

## 2004 COMMUNITY PRACTICE REVIEW

### SOUTHEAST 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 my gratitude to all of the Southeast Regional Office staff including Kay Bhakta, Regional Program Manager, Robert Mendoza and Jessica Renteria for coordinating an extremely well organized review. Thank you to Robert for keeping me so well informed, to Jessica for preparing most of the documentation and to Laura Patterson and Debra Ortiz for helping to prepare for and be available to all of us during the actual audit days.

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.

My appreciation also goes out to Jessica, Sandra Renteria, Brianna Massey, Debra, Laura, Melba Gonzales, Paula Summers, Pamela Dobson and Elaine Bell for all your efforts after the review.

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.

  
Lynn Rucker, Community Monitor

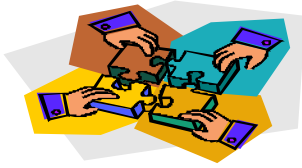


TABLE OF CONTENTS

I. Introduction and Review of Methodology	Page 3
II. Categories, Definitions and Timelines	Page 7
A. Individuals Needing Immediate Attention	Page 7
B. Individuals Needing Special Attention	Page 8
C. Individual Findings and Recommendations	Page 8
III. Quality and Overall Satisfaction	Page 9
IV. Effectiveness of Personal Safeguards	Page 11
A. Guardianship	Page 11
B. Case Management	Page 12
V. Adequacy of Planning and Implementation	Page 14
A. Assessments	Page 14
B. The Planning Team	Page 15
C. The Individual Service Plan (ISP)	Page 16
D. ISP Team Member and Process Expectations	Page 17
E. Implementation of the ISP	Page 18
F. Adaptive Equipment and Augmentative Communication	Page 19
<b>Historical Scoring: Adaptive Equipment/Augmentative Communication</b>	Page 19
G. Overall adequacy/intensity of ISP	Page 20
<b>Historical Scoring: Overall Adequacy/Intensity of ISP</b>	Page 20
VI. Community Integration and Membership	Page 20
A. Valued Roles, Friends and Natural Supports	Page 20
B. Work/Day Supports and Services	Page 22
C. Supported Employment	Page 22
<b>Historical Scoring: Supported Employment</b>	Page 23
D. Home	Page 23
VII. Wellness	Page 24
A. Health and Medical	Page 25
B. Behavioral	Page 25
<b>Historical Scoring: Behavior</b>	Page 25
Attachment A: Individual Findings	

## I. INTRODUCTION AND REVIEW OF METHODOLOGY

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

<b>Phase I</b>	<b>Sample Selection, Review Preparation</b>	<b>April 12, 2004 to May 14, 2004</b>
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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 Robert Mendoza reconciled the regional list with the LTSD (Santa Fe) list of Class Members and where they live.
- The Community Monitor selected the sample.
- The Regional Office then began to gather documents required for the review. They did this in concert with local independent case managers.
- The Regional Office 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 SE Region was 44. The total number of class members selected for the review was fifteen or 34% 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 SE Region.

Based on this information the number of class members to be reviewed was set at 15 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 SE 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 7<sup>th</sup> 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**

The reviewers for the SE Region included Long Term Services Division or Department of Health Improvement staff. In addition, each case judge reviewed one person and the Community Monitor reviewed one person. The only restrictive "criteria" for reviewers, other than that 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 judge with that background was assigned and so on.

Reviewers included:

Wanda Black, Case Judge	Carly Crawford, Case Judge
Keytha Jones, Case Judge	Marti Madrid, DHI
Kerry Palma, LTSD	Lyn Rucker, Community Monitor
Deb Russell, DHI	Donna Storey, DHI
Valerie Valdez, DHI	

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

Wanda Black	Carly Crawford
Keytha Jones	

### **Phase II On Site Information Gathering**

**May 17 to May 21, 2004**

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

- 4 independent case management agencies (DSL, J & J, PRMC, and Sun Country) and one Long Term Services Division case manager (supporting one person who resides in an ICF/MR);
- 8 day service providers (Alliance, CARC, Casa Allegre, Door of Opportunity, ENMRSH, Leaders, ResCare, and Tobosa); and
- 9 residential providers (Alliance, CARC, Casa Allegre, Door of Opportunity, ENMRSH, High Desert, Leaders, ResCare, and Tobosa).

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 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.

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. This 'status update' included regional office staff and representatives from LTSD.

At the conclusion of this meeting, 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"<sup>1</sup> 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?") the 2002 Protocol Book offered no criteria against which to measure the answer. The 2004 Protocol Book defines

<sup>1</sup> 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.

'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 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 Southeast Regional Office and LTSD.
- Review #4: The Regional Program Manager and Southeast 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 SE Regional Office.
- Review #6: The Community Monitor met with the Regional Office staff, and gave them another opportunity to identify areas that needed further clarification. Where measurability for monitoring and follow-up was needed, it was added.

Review #7: The Community Monitor met with over 40 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, DHI Information Systems Bureau Chief, 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 Southeast Regional Office staff, representatives from LTSD, and providers/case managers, this PowerPoint presentation has been modified and revised.

#### **Phase IV      Editing/Writing**

**September to November 2004**

The information gathered as a part of this process was brought together, analyzed and forms the foundation of this report.

## **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”**

Four individuals (27%) 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”

Two individuals (13%) 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 6 individuals (40% 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
DSL M	2	1	3
J&J	1	0	1
LTSD	0	0	0
PRMC	1	1	2
Sun Country	0	0	0
<b>Total</b>	<b>4</b>	<b>2</b>	<b>6</b>

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

	Immediate Need	Special Attention	Total
Alliance	0	0	0
CARC	0	0	0
Casa Allegre	0	0	0
Door of Opportunity	0	0	0
ENMRSH	1	1	2
High Desert	1	0	1
Leaders	1	0	1
ResCare	2	1	3
Tobosa	0	0	0

## 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 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.

Providers are making efforts to accommodate cultural preferences.

8 class members are enabled to make personal choices about things like where and with whom to live.

It is important to note that eight 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 reviewed.

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 8 Partial 1 No
Does the person have the opportunity to make informed choices? (3 CND)	8 Yes 3 Partial 1 No
<ul style="list-style-type: none"> <li>▪ About where and with whom to live? (3 CND)</li> </ul>	8 Yes 3 Partial 1 No
<ul style="list-style-type: none"> <li>▪ About where and with whom to work/spend his/her day? (3 CND)</li> </ul>	7 Yes 4 Partial 1 No
<ul style="list-style-type: none"> <li>▪ About where and with whom to socialize/spend leisure time? (3 CND)</li> </ul>	7 Yes 5 Partial
Providers do not prevent the person from pursuing relationships and are respecting the rights of this person?	11 Yes 4 Partial
Does the person have daily choices/appropriate autonomy over his/her life?	10 Yes 4 Partial 1 No

QUALITY OF LIFE	Response
Have the person's cultural preferences been accommodated? (1 CND)	9 Yes 4 Partial 1 No
Is the person treated with dignity and respect?	7 Yes 7 Partial 1 No

The majority of Class Members able to respond find case managers helpful and get along well with their day and residential staff.

Individuals who were able and willing to answer questions regarding their level of satisfaction with services provided very helpful and generally very positive information. Case managers and direct support staff are to be recognized and thanked for developing positive relationships with those whom they support.

CND = Can not determine

SATISFACTION	Response	% Yes <sup>2</sup>
Overall, is the person satisfied with the current services? (6 CND)	5 Yes 4 Partial	56%
Does the person get along with the case manager? (8 CND)	7 Yes	100%
Does the person find the case manager helpful? (9 CND)	6 Yes	100%
Does the legal guardian find the case manager helpful? (4 CND, 1 N/A)	7 Yes 2 Partial 1 No	70%
Does the person have adequate food and drink available?	13 Yes 2 Partial	87%
Does the person have adequate transportation to meet his/her needs?	11 Yes 3 Partial 1 No	73%
Does the person have sufficient personal money? (5 CND)	9 Yes 1 Partial	90%
Does the person get along with their day program/employment staff? (3 CND)	11 Yes 1 Partial	92%
Does the person get along with the residential provider staff? (4 CND)	10 Yes 1 Partial	91%

Level of satisfaction 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

87% (13) of day staff "know" the person well.  
73% (11) of home staff "know" the person well.

<sup>2</sup> When reflecting the "% Yes" individuals for whom reviewers could not determine an answer or for whom the question does not apply are not reflected in the denominator. The "Can Not Determine" number and the "Not Applicable" number are subtracted from the "total possible number" and then the percentage is calculated.

competent, kind and knowledgeable staff. These staff appear to know the person well and have developed a caring and supportive relationship.

- Ten people were identified as getting along well with their residential support staff. (4 CND)
- Eleven people were identified as getting along well with their day/employment staff. (3 CND)
- For eight of the people reviewed, there was evidence that they have achieved progress in the past year.
- Six people are involved in employment, four (27%) of whom met the 'minimal' supported employment criteria agreed to by the parties.
- Five people are adequately integrated into the community.
- Eleven people were identified as having access to adequate transportation.
- Nine people were identified as having sufficient personal money.

53% of class members reviewed show evidence of progress in the past year.  
27% were involved in Supported Employment.  
33% are adequately integrated into the community.  
73% have adequate transportation.  
90% have sufficient personal money.

Generally, people were found to be supported by informed staff that care for and work well with the individual. As highlighted earlier, people who could express themselves, in the majority of 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 "in charge" of "my own home", having adequate money, 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.

#### IV. EFFECTIVENESS OF PERSONAL SAFEGUARDS

##### A. GUARDIANSHIP

Fourteen of the fifteen individuals reported as a part of this review have guardians. Four of these individuals have guardians who are actively involved with them, six have moderately involved guardians, and four have guardians who are involved in only a limited way.

29% have active participation of guardians;  
43% have moderate participation; and  
29% have limited participation.

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

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

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;
- would like or needs information and/or assistance; and
- the person is getting a new guardian.

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. In the mean time, the individual needs support and personal attention, consequently, three people were seen as needing a friend-advocate or someone unrelated to service provision to fill in for this missing safeguard.

3 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 seen 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.

53% 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 and reports of proactive advocacy. There were compliments given to case managers who understood his/her role and job (10 case managers) and 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. Eleven 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.

Only 27% have documentation that the cm is monitoring and tracking the delivery of services as outlined in the ISP. The expectation is 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 case managers provide case management services at the level needed by the class member (2 people), too frequently the case manager does not. In some cases the case manager has not received all of the training needed (7 people) or 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.

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 9 Partial	40%
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 10 Partial 1 No	27%
Does the cm provide cm services at the level needed by this person?	2 Yes 12 Partial 1 No	13%
Does the legal guardian find the cm helpful? (4 CND, 1 NA)	7 Yes 2 Partial 1 No	70%

Throughout the service system, expectations create the boundaries for individuals receiving supports. 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.

Only 20% (3) of the case managers were seen as having “an appropriate expectation of growth” for the person they are 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 <sup>3</sup>)

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 20% of the time.

Only three people's teams 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 clearly used to influence planning for only three people.

Question	Response	% Yes
Did the team consider what assessments the person needs and would be relevant to the team's planning efforts?	4 Yes 10 Partial 1 No	27%
Did the team arrange for and obtain the needed, relevant assessments?	3 Yes 11 partial 1 No	20%
Are the assessments adequate for planning?	4 Yes 9 Partial 2 No	27%

<sup>3</sup> CFR Active Treatment Requirements, these are the corresponding "Tag Numbers".

Question	Response	% Yes
Were the recommendations from assessments used in planning?	3 Yes 8 Partial 4 No	20%

## 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 4 (27%) 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 four of the fifteen people 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.

Team ‘**membership**’, like assessments, is a foundation essential for the development of a comprehensive and 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 three of the twelve relevant teams 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 (33%) had an “appropriately constituted team”.

Only 3 people (25%) who had team members “missing” from meetings had these members participating in development of the ISP.

87% (13) of the day staff knew the person well but only 53% (8) 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.

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 should, therefore, be very 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 day staff were more likely (than residential staff) to know the person well, but residential staff were more likely to have 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.*

All of the individuals in the review had an ISP. Only eight (53%) 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. Generally, the ISP's appeared to be much the same from year to year to year. 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.

	<b>Met Paper Expectation</b>	<b>Met Content Requirements</b>
There is a document called an ISP	100%	
▪ Long-term vision is adequate?		(4) 27%
▪ Goals include criteria by which the team can determine when the goal(s) have been achieved?		(2) 13%
▪ ISP goals related to achieving the person's long-term vision?		(3) 20%

	Met Paper Expectation	Met Content Requirements
▪ ISP goals address the person's major needs?		(1) 7%
▪ The recommendations and/or objectives of ancillary providers are integrated into the goals, objectives and strategies of the ISP? (2 N/A)		(1) 8%
▪ 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? (2 N/A)		(3) 23%
▪ Does the ISP contain specific arrangements for primary health care?		(6) 40%
▪ Does the ISP reflect how the person will obtain prescribed medications?		(3) 20%
▪ Does the ISP contain a list of adaptive equipment needed and who will provide it? (5 N/A)		(3) 30%

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	33%
▪ used as the basis for goal development for only 4 people.	27%

#### 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 not consistently seen. The good news in this region, which has not been the case in some of the others, is that all of the residential changes were seen as "appropriate to meet the person needs".

	Yes/No	Met Process or Outcome Expectations
Was the person provided the assistance and support needed to participate meaningfully in the planning process?	10 Yes 5 Partial	67% Yes
Is there evidence that the ISP was reviewed by the team within the last 6 months? (5 N/A not included in the denominator)	10 Yes	100% Yes

	<b>Yes/No</b>	<b>Met Process or Outcome Expectations</b>
Do records or facts exist to indicate that the team convened meetings as needed due to changed circumstances and/or needs? (1 CND, 4 N/A)	4 Yes 6 No	40% Yes
Has the person changed residential/day services in the last year?	3 Yes 12 No	20% Yes
<ul style="list-style-type: none"> <li>▪ Was this change planned by the team? (12 N/A)</li> </ul>	2 Yes 1 No	67% Yes
<ul style="list-style-type: none"> <li>▪ Was this change appropriate to meet the person's needs? (12 N/A)</li> </ul>	3 Yes	100% Yes

One team was 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.

	<b>Yes/No</b>	<b>Met Process or Outcome Expectations</b>
Are the individual members of the team following up on their responsibilities?	4 Yes 11 Partial	27%
If there is evidence of team conflict, in the reviewer's opinion, has the team made efforts to build consensus? (13 N/A)	2 Yes	100%
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%

	Yes/No	Met Process or Outcome Expectations
Is there evidence or documentation of physical regression in the last year?	5 Yes 10 No	33%
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 the denominator)	1 Yes 2 Partial 2 No	20%
Has the team process been adequate for assessing, planning, implementing and monitoring of services for this person?	2 Yes 12 Partial 1 No	13%
Overall, is the ISP adequate to meet the person's needs?	0 Yes 12 Partial 3 No	0%
Is the program of the level of intensity adequate to meet this person's needs?	2 Yes 13 Partial	13%

#### 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 needs to be updated, device not available to the person at all times across environments, device not working or missing, and device not being used across environments.

#### Historical Scoring: Adaptive Equipment/Augmentative Communication

Question	2000	2001	2002	2003	2004
Has the person received all adaptive equipment needed?	59%	73%	83%		67%
Has the person received all assistive technology needed?	54%	60%	81%		29%
Has the person received all communication assessments and services needed?	49%	51%	61%		36%

## 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 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?	69%	62%	57%		53%
Does the person have an ISP that contains a functional supports assessment based on a long-term view?	100%	85%	64%		60%
Does the person receive services and supports recommended in the ISP?	62%	54%	50%		40%
Does the person have adequate access to and use of generic services and natural supports?	69%	69%	64%		40%
Is the person adequately integrated into the community?	92%	62%	71%		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 they wish to do; and has control over personal resources.

### 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."<sup>4</sup>

<sup>4</sup> John O'Brien and Connie Lyle O'Brien, Members of Each Other, Responsive Systems Associates, 1991.

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**

- 4 people have supported employment, and have the role of employee.\*
- 6 people total have some community employment.\*
- 1 person does volunteer work.
- 1 person is a Board Member.
- 1 person is a member of People First.
- 4 people attend church regularly, one person sings along with the choir.
- 9 people were described as having 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 – and personally selected)**

- 2 people were identified as having (non-paid) friends. Unfortunately one of these people is unable to see his friends as he would like.

### **People have natural supports**

- 9 people were identified as participating in activities in their community resulting in them becoming known and familiar (going to the barber shop, attending the Senior Center regularly, going to the beauty salon, attending movies, eating out, etc.)

## People have their own homes and neighborhoods

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

## People show evidence of progress

8 people have gained skills and shown improvement.\*

### B. WORK/DAY SUPPORTS AND SERVICES

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

	<b># of Yes/No</b>	<b>% Yes</b>
Did the direct service staff receive training on implementing this person's ISP?	7 Yes 8 Partial	47 %
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?	10 Yes 3 Partial 2 No	67%
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	10 Yes 5 Partial	67%
Does the direct service staff have an appropriate expectation of growth for this person?	10 Yes 4 Partial 1 No	67%
Is the day/employment environment generally clean, free of safety hazards and conducive to the work/activity intended? (2 CND; 2 N/A)	5 Yes 5 Partial 1 No	45%

### 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 employment 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?	62%	100%	79%		73%
Need supported employment?	46%	85%	71%		67%
Receive supported employment assessment?	100%	100%	73%		91%
Assessment conforms to DOH Regs?	88%	92%	64%		9%
Has a Career Development Plan?	100%	36%	50%		0%
Is supported work in line with requirements?	83%	55%	30%		40%

#### D. HOME

Interviews at home 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.

	<b># of Yes/No</b>	<b>% Yes</b>
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?)	13 Yes 2 No	87%
Was the direct service staff able to describe his/her responsibilities in providing daily care/supports to the person?	12 Yes 3 Partial	80%
Did the direct service staff have training in the ISP process?	11 Yes 3 Partial 1 No	73%
Did the direct services staff have training on the provider's complaint process and on abuse, neglect and exploitation?	9 Yes 6 Partial	60%
Does the direct service staff have an appropriate expectation of growth for this person?	9 Yes 5 Partial 1 No	60%
Does the person's home offer a minimal level of quality of life?	11 Yes 4 Partial	73%

## 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 in the Southeast that emerged from this review seemed to cluster in the following areas.

- There appears to be a **lack of clear follow-up on recommendations made by health care professionals** and others.
  - For 9 of the 15 people reviewed (60%), recommendations made by specialists appear not to have been followed.
  - For 8 people diagnostic tests were not completed (e.g. lab work, neurological, nutritional evaluation, hearing exam, eye exam, physical, bone density study).
  - Also, questions were raised regarding the apparent lack of follow through to acquire recommended diagnostic testing, lab work, or equipment.
- For 9 of the 15 people reviewed (60%), recommendations made by specialists appear not to have been followed.
- For one class member, **suspicious regarding the person's health status appear to remain unresolved**. Symptoms appear to be clearly identified but the cause remains undiagnosed. For another, the diagnosis was made several years ago but staff do not appear to be following instructions provided to limit the impact of the diagnosis or are not ensuring that tracking and needed follow-up is taking place.
- The Southeast Regional Office does have one FTE nurse on staff which is a tremendous benefit and safeguard. Currently there is **no Medical Champion** in the SE Region. The Medical Champion from the Southwest Region "covers" this region if time allows.
- It was reported that **emergency room services cannot be relied on** to provide timely and needed interventions. Technical Assistance is needed.
- It was reported that a **hospital would not allow trained staff to provide the support or guidance needed** in order to ensure the health and safety of an individual admitted. The individual passed away in the hospital.
- As is the case in the other regions, all the needed team members are not regularly attending meetings. When there is **inconsistent participation in team meetings, lack of diligent and informed oversight and supervision, and poor communication/documentation**, people are in jeopardy of receiving poor, inaccurate or ineffective interventions. As identified below, only 4 people were identified as having their "health supports/needs adequately addressed".

- 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.

A. HEALTH AND MEDICAL

	# of Yes/No	% Yes
Was the employment/day direct service staff able to describe this person's health-related needs?	10 Yes 4 Partial 1 No	67%
Was the residential direct service staff able to describe this person's health-related needs?	9 Yes 6 Partial	60%
Overall, were the team members interviewed able to describe the person's health-related needs?	4 Yes 11 Partial	27%
Is there evidence that the team discussed the person's health-related issues?	8 Yes 7 Partial	53%
In the opinion of the reviewer, are the person's health supports/needs being adequately addressed?	4 Yes 9 Partial 2 No	27%

B. BEHAVIORAL SUPPORTS

**Historical Scoring: Behavioral**

Question	2000	2001	2002	2003	2004
Does the person need behavioral services?	62%	77%	71%		67%
Have adequate behavioral assessments been completed?	88%	70%	40%		30%
Does the person have behavior support plan developed out of the behavior assessments that meet the person's needs?	88%	70%	50%		50%
Have the staff been trained on the behavior support plan?	88%	90%	90%		50%
Does the person receive behavioral services consistent with his/her needs?	88%	60%	60%		40%
Are behavioral support services integrated into the ISP?	13%	80%	60%		30%