follow-up was needed, it was added.
- Review #7: The Community Monitor met with over 60 representatives of providers/staff and case management agencies/staff and conducted a final review/explanation of the individual findings. Some additional edits were made after this review.
- Review #8: Following these meetings, the Community Monitor and Regional Office staff edited the individual summaries again. Follow-up calls were made in order to gain clarification where needed.

In addition to the individual findings and recommendations, the numerical ratings for questions 1 to 147 were recorded by each reviewer for each class member and reviewed with a case judge. The finished Protocol Books were taken to Santa Fe where the numerical ratings were entered by DHI. Summaries of these "scores" were generated and sent to the Community Monitor. The Community Monitor in conjunction with Edna Ortiz reviewed and clarified data where necessary. These changes were re-entered by DHI and a revised report was issued. This corrected data was used to develop this report.

The Community Monitor reviewed and analyzed the information and summarized her preliminary findings in a draft PowerPoint presentation that was sent to all of the parties. As a result of the meetings held with the Southwest Regional Office staff, representatives from LTSD, Plan of Action Office and providers/case managers, the PowerPoint presentation has been modified and revised.

Phase IV

Editing/Writing

May 28 to November, 2004

The information gathered as a part of this process was brought together, analyzed and forms the foundation of this report. The edited individual findings and recommendations were issued June 4, 2004. The first draft of this report was issued June 13, 2004.

II. CATEGORIES, DEFINITIONS AND TIMELINES

This section highlights the issues identified at the individual, provider (case management and day/residential) agency and systems levels.

A. INDIVIDUALS “NEEDING IMMEDIATE ATTENTION”

Five individuals (33%) of the fifteen class members reviewed were identified as “needing immediate attention”. Individuals identified as “*needing immediate attention*” are persons for whom health, safety, environment and/or abuse/neglect issues were identified. For each person identified as needing immediate attention, the Community Monitor requested immediate follow-up/intervention and feedback (in no instance to exceed 30 days) on the identified items. 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.

B. INDIVIDUALS “NEEDING SPECIAL ATTENTION”

Five individuals (33%) of the fifteen 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 ten individuals (67% 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
Desert State	2	1	3
NM Quality	0	0	0
Peak	0	0	0
Sun Country	3	4	7
Total	5	5	10

**Provider Agencies
Supporting People with Immediate or Special Needs**

	Immediate Need	Special Attention	Total
Alliance	1	0	1
Life Quest	0	1	1
Opportunity Center	1	0	1
Progressive	0	0	0
ResCare	1	1	2
Tresco	2	2	4
WNG	0	1	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

*“I didn’t think it (placement in the community) would work
and I thought there was no hope for the future.
Now, (my daughter) is in a place I never expected her to be.
I am so pleased with how her life has evolved.”*

Parent and guardian
Interviewed during 2004 CPR

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 protocol developed by the previous Court Monitor that, in turn, is 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.

<p>Providers are making efforts to accommodate cultural preferences.</p>	<p>The following chart summarizes some of the quality of life information gathered during the review. As is evident, providers are making efforts to accommodate people’s cultural preferences. Evidence of this effort frequently included serving preferred ethnic foods, providing appropriately bilingual staff or staff attempting to learn phrases, the regular inclusion of preferred music, and enabling the person to attend special celebrations.</p>
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It is important to note that nine class members do have the opportunity to make some informed choices. However, personal quality of life limitations remain. Some class members are not enabled to make personal choices such as where and with whom to live, and how or with whom to spend leisure time. These rights that so many Americans take for granted have not become integrated into the fabric of life for all class members.

9 class members are enabled to make personal choices about things like where and with whom to work/spend their day.

CND = Can not determine

QUALITY OF LIFE	Response
Person is offered a range of opportunities for participation in each of the life areas.	6 Yes 9 Partial
Does the person have the opportunity to make informed choices? (2 CND)	10 Yes 3 Partial
<ul style="list-style-type: none"> ▪ About where and with whom to live? (3 CND) 	6 Yes 4 Partial 2 No
<ul style="list-style-type: none"> ▪ About where and with whom to work/spend his/her day? (2 CND) 	9 Yes 4 Partial
<ul style="list-style-type: none"> ▪ About where and with whom to socialize/spend leisure time? (3 CND) 	8 Yes 4 Partial
Providers do not prevent the person from pursuing relationships and are respecting the rights of this person? (1 CND)	11 Yes 2 Partial 1 No
Does the person have daily choices/appropriate autonomy over his/her life?	10 Yes 3 Partial 2 No
Have the person's cultural preferences been accommodated? (1 N/A, 1 CND)	10 Yes 3 Partial
Is the person treated with dignity and respect?	11 Yes 3 Partial 1 No

SATISFACTION	Response
Overall, is the person satisfied with the current services? (3 CND)	7 Yes 3 Partial 2 No
Does the person get along with the case manager? (10 CND)	5 Yes
Does the person find the case manager helpful? (12 CND)	3 Yes
Does the legal guardian find the case manager helpful? (5 CND, 1 N/A)	7 Yes 1 Partial 1 No
Does the person have adequate food and drink available? (3 CND)	10 Yes 2 Partial

SATISFACTION	Response
Does the person have adequate transportation to meet his/her needs?	13 Yes 1 Partial 1 No
Does the person have sufficient personal money? (6 CND)	8 Yes 1 No
Does the person get along with their day program/employment staff? (6 CND)	8 Yes 1 Partial
Does the person get along with the residential provider staff? (1 CND)	12 Yes 2 Partial

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

- Several people are with staff that have been with and supported them for many years. These staff know the person well and have developed a caring and supportive relationship.
- Examples were given of teams working to accommodate a person's culture through cultural activities, providing foods and music of choice and going to major celebrations.
- Twelve people were identified as getting along well with their residential support staff.
- For nine of the people reviewed, there was evidence that they have achieved progress in the past year. (1 CND) For example, PL has had a lot of challenging behaviors in the past, but since changing residential and day service providers there has been a tremendous reduction in her behavior.
- Ten people were identified as having the opportunity to make informed choices. (2 CND)
- Eleven people were identified as being able to pursue relationships and having providers who respect their right to do so. (1 CND)
- Five people had jobs. One person had recently gotten a job. Another person who had worked for 8 years to get a job continues to be employed. Two people are employed in accordance with the minimally required standards agreed to by the parties.
- Thirteen people indicated that they have adequate transportation to meet his/her needs.

67% of day staff "know" the person.
73% of home staff "know" the person.
86% get along well with residential staff. (1 CND)
60% show evidence of progress.
73% are able to pursue relationships.
33% had jobs, 13% were in line with agreed upon requirements to qualify for Supported Employment status.
87% have adequate transportation

Generally, people were found to be supported by informed staff that 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. The lack of overwhelming satisfaction with services was influenced by numerous things: unacceptable or unsafe housing; being moved without consent or prior planning; incompatibility with roommates; preferences not being honored; etc.

IV. EFFECTIVENESS OF PERSONAL SAFEGUARDS

A. GUARDIANSHIP

Fourteen of the fifteen individuals reported as a part of this review have guardians.

14 % have active participation of guardians;
29% have moderate participation;
50% have limited participation; and
7% have no participation.

Those individuals who have guardians who are able and willing to attend meetings, monitor service activity and articulate clear service expectations benefit from the love and support received from their guardians. We heard of specific instances where staff were honoring, in exemplary ways, the guardians' desires that the class member stay a part of his/her culture. We also heard of a guardian who actively intervened when inappropriate and ineffective services were being provided and moved the class member to a different and more responsive provider.

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. However, this review shows that there are a growing number of guardians who are in declining health or who are unable or unwilling to be actively involved in the life of the person for whom they have been named guardian. In instances, it goes beyond lack of involvement to guardians actually refusing to allow needed dental and/or medical treatment/diagnosis. In some cases, this is in response to resistance on the part of the class member to the proposed intervention or fear that the class member may not respond well.

There are a growing number of guardians who are in declining health or who are unable or unwilling to be actively involved.

The 1999 SW audit recommended a transition of guardianship for one individual in this review - that transition has still not taken place.

This is not a new issue for Class Members. In fact, the 1999 SW audit recommended a transition of guardianship for one individual who was also reviewed during this 2004 review. This transition has still not taken place. Another class member's team has identified the need for an alternative guardian for over three years. This issue appears to be growing both in terms of frequency with which it is occurring, as well as the level of risk it potentially carries for individuals with uninformed guardians or guardians who are reluctant to intervene.

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.

Nine of the 15 people reviewed (60%) have guardians who are older, in declining health or who are not and have not been attending planning meetings and/or know little about the person's life.

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, five people were seen as needing a friend-advocate or someone unrelated to service provision to fill in for this missing safeguard.

5 people were seen as needing a friend-advocate.

B. CASE MANAGEMENT

“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. Ten (67%) 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.

67% of the cm knew the person.
67% of the cm understood the role/job.
73% were seen as available to the person.

In addition to “knowing” the individual, there was evidence of long term relationships, reports of proactive advocacy that, in at least one case, resulted in a change in service providers and improved supports and services. There were compliments given to a case manager who initiated quick follow-up to avoid gaps in service or lack of diligent and swift intervention.

Presence is an essential component of “getting to know” and “being aware” enough to initiate informed action on behalf of an individual. Case managers for eleven people were 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.

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. Unfortunately, while evidence documented that some certainly do, too frequently the case manager has not gathered enough information about the individual or does not know him or her well enough to facilitate the development of an ISP that will adequately meet the needs of the class member.

cm = case manager/case management

CND: Can Not Determine

N/A Not Applicable

Question	Number	% Yes
Was the cm able to describe the person's health related needs?	7 Yes 8 Partial	47%
Does the cm record contain documentation that the case manager is monitoring and tracking the delivery of services as outlined in the ISP?	6 Yes 8 Partial 1 No	40%
Does the cm provide cm services at the level needed by this person?	6 Yes 7 Partial 2 No	40%
Does the legal guardian find the cm helpful? (5 CND; 1 N/A)	7 Yes 1 Partial 1 No	78%

Throughout the service system, expectations create the boundaries for individuals supported. The person must be seen as "able" to grow, develop and progress. The person must be seen as capable, respectable, accomplished and competent in order to first have, and then pursue, his/her desired life outcomes. If the person is seen as "able" then the self-fulfilling prophecy will be a desired one. However, if the person is seen as "un-able" to grow, develop and progress, maintenance – or worse, regression – can become the outcome. Only 47% of the people reviewed had case managers who were seen as having "an appropriate expectation of growth" for the people they were supporting.

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.

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

- ✓ 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 13% of the time. Only two people had teams that obtained the needed assessments in order to do adequate planning. Assessments that were obtained were seen as “adequate” for planning for only four people and were used to influence planning for only two people.

Question	Number	% Yes
Did the team consider what assessments the person needs and would be relevant to the team’s planning efforts?	8 Yes 7 Partial	53% Yes
Did the team arrange for and obtain the needed, relevant assessments?	2 Yes 12 Partial 1 No	13% Yes
Are the assessments adequate for planning?	4 Yes 10 Partial 1 No	27% Yes
Were the recommendations from assessments used in planning?	2 Yes 11 Partial 2 No	13% Yes

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 2 (13%) 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 two people of those reviewed.

The responsibilities of providers include, in part, completion of assessments or professional consultations; working collaboratively with the individual and other team members to identify the

individual's goals; and development of an ISP which is likely to be effective in assisting the individual to achieve his/her goals.

27% had an "appropriately constituted team".	An "appropriately constituted team", like assessments, is a foundation essential for the development of an effective ISP. For the people we reviewed, four people had an "appropriately constituted team". People typically missing were therapists, direct support staff and nurses. In only two cases was there evidence of consistent participation of team members not physically present at the team meeting in the development of the ISP. It is important to note that New Mexico requires therapists to attend ISP meetings in person, via videoconference or by telephone, yet they are neither typically nor consistently complying.
Only 13% of the people who had team members 'missing' from meetings had these members participating in development of the ISP.	

Direct Support Staff play a key and central role in support of the individual. They are the staff that work with the person the most and therefore should be one of the most knowledgeable about the person's needs, 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 day/employment staff for seven (47%) people provided adequate input to the person's ISP. Nine (60%) people had residential staff providing adequate input into their ISP.

67% (10) of the day staff knew the person well, but only
47% (7) had adequate input into the person's ISP.
73% (11) of residential staff knew the person well, but only
60% (9) had adequate input into the person's ISP.

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.

The good news is that everyone reviewed had an ISP. Ten (67%) of those ISPs addressed living, learning/working and social/leisure in a way that correlates with the person's desires and capabilities.

However the overall findings regarding the quality of the ISP and its component parts were quite disappointing. The challenge comes when reviewing the content and the quality of the content as is demonstrated by the summary below. Also many of the ISP's appeared to be much the same from year to year to year. It appears that many ISPs are just duplicated word for word from year to year with little or no change in the content in spite of the person's evolution.

	Met Paper Expectation	Content Adequate
There is a document called an ISP	100%	
<ul style="list-style-type: none"> ▪ Long-term vision is adequate? (4) 27% ▪ 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? (4) 27% ▪ ISP goals address the person's major needs? (3) 20% ▪ The recommendations and/or objectives of ancillary providers are integrated into the goals, objectives and strategies of the ISP? (1 N/A not included in denominator) (2) 14% ▪ Does the ISP reflect how the person will get to work/day activities, shopping, and social activities? (12) 80% ▪ Does the ISP contain a specific crisis plan that meets the person's needs? (1 N/A not included in denominator) (4) 29% ▪ Does the ISP contain specific arrangements for primary health care? (9) 60% ▪ Does the ISP reflect how the person will obtain prescribed medications? (10) 67% ▪ Does the ISP contain a list of adaptive equipment needed and who will provide it? (6 N/A not included in denominator) (2) 22% 		

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

- was found only four times to give adequate guidance to achieving the person's long-term vision; and was 27%
- determined to have been used only six times as the basis for goal development. 40%

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 devastating.

	# of Yes/No	Met Process or Outcome Expectations
Was the person provided the assistance and support needed to participate meaningfully in the planning process? (5 CND)	9 Yes 1 Partial	60%
Is there evidence that the ISP was reviewed by the team within the last 6 months? (2 N/A not included in denominator)	13 Yes	100%
Do records or facts exist to indicate that the team convened meetings as needed due to changed circumstances and/or needs? (4 N/A, 1 CND not included in denominator)	7 Yes 3 No	70%
Has the person changed residential/day services in the last year?	5 Yes 10 No	33%
<ul style="list-style-type: none"> ▪ Was this change planned by the team? (1 N/A) 	2 Yes 1 Partial 1 No	50%
<ul style="list-style-type: none"> ▪ Was this change appropriate to meet the person’s needs? (1 N/A) 	1 Yes 2 Partial 1 No	25%

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.

	# of Yes/No	Met Process or Outcome Expectations
Are the individual members of the team following up on their responsibilities?	2 Yes 12 Partial 1 No	13%
If there is evidence of team conflict, in the reviewer's opinion, has the team made efforts to build consensus? (10 N/A not included in denominator)	2 Yes 2 Partial 1 No	40%
Is there adequate communication among team members between meetings to ensure the person's program can be/is being implemented?	6 Yes 8 Partial 1 No	40%
Is there evidence or documentation of physical regression in the last year? (1 CND not included in denominator)	4 Yes 10 No	29%
Is there evidence or documentation of behavioral or functional regression in the last year?	4 Yes 11 No	27%
If there is evidence of regression, is/has the team adequately addressing the regression? (10 N/A not included in denominator)	0 Yes 3 Partial 2 No	0%
Has the IDT process been adequate for assessing, planning, implementing and monitoring of services for this person?	2 Yes 11 Partial 2 No	13%
Overall, is the ISP adequate to meet the person's needs?	1 Yes 11 Partial 3 No	7%
Is the program of the level of intensity adequate to meet this person's needs?	1 Yes 13 Partial 1 No	7%

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: device not available to the person at all times across environments or not being used in all places, devices not working or missing, and staff unable or unwilling to assist the individual so he/she can use the device.

Historical Scoring: Adaptive Equipment/Augmentative Communication

Question	2000	2001	2002	2003	2004
Has the person received all adaptive equipment needed?	67%	80%	86%		38%
Has the person received all assistive technology needed?	36%	38%	70%		56%
Has the person received all communication assessments and services needed?	9%	11%	73%		33%

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 ...ISP ...address living, learning/working and social/leisure that correlates with the person's desires and capabilities, in accordance with DOH regs?	64%	79%	92%		67%
Does the person have an ISP that contains a functional supports assessment based on a long-term view?	100%	86%	77%		67%
Does the person receive services and supports recommended in the ISP?	57%	79%	62%		40%
Does the person have adequate access to and use of generic services and natural supports?	64%	86%	69%		27%
Is the person adequately integrated into the community?	64%	79%	62%		33%

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 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 have supported employment, and have the role of employee.*

5 people total have some community employment.*

1 person does volunteer work 2 days a week.

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

1 person participates in integrated community sports/leisure activities.

10 people have had their cultural preferences accommodated.*

People are a part of and integrated into their communities

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

People have friends (non-paid – would prefer personally selected)

3 people identified as liking roommates with whom s/he has lived for years.

1 person spends time with non-disabled friends on a regular basis.

People have natural supports

2 people were identified as enjoying the consistent involvement of family.

People have their own homes and neighborhoods

7 people were reported to be living in homes marked with their own personal touch.

People show evidence of progress

9 people have gained skills and shown improvement.

2 people are expressing themselves more frequently.

1 person is using adaptive equipment more regularly.

1 person has had no skin breakdown and no instances of aspiration during the past year.

B. WORK/DAY SUPPORTS AND SERVICES

Interviews with those individuals who work with the individual during the day gave reviewers the opportunity to speak directly with the person's direct support staff. The following summarizes some of the information received from these interviews.

	# of Yes/No	% Yes
Did the direct service staff receive training on implementing this person's ISP?	10 Yes 4 Partial 1 No	67%
Was the direct service staff able to describe his/her responsibilities in providing daily care/supports to the person?	11 Yes 4 Partial	73%
Did the direct service staff have training in the ISP process?	9 Yes 3 Partial 3 No	60%
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	2 Yes 12 Partial 1 No	13%
Does the direct service staff have an appropriate expectation of growth for this person?	9 Yes 6 Partial	60%
Is the day/employment environment generally clean, free of safety hazards and conducive to the work/activity intended? (2 CND not included in denominator; 4 N/A)	8 Yes 1 Partial	89%

C. SUPPORTED EMPLOYMENT

Highlights from Ruby Moore's Observations...

- At the time of the review, the Supported Employment position responsible for both the Southeast and Southwest Region was filled after being vacant for 11 months. Great news!
- Most of the people who have had jobs in the past continue to be working.
- Paperwork continues to be a challenge. Career Plans and Vocational Assessments are not current and updated. For example, some people's assessments are seven years old. Assessments should be completed once every three years so the original reviews are not outdated. There have been some updates, but a few were very perfunctory.
- There was some evidence of Meaningful Day Assessments that were very promising. They consisted of great ideas and great plans. Unfortunately, in some instances the teams have not embraced and implemented some of these Assessments/Plans. Ruby did observe examples of good collaboration between Employment and Meaningful Day Coordinators.

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?	86%	100%	85%		100%
Need supported employment?	57%	50%	69%		67%
Receive supported employment assessment?	92%	100%	100%		100%
Assessment conforms to DOH Regs?	25%	100%	82%		40%
Has a Career Development Plan?	25%	43%	22%		40%
Is supported work provided in line with requirements?	25%	43%	22%		20%

D. HOME

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

	# of Yes/No	% Yes
Did the direct service staff receive training on implementing this person's ISP?	11 Yes 3 Partial 1 No	73%
Is the home safe for individuals? (void of hazards?)	12 Yes 3 No	80%
Was the direct service staff able to describe his/her responsibilities in providing daily care/supports to the person?	10 Yes 5 Partial	67%
Did the direct service staff have training in the ISP process?	9 Yes 3 Partial 3 No	60%

	# of Yes/No	% Yes
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	5 Yes 10 Partial	33%
Does the direct service staff have an appropriate expectation of growth for this person?	8 Yes 6 Partial 1 No	53%
Does the person's home offer a minimal level of quality of life?	13 Yes 2 Partial	87%

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 serious health and wellness challenges that emerged from this review seemed to cluster in the following areas. When these issues are combined in one person or a group of people, as was found in the SW, it significantly increases the potential for health complications and crisis, as described below.

- Class Members were ***taking multiple medications prescribed from multiple physicians, each of whom is diagnosing and treating varied and complex issues***, that range from GERD to constipation to psychotic illnesses to anxiety to seizures to cancer to cataracts or most of the above.
- Class Members ***physicians are requesting multiple diagnostic and preventative tests*** (CBC, blood chemistry, lipid, urinalysis, retinal screens, colonoscopy, mammograms, vision, hearing, swallow, blood pressure, cancer biopsy, TD/AIMS, etc.) that need to be scheduled, done, results identified and interventions defined, understood and implemented.
- Class Members are ***aging and experiencing health and physical complications*** indicative of people who live sedentary lifestyles and who are growing older.
- When ***staff have low expectations*** for wellness, activity and recovery; aggressive interventions to diagnose, treat, eliminate or retard regression are not as likely to take place.

- When there is **significant staff turnover, inconsistent participation in team meetings, and lack of diligent and informed oversight and supervision**, 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, 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.
- 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**.

A. HEALTH AND MEDICAL

	# of Yes/No	% Yes
Was the employment/day direct service staff able to describe this person's health-related needs?	5 Yes 8 Partial 2 No	33%
Was the residential direct service staff able to describe this person's health-related needs?	6 Yes 9 Partial	40%
Overall, were the team members interviewed able to describe the person's health-related needs?	3 Yes 12 Partial	20%
Is there evidence that the team discussed the person's health-related issues?	8 Yes 5 Partial 2 No	53%
In the opinion of the reviewer, are the person's health supports/needs being adequately addressed?	3 Yes 7 Partial 5 No	20%

B. BEHAVIORAL

Historical Scoring: Behavioral

Question	2000	2001	2002	2003	2004
Does the person need behavioral services?	64%	71%	69%		67%
Have adequate behavioral assessments been completed?	78%	80%	78%		70%
Does the person have behavior support plan developed out of the behavior assessments that meet the person's needs?	100%	90%	78%		80%
Have the staff been trained on the behavior support plan?	67%	80%	88%		80%
Does the person receive behavioral services consistent with his/her needs?	33%	80%	89%		80%
Are behavioral support services integrated into the ISP?	0%	40%	22%		40%