

1992-1993 Behavioral Outcome Study

**Facility-Wide Study on
Changes in Challenging Behavior
for Persons with Developmental Disabilities
and Implications for Changes in
Rendering Behavioral Supports**

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A special thanks to Melina Gabriella Baron-Deutsch, the best "outcome" for 1994 that a first-time father could ever hope for.

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Two versions of this report are available: (1) Person names *included* on spreadsheets in appendices. (2) Person names *excluded* on spreadsheets in appendices. Version with person names included provided only to those who work directly with, supervise providers who work directly with, or are responsible for monitoring such persons receiving services.

The sign of a first rate intelligence is the ability to hold two opposite ideas in one's mind at the same time without going crazy. One should, for example, be able to see that things are hopeless and still strive to make them better.

F. Scott Fitzgerald
The Crack-Up

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Abstract

A facility-wide study of behavioral outcome associated with 240 behavioral programs in place on 12/31/93 for 132 persons with developmental disabilities was undertaken. Two indicators of change between 1992 and 1993 were used: (1) Changes in rates of challenging behavior as revealed by behavioral data, and (2) Staff observation of change in a person's challenging behavior.

Behavioral Data. When behavioral rate data were used, degrees of change (for 193 programs which allowed for cross-year comparisons) were collapsed into three categories: (1) worse: regression of -11% or more between 1992 to 1993, (2) same: variation from -10% to +10% between 1992 and 1993, and (3) better: improvement of +11% or more between 1992 to 1993. About half of all behavioral programs were associated with moderate or significant improvement, approximately one fourth remained about the same, and another fourth were associated with moderate or significant regression. However, when programs were analyzed in terms of whether psychoactive medications were used adjunctively, a considerably different picture emerges:

Treatment (n)	Worse ≤ -11%	Same -10% to +10%	Better ≥ +11%
ON meds (115) ¹	37 % (43)	23 % (27)	39 % (45)
OFF meds (78) ²	12 % (9)	24 % (19)	64 % (50)

¹65 persons with 115 programs; ²67 persons with 78 programs

Behavioral programs for persons on psychoactive medications were as likely to demonstrate behavioral improvement (39%) as regression (37%). In contrast, those programs without the use of such medications had a greater than 5:1 ratio of improvement to regression (64% vs. 12%). Moreover, relative to those programs without, those *with* psychoactive medications had three times the rate of behavioral regression (37% vs. 12%). While one may speculate that the use of psychoactive medications is associated with lower success and higher regression rates, one can also posit that such are used with the more behaviorally challenged person and that the withdrawal of its use might be associated with still lower rates of success and higher rates of regression. However, there appeared to be another possibility: The reduction of psychoactive medication and/or the introduction or the increase in dosage level (where already concurrently in place) of anticonvulsant medication may hold promise for behavioral success. Examples were provided where 60%-80% reductions in challenging behavior were associated with the use of anticonvulsant medications.

Staff Observation. Staff who knew the person a year or more were asked to assess a person's target behavior "now compared to a year ago." Data were collapsed into three categories: any worse, about the same, and any better. When staff observations of behavioral change were analyzed in terms of whether psychoactive medications were used adjunctively, a similar, though less dramatic picture than the one based on behavioral data emerges:

Treatment (n)	Any Worse	About Same	Any Better
ON meds (122) ¹	20 % (25)	43 % (53)	36 % (44)
OFF meds (89) ²	8 % (7)	45 % (40)	47 % (42)

¹65 persons with 122 programs; ²67 persons with 89 programs

Again we see a greater than 5:1 ratio of improvement (47%) to regression (8%) associated with those behavioral programs which were *not* accompanied with psychoactive medication. And, as with behavioral data, there is nearly three times the rate of regression shown with the use of psychoactive medication (20%) than without its use (8%). It is not unreasonable that some behavioral rate changes outside the -10% to +10% range would not be readily perceptible as better or worse, and therefore would contribute to an increased number of staff responses of “about the same.”

Both behavioral and staff observation data suggest that a greater number of persons with challenging behavior improved than regressed between 1992 and 1993 (by a 2:1 to 3:1 ratio). As well, individuals *without* psychoactive medications had a still greater improvement/regression ratio (greater than 5:1, using either behavioral data or staff observation) than those with such medication (about 1:1 or nearly 2:1, based on behavioral or staff observation, respectively).

Discussion covered a wide range of topics, including, for example, establishing criteria for success, spreadsheet layouts (which allow comparison of behavioral outcome by cottage, by rank order of improvement, by category of behavior, and by person name), Written Training Plans, psychoactive medication, and psychological evaluations. See the Table of Contents for the complete list of topical areas.

Recommendations included 21 specific actions geared toward LLCPPDD and the New Mexico Task Force for the Development of a Behavioral Support System (BSS) for Persons with Developmental Disabilities and Challenging Behaviors. Some included: the adoption of a mission statement and means by which to determine if the mission is accomplished, ideas for revamping evaluations and Written Training Plans, the considered use of anticonvulsant in place of or in addition to psychoactive medications, establishing a statewide computer database of behavioral program information to increase information sharing and to allow for better monitoring of programs, and investigating the ingredients to behavioral successes. The full list of recommendations is summarized in the Table of Contents.

Purpose

The purpose of this study was threefold: (1) to develop a means of tracking behavioral outcome for persons with developmental disabilities and challenging behaviors on a facility-wide basis, (2) to determine what the specific behavioral outcomes were, and (3) to provide the data needed to form the basis of determining the correlates of behavioral success and regression.

Method

A facility-wide study of behavioral outcome associated with 240 behavioral programs in place on 12/31/93 for 132 persons with developmental disabilities was undertaken. Two indicators of change between 1992 and 1993 were used: (1) Changes in rates of challenging behavior as revealed by behavioral data, and (2) Staff observation of change in a person's challenging behavior.

Behavioral Data. Behavioral data were collected in one of three formats: (1) Format A: Frequency count, or the number of incidents, of challenging behavior per observation period. For example, 2400 incidents of aggressive behavior during 400 hours of observation would yield a rate of 6.0 incidents per hour. If this rate of 6.0 reduced to, say, 4.0 between 1992 and 1993, this would equal a 33% improvement. (2) Format B: Time sampling of challenging behavior, or the percentage of observations during which the challenging behavior occurred. For example, self-injurious behavior occurring during 100 of 500 workshifts would yield a rate of 20%. If this rate of 20% went up to, say, 35% between 1992 and 1993, this would represent a 15% regression. (3) Format C: Time sampling of adaptive behavior, or the percentage of observations during which the adaptive behavior occurred. For example, appropriate eating behavior occurring during 400 of 500 mealtime observation periods would yield a rate of 80%. If this rate of 80% increased to, say, 90% between 1992 and 1993, this would represent a 10% improvement. Programs using Format C sometimes addressed the "glass being half full," that is, they might focus on the control or absence of the maladaptive behavior. An 80% success rate on Format C targeting "appropriate eating" would be equivalent to a 20% rate on Format B targeting "inappropriate eating." Differences in formats will be further discussed later.

Staff Observation. Success was measured not only in terms of behavioral rates reflected in the data, but by staff observation of perceived change in a person's behavior over the past year. Staff who knew the person at least a year were asked by psychological technicians to assess a person's target behavior "now compared to a year ago," where 1 = much worse, 2 = worse, 3 = about the same, 4 = better, and 5 = much better. If the person had more than one target behavior, the staff member would be asked to assess level of change for each target behavior.

Results

Behavioral Data. When behavioral rate data were used, degree of change (for 193 programs which allowed for cross-year comparisons) fell into five categories, as follows: (1) regression of -40% or more from 1992 to 1993, (2) regression between -39% and -11%, (3) variation between -10% and +10%, (4) improvement between +11% and +39%, and (5) improvement of 40% or greater. Changes in behavioral rates were as follows:

Behavior Rate Change	1 ≤ -40%	2 -39% to -11%	3 -10% to +10%	4 +11% to +39%	5 ≥ +40%	Σ	Worse ≤ -11%	Same -10% to +10%	Better ≥ +11%
% (n)	11% (21)	16% (31)	24% (46)	27% (53)	22% (42)	100% (193)	27% (52)	24% (46)	49% (95)

About half of all behavioral programs were associated with moderate or significant improvement, about one fourth remained about the same, and another fourth were associated with moderate or significant regression. However, when programs were analyzed in terms of whether psychoactive medications were used adjunctively, a considerably different picture emerges:

Treatment (n)	Worse ≤ -11%	Same -10% to +10%	Better ≥ +11%
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Behavioral programs for persons on psychoactive medications were as likely to demonstrate behavioral improvement (39%) as regression (37%). In contrast, those programs without the use of such medications had a greater than 5:1 ratio of improvement to regression (64% vs. 12%). Moreover, relative to those programs without, those *with* psychoactive medications had three times the rate of behavioral regression (37% vs. 12%). While one may speculate that the use of psychoactive medications is associated with lower success and higher regression rates, one can also posit that such are used with the more behaviorally challenged person and that the withdrawal of its use might be associated with still lower rates of success and higher rates of regression.

However, there appears to be another possibility: The reduction of psychoactive medication and/or the introduction or, where already concurrently in place the increase in dosage level, of anticonvulsant medication may hold promise for behavioral success. Attached are examples of two actual persons, though here

identified as “John Doe” (Appendix A) and “Mary Doe” (Appendix B), who appear to have 60%-80% reductions in behavior associated with the use of anticonvulsants. In John’s case, the introduction of anticonvulsants (tegreol and depekote) to the pre-existing use of psychoactives (haldol and lithium) was associated with a 78% reduction in challenging behaviors (SIB, aggression, pica). In Mary’s case, the reduction in level of psychoactive (mellaril) and increase in anticonvulsant (tegreol) medications were associated with a 60% reduction in challenging behaviors (tantrums and aggression). Other examples are available.

Staff Observation. Success was measured not only in terms of behavioral rates reflected in the data, but by staff observation of perceived change in a person’s behavior over the past year. When asked to assess a person’s target behavior “now compared to a year ago,” where 1 = much worse, 2 = worse, 3 = about the same, 4 = better, and 5 = much better, staff observations were as follows:

Staff Observ.	1 Much Worse	2 Worse	3 About Same	4 Better	5 Much Better	Σ	Any Worse	About Same	Any Better
% (n)	4% (8)	12% (24)	44% (93)	30% (63)	11% (23)	100% (211)	15% (32)	44% (93)	41% (86)

Similar to behavioral rate changes noted earlier, there is a greater percentage of challenging behaviors assessed by staff as better than worse (here, 41%:15%, compared to 49%:27% on behavioral data), but a greater number are assessed by staff as about the same (here, 44%, compared to 24% on behavioral data). It is not unreasonable that some behavioral rate changes outside the -10% to +10% range would not be readily perceptible as better or worse, and therefore would contribute to an increased number of staff responses of “about the same.”

When staff observations of behavioral change were analyzed in terms of whether psychoactive medications were used adjunctively, a similar, though less dramatic picture than the one based on behavioral data emerges:

Treatment (n)	Any Worse	About Same	Any Better
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¹ 65 persons with 122 programs; 67 persons with 89 programs

Again we see a greater than 5:1 ratio of improvement (47%) to regression (8%) associated with those behavioral programs which were *not* accompanied with psychoactive medication. And, as with behavioral data, there is nearly three times

the rate of regression shown with the use of psychoactive medication (20%) than without its use (8%).

Both behavioral and staff observation data suggest that a greater number of persons with challenging behavior improved than regressed between 1992 and 1993 (by a 2:1 to 3:1 ratio). As well, individuals *without* psychoactive medications had a still greater improvement/regression ratio (greater than 5:1, using both behavioral data or staff observation) than those with such medication (about 1:1 or nearly 2:1, based on behavioral or staff observation, respectively).

Discussion

Criteria for Success: The False “Versus” Dichotomy. Dr. Wade Hitzing told of the “million dollar man” at a recent task force meeting (4/21/94, personal communication), where a large amount of money was spent enhancing the environment for a gentleman with considerable aggressive behaviors. The expenditure notwithstanding, his aggressive behaviors persisted. The false “versus” dichotomy is the belief that positive behavioral supports are somehow at odds with using rates of challenging behavior. Positive behavioral supports are, hopefully, *means* to ameliorating rates of challenging behaviors. If positive behavioral support is the method, rate of challenging behavior would be one desired outcome. “Quality of Life,” an often used term in the social sciences, may be both a means and an end, but the efficacy of the intervention with the million dollar man was measured not by the beauty of his revamped surroundings but by the persistence of his aggressive behavior. The entire premise of providing supports for developmentally disabled persons “with challenging behaviors” is that if the “right support” is given, challenging behaviors may dissipate. The determination of the right support will depend upon knowing its correlation with the challenging behavioral outcome. Outcome variables may include behavioral rates, staff perception of behavioral change, General Maladaptive Index score on the Inventory for Client and Agency Planning (ICAP), required days of one-on-one staffing, number and lengths of psychiatric hospitalizations, etc.

Tracking. Without adequate tracking of behavioral outcome, the person with challenging behavior is at greater risk to persist or regress with such behavior. Apart from regulatory and ethical obligations to maintain adequate records of behavioral progress, the clinician needs to know if she or he is on the right path or if a new game plan is needed. Moreover, when psychoactive medications are used as adjuncts to behavioral programs, their efficacy needs to be closely monitored due to the potential deleterious side effects of such medications.

Spreadsheet by Cottage and Last Name. Appendix C presents a listing of all persons at the facility, listed first alphabetically by cottage (the “COT” column),

then within each cottage by the person's last name (the first column). The assigned psychologist and psych tech are noted. As well the target behavior(s) for each person is listed, along with, for 1992 and 1993, the behavioral data format used (A, B, or C), observation time length, raw data totals (number of occurrences divided by the number of observations), and the resulting behavioral rate for each year. The percentage improvement or regression in behavioral rate between 1992 and 1993 is noted, then coded 1-5 based on the degree of change in rate (1 = $\leq -40\%$, 2 = -39 to -11% , 3 = -10 to $+10\%$, 4 = $+11$ to $+39\%$, 5 = $\geq +40\%$). Additionally, the staff observation of change between 1992 and 1993 is noted, rated 1-5 (where 1 = much worse, 2 = worse, 3 = about the same, 4 = better, 5 = much better). The staff observer's initials are indicated. It is then noted if the person is receiving psychoactive medication as an adjunct to behavioral programming. Lastly, room for comments is provided.

Outcome by Cottage Location. Behavioral outcome measures were sorted by cottage location. Here are the percentages of behavioral programs, by cottage, which were associated with behaviors regressing (-), staying about the same (0), or improving (+). These figures reflect the average between using behavioral rate change data and staff observation of change data. For a complete breakdown of each of these criteria by cottage, as well as degree of change, see Appendix D.

COTTAGE	-	0	+
Bashein East	25	67	9
Bashein West	0	17	84
Burroughs	0	64	37
Chavez West	0	0	100
Dillon	36	34	30
Huning	33	22	45
Otero	35	22	43
Seligman	0	0	0
Simms	17	50	33
1	50	50	0
2	0	21	79
3	15	35	50
4	22	56	22
5	20	45	35
6	0	37	64
7	14	44	42
8	8	15	77
9	21	39	41
10	0	23	78
TOTALS	21	34	45

Any speculations entertained on cottage differences need to take into account the number of programs contributing to the percentage figures above. For example, the 100% improvement rate for Chavez West is based on only one program evaluated by both criteria (behavioral data and staff observation) and the 50% regression rate for Cottage 1 is the function of but two program. The reader is advised to look to Appendix D for further information. However, the above table does suggest that when both criteria are averaged together, there is a better than 2:1 ratio of improvement to regression (45%:21%) across the facility. Those cottages with a significantly greater than 2:1 ratio and which also had at least five programs assessed using each criteria include (% improvement:regression):

Cottage	+	-
Burroughs	37	0
Cottage 2	79	0
Cottage 3	50	15
Cottage 6	64	0
Cottage 7	42	14
Cottage 8	77	8
Cottage 10	78	0

It may prove quite helpful to determine aspects of the cottage environments of these cottages which may have contributed to these significantly positive ratios. In contrast, of the 52 behavioral programs throughout the facility associated with behavioral data rates regressing by -11% or more, 26, or half, of them were programs for persons located in Dillon and Otero cottages. As persons in Dillon and Otero have a greater number of programs in place (63, or 33% of all programs at the facility which allowed for cross-year comparisons) than any other two cottages, one would expect a greater number of programs associated with regression to be located there. However, there is a disproportionately greater number of programs associated with regression than would generally be predicted (50% vs. 33%).

Another factor may explain: psychoactive medications. Of the 26 persons in both Dillon and Otero, 21 (81%) receive one or more psychoactive medications. No two other cottages contain a greater number nor a greater percentage of persons on such medications. Behavioral program outcome for persons on and off psychoactive medications within Dillon and Otero cottages are compared against all other persons on and off psychoactive medications in all other cottages below. Behavioral program outcome here utilizes solely behavioral rate change data.

COTTAGE	TREATMENT	N ¹	n ²	WORSE	SAME	BETTER
DILLON	ON meds	11	25	40% (10)	24% (6)	36% (9)
	OFF meds	0	0	0% (0)	0% (0)	0% (0)
OTERO	ON meds	10	28	54% (15)	21% (6)	25% (7)
	OFF meds	5	10	10% (1)	10% (1)	80% (8)
ALL OTHERS	ON meds	44	62	29% (18)	24% (15)	47% (29)
	OFF meds	62	68	12% (8)	26% (18)	62% (42)
TOTALS	ON meds	65	115	37% (43)	23% (27)	39% (45)
	OFF meds	67	78	12% (9)	24% (19)	64% (50)
TOTALS	ON+OFF	132	193	27% (52)	24% (46)	49% (95)

¹ N = Number of persons

² n = number of behavioral programs

The regression rates for persons on psychoactive medications in Dillon (40%) and Otero (54%) exceed the regression rates for all other persons on psychoactive medications (29%) and this gap is wider when comparing regression rates of all persons off such medications (12%). All persons in Dillon Cottage receive psychoactive medications. Data for Otero Cottage are highlighted as it affords the opportunity to compare individuals on and off psychoactive medications while controlling for cottage environment. Relative to all other cottages, Otero's 15 residents have the largest total number of programs in place (41, 38 of which allowed for cross-year comparisons). The ratio of improvement to regression for those on meds (25%:54%) stands in stark contrast to those off meds (80%:10%). As previously noted, an alternative medication regimen, particularly one with the greater use of anticonvulsants, appears to show promise.

A breakdown by cottage of the number of persons within each cottage, the number with challenging behaviors, the number of behavioral programs in place, and the number of persons receiving psychoactive medications can be found in Appendix E.

Data: Clinical vs. Statistical Differences. A person reduces incidents of self-injurious behavior from 400 to 200 per month. This represents a 50% improvement. Another person's SIB reduces from 4 down to 2 per month, also a 50% improvement. The former may represent a clinically significant change, whereas the latter may represent random fluctuation. For purposes of this study, no judgements were made as to what constitutes "clinically significant." Presumably, a person with 4 SIB incidents a month has a program in place

because the behavior, despite its relative infrequency, is still considered problematic. (There are but 12 programs included in this study where the frequency of behavior was less than five incidents per month, and their inclusion or exclusion from this study did not affect the overall findings.) No attempt was made in this study to address the intensity of behavior. Does a person, then, who reduces his or her SIB, for example, from 400 to 200 (-50%) show a smaller improvement than, say, another person whose SIB reduced from 20 to 8 (-60%)? This study clearly excluded such subjective judgements. However, another tack to take for future determination of outcome would be change in General Maladaptive Index (GMI) scores on the Inventory for Client and Agency Planning (ICAP). This would reveal not only the degree of behavioral change for a person relative to his or her starting point, but would also yield information on the degree to which this person's problematic behaviors, if any, are approximating a "normal" range. The current study's use of percentage improvement in rate of behavior (or staff's observation of change) can only give a picture of *intrapersonal* behavioral success (no small accomplishment!), but there is no way such data can reveal how far the person has yet to go. The ICAP's GMI score may assist in enlarging the behavioral picture.

Psychoactive Medication. It is speculated that a number of behavioral programs with the adjunctive use of psychoactive medications may fare better with the replacement or reduction of psychoactive medications and with the introduction or increase in anticonvulsant medication. Implications for changes in diagnoses, from those of a psychiatric to those of a neurological base, are theoretically more speculative. However, a more pragmatic approach, independent of diagnostic formulation, may be to have the efficacy of the medication (or behavioral program without medication) lead to the decision to "stay the course" where associated with success or to change the treatment regimen where success has not been achieved.

Congruence Among Symptoms, Diagnoses, Behavioral Programming, Data Collection, and Medication. It may be the case that at one time, long ago, psychoactive medications were used to sedate behavior and that subsequent diagnoses were offered to fit the medication, rather than the other way around. Moreover, even where diagnoses fit the symptomology, the medication might not fit the diagnoses. Alternatively, where medication may be consistent with the diagnosis, e.g., lithium for bipolar mood disorder, the behaviors addressed through programming (for which the medication is to be used adjunctively) and the data therewith collected, may have little bearing on the symptomology generally associated with the disorder. Rather than information acquired on mania and depression, more congruent with the diagnosis of a bipolar disorder, behavioral programs may be addressing "inappropriate social greetings" or "public masturbation." LLCPPDD has made significant strides here, but there is

the need for further improvement in the area of congruence among observable symptoms, diagnoses, behavioral programming, data collection, and medication. With greater team process and dialogue, particularly with the consulting psychiatrist, and with added *documentation of DSM-III-R defined criteria for diagnoses*, there will be still further congruence achieved.

Types of Challenging Behaviors. The types of behaviors which behavioral programs address are quite variable. Whether a program targeted the reduction of, or increase in “control of,” aggression or self-injurious behavior (SIB), it would be categorized here under aggression or SIB, respectively. Programs addressing “destructiveness” or “property destruction” were combined. When limited to the following five categories, the breakdown is as follows:

Aggression	71 (30%)
SIB*	52 (22%)
Pica	9 (4%)
Destructiveness	7 (3%)
Other	101 (42%)
<u>Totals</u>	<u>240 (100%)</u>

* includes Handbiting

Herewith is an alphabetical list of targeted behaviors, taken from Appendix F, and the number of behavioral programs in place for each category:

69 Aggression	3 Hallucinations	1 Public masturbation
2 Aggression + other	2 Handbiting	1 Rectal digging
5 Agitation	5 Handmouthing	1 Refusal to leave
2 Anger	1 Hyperactive/repetitive	1 Resist class transport
2 Appropriate behavior	1 Hyperventilation	1 Rumination
2 Compulsive behavior	1 Inapprop social	2 Screaming
1 Control obj/hndmouth	1 Inapprop attent seek	7 Self-stimulation
1 Control self-restraint	1 Inapprop socl exchn	2 Sexually inapprop
1 Control handmouth	1 Intense screaming	49 SIB
1 Control stripping	1 Intentional falling	1 SIB + other
2 Crying	1 Manic behavior	1 Simulated seizures
1 Cursing	1 Moaning	10 Socially appropriate
5 Destructiveness	1 Non-compliance	1 Stay on task
4 Disruptive	1 Object manipulation	1 Stripping
9 Elopement	2 Participation	2 Tantrums
1 Fabric/handmouth	9 Pica	2 Throwing
1 Finger picking	1 Profanity	1 Thumbsucking
1 Food grabbing	2 Property destruction	1 Toileting accidents
1 Food throwing	1 Prosocial	1 Tolerates group activ
1 Grabbing	1 Provoking/teasing	1 Urination/defecation
1 Grooming control	1 Perseverative speech	2 Verbal aggression

The advantage of a printout such as Appendix F, listing programs alphabetically by targeted behaviors (in the “Target Behavior” column), is that it allows staff to be aware of what other colleague’s programs are in place for similar behaviors, and to promote exchange of ideas on such programs. As well, one can see which programs within one behavioral area appear to be associated with greatest success. What may help further is standardizing the taxonomy of behavioral categories, so that, for example, the following might not be grouped separately as they are now:

- Aggression-Control of aggression (combined in table above)
- Appropriate behavior-Inappropriate social-Prosocial-Socially appropriate
- Control handmouthing-Fabric/handmouthing-Handmouthing
- Control SIB-SIB (combined in table above)-Handbiting
- Control stripping-Stripping
- Cursing-Profanity-Verbal aggression
- Destructiveness-Property destruction
- Intense Screaming-Screaming

The use of the phrase “control of” does, however, allow the reader to know the focus or target is a positive rather than negative behavior.

Night Shift Data. A number of behavioral programs, particularly those in Dillon and Otero cottages, have indicated that behavioral data be collected during the night shift. When it became apparent that night shift data consistently showed that virtually no behavioral incidents occurred at night, and generally accounted for less than one percent of all incidents, such programs were modified to exclude night shift behavioral data collection. (All spreadsheet data for persons in Dillon and Otero cottages have their night shift data excluded, and, where excluded, shown under the “Comments” column.) Even if night shift rates were identical to, say, the A.M. shift rates, one could readily exclude the collection of night shift data. The reason is that data collection is not intended to provide Truth with a capital “T” and to note every behavioral incident. Rather, data collection should be as *minimal* as possible while still allowing for a fairly accurate determination of progress or regression. This is *not* to say that night shift providers be uninformed of the appropriate prevention and intervention techniques to use. Simply that we not encumber staff with more data collection than is really needed to assess progress.

Written Training Plans. The Written Training Plan (WTP) is the document which delineates the behavioral program: the goal, the method by which to attain the goal, and the system of data collection which can help determine progress toward that goal. Such programs generally have both prevention and intervention components and utilize positive reinforcement. As well, adaptive skill development, as an alternative to maladaptive behavior, can add significantly to the success of a behavioral program. An example of such a program is included

in Appendix G. Though the goal in this program is the reduction of incidents of pica, the method includes the enhancement of receptive communication skills, social skills, functional object usage, and increased choice-making. The attached WTP was developed by Doug Baker, whose two cottages (8 and 10), when combined, had a very high ratio of 78% success to only 4% regression between 1992 and 1993. (Let's applaud the efforts of these two cottages and day program providers. Doug assumed duties at these two cottages in August, 1993.) This is a good example where positive behavioral supports and noting maladaptive behavioral rates are highly compatible endeavors.

Behavior Observation Form (BOF). The BOF (Appendix H) was developed by the author and incorporated across the facility in August, 1991. It permitted standardization of data collection, though allows for three formats (A, B, C; described earlier within the "Method" section) to be used. It previously included an "Antecedents" section, which was reformulated in July, 1993 to an easier-to-understand "Behavior Comments" section, which includes room for "Before" and "After" comments. The BOF attempts to obtain both quantitative and qualitative behavioral data in the hopes of determining not only the frequency and intensity of behavior but the setting conditions and possible effective interventions. The past three years have witnessed a great improvement in the acquisition of quantitative data. At this time, an emphasis needs to be placed on the qualitative data, particularly of possible effective interventions. Encouraging staff to indicate more of "What worked?" under the Behavior Comments' "After" section can add significantly to further improving the success rates of more programs.

Reliability Checks. Pursuant to Department of Justice recommendations, monthly reliability checks were begun January 1993 requiring psychologists and psych techs to monitor the reliability of behavioral data acquired. The psychologist or psych tech would inform the care provider that such a reliability check was beginning, observe the person with a behavioral program for 15 minutes, and record the frequency of the targeted behavior. This would be compared against the frequency count of the provider. The results of such reliability checks, including discrepancies, would be discussed with the provider and recorded in the person's progress notes. At least three difficulties with this process arise: (1) Most behaviors are of such frequency that they are likely *not* to occur during a random 15-minute observation. (2) Informing the provider of the observation may have contributed to the provider being more vigilant than if not so informed (though warnings were provided to reduce the anxiety level of staff who often felt run through the "gotcha mill" of outside surveyors). (3) With nearly 250 programs to monitor, this appears to be a misuse of human resources. Data collection is simply a means to assess the direction of program efficacy and to determine if changes are warranted. Whether John Doe's SIB reduced from a rate of 100 to 75 or "really" from 116 to 82 times a month is not as critical an

issue as is the fact that improvement is underway. How such time devoted to reliability checks might better be used would be in checking not upon the behavioral data but upon the implementation of program methodology: Is the provider sufficiently familiar with and following the program? Such 15-minute times might be better spent observing the positive prevention and intervention techniques of the provider and, if opportunities for intervention do not arise during these 15 minutes (the majority of the time), inquiring of the staff "What would you do if . . . ?"

B-Med Spreadsheet (BMS). Just as the BOF is a means to keep track of information on behavioral data and comments which may help identify antecedents or consequences of such behavior, the Behavior-Medication Spreadsheet, or "B-Med Spreadsheet" is a way of keeping track of psychoactive medication regimens and their correlated behavioral outcomes. Sometimes when services are provided by a large number of people for one person, it is possible for "the left hand not knowing what the right hand is doing." In 1992, the author introduced the B-Med *graph*, a month-by-month pictorial representation of both the medication dosage and behavioral levels. However, in spring 1993, new physicians were making a number of medication changes within each month. These frequent changes and their correlated behavioral outcomes could not be depicted with a graph limited to twelve monthly entries.

At the summer 1993 psych retreat, the first BMS was presented, showing that a person receiving thorazine over the prior four years had an associated combination of SIB and aggression levels about 50% higher than when he had been off such medications six months prior to this four-year "trial" period. By fall 1993, Psych Services provided BMSs for *all* persons receiving psychoactive medications alone or in combination with anticonvulsant medications, although medication regimens were listed only from January 1993 forward. Samples of such BMSs are provided in Appendices A and B. The BMS allows the reader to quickly see the history of medication regimens, the associated behavioral levels, any comments entered regarding other factors which may have impinged upon the person, and a trend analysis with implications for possible treatment concerns.

One of the outgrowths of the BMS is that "all the players" on the team have an opportunity to see, on a *timely* basis, the treatments tried and results obtained. No person need wait four years to discover an inefficacious treatment regimen. The BMS also allows for greater monitoring of *congruence*, alluded to earlier, of diagnosis (though this specifically needs to be entered onto the BMS), symptoms, behavioral programming, data collection, and medication.

As already shown, there was a 50-50 chance of behavioral improvement or regression for persons on psychoactive medications (actually, 39-37, with 24%

remaining about the same). It was also demonstrated that anticonvulsant medications show great promise for a number of persons with challenging behaviors. Given the potential side effects of a number of psychoactive medications and its demonstrated 50-50 track record (and the 5:1 ratio of improvement to regression for persons *not* on such medications), the supplementation or replacement of psychoactive with anticonvulsant medications may be a route to seriously consider. Without the BMS, this may not have been discovered.

As people are transferred from LLCPPDD and other institutions into the community, where service providers (psychologists, psych techs, nurses, physicians, psychiatrists, case managers, etc.) are generally less accessible to one another, the significance of the BMS as a means to convey “what the left hand is doing” is multiplied. The community hopes to develop expertise in assisting persons with developmental disabilities and challenging behaviors. Human resources at this time in New Mexico are limited, though expanding. Where staff turnover remains problematic, a document such as the BMS can help fill in a succinct historical treatment perspective for the next staff or team of staff service providers. The Behavior Management and Human Rights Committee members have also found this a succinct way to determine past, present, and proposed future courses of treatment.

Ceiling Effects. If a person has a 90% success rate using Format C (or a 10% failure rate using Format B) at the outset of a treatment program, this study’s definition of improvement (+11% or greater) would categorize any improvement shown to be “about the same.” This is the ceiling effect where a person is already near the “ceiling” of achievement. (Only 9 programs in 1992 which could be compared in 1993 started at this level.) Similarly, persons whose behavioral frequencies, using Format A, are at a level of 0.05 or less per workshift (4 times per month) have more room for staying “about the same” and for regression than for improvement (only 12 programs in 1992 which could be compared in 1993 started at this level). For such programs, their continuation may be justified by the severity level of what infrequent behaviors emerge, and therefore, severity level should be a requisite component of such programs. When a person has achieved such levels “for three consecutive months,” the usual criterion length of time, an author may choose to discontinue the program altogether or make it a “service need.” Alternatively, and perhaps wisely, the author may opt to make it a “maintenance goal,” where the behavioral target level may be the currently achieved one (above 90% success rate or below .05 incidents per workshift) and the criterion length may be expanded from three to six or more consecutive months. This can allow for greater confidence that lasting results have been achieved.

Psychological Evaluations. LLCRDD is compelled by external regulations and internal procedures to provide annual psychological updates on all persons, whether or not such persons have challenging behaviors. Additionally, persons under 21 require a three-year re-evaluation and persons over 21 require a five-year re-evaluation. The structure or component parts of such updates and evaluations include:

- Reason for Referral
- Background Information
- Evaluation and Treatment History
- Evaluation Results and Interpretations
 - Cognitive Development
 - Affective Development
 - Adaptive Behavior
 - Maladaptive Behavior
- Summary
- Recommendations

As a member of a task force to help develop a Behavior Support System for developmentally disabled persons in New Mexico with challenging behaviors, the author addressed concerns regarding such evaluations (Appendix I). As the people in the general population do not have psychological evaluations performed yearly or even quintennially, it would appear a better use of human resources to have annual updates provided only for those persons with behavioral programs and evaluations performed only on an “as needed” or referral basis. Annual updates would then focus on summarizing behavioral program methods used, progress or regression attained, and implications for subsequent treatment. Given the information reviewed and summarized, what are the implications for treatment? It would appear that the most important part of an evaluation would be the recommendations. Where a person is evaluated on an as-needed or referral basis, or even in the case of an annual update for someone with an existing challenging behavior, the primary concern generally is “What should we do now to assist this person?” That is where greater specificity of treatment strategies, techniques, and reinforcers within the Recommendations section will best serve the reader and the person to be assisted.

To the degree certain information gathered within the report consistently proves irrelevant in formulating recommendations, such information gathering might be discontinued. For example, while information in the Motor Skills section of the ICAP is regularly acquired, it has little or no impact upon recommendations within psychological reports. It may be information better acquired by occupational or physical therapists than by psychologists.

If a person's quality of life remains unaffected by the evaluation, we need to ask ourselves why we engaged in the evaluation process. This paper has emphasized the importance of looking at behavioral outcome associated with behavior programs. Similarly, evaluations become meaningful only to the degree that recommendations made within them are specific, implemented, and show positive, observable results. Recommendations such as "Continue behavioral programming," or "Continue residential placement" do not inform the reader if and how the person's life can be enhanced. It was suggested above that updates and evaluations be done only where there is a challenging behavior currently being or to be addressed. While 39% of those programs adjunctively using psychoactive medications and 64% of those programs without such medications are associated with slight or significant behavioral improvement, there are the other 61% and 36% of programs with and without meds, respectively, *not* associated with improvement. The Recommendations section in reports for at least these persons should suggest *specific* new ways of addressing their challenging behaviors. This may require that a functional analysis, in-depth ABC behavioral analysis interview, or reinforcer survey be performed. But without specific new ways being recommended to address challenging behaviors, we are left with a document which may simply satisfy a regulatory agency while remaining unresponsive to the needs of the person.

Spreadsheet by Behavioral Outcome Level. Appendix J sequences behavioral programs in descending order, based on percentage of improvement (column entitled "% IMPR") in behavioral data rates demonstrated between 1992 and 1993. Such a listing may prove to be the most meaningful in beginning to understand the ingredients to success. Having a rank-ordering of programs based on success rates allows for the comparison of programs associated with the greatest improvement versus those with the greatest regression. For example, it may prove informative to see if the top 40 improvers (with clinically, not just statistically, improved rates) differ from the 40 programs associated with the greatest regression in behavioral rates. At a psych staff retreat, the following factors were speculated to affect behavioral outcome:

1. Direct care provider's belief in the person's capacity for change.
2. Frequency of reinforcement.
3. Staff turnover.
4. Level of active treatment or activities of interest.
5. Closeness of relationship between provider and person.
6. Tone or atmosphere set by cottage supervisor.

The following questions to appropriate staff members may yield the desired information:

1. To what degree do you believe ____ can improve on (target behavior) within the next year?

(1) will remain the same	(4) significantly
(2) slightly	(5) completely
(3) moderately	
2. How frequently would you say ____ is provided reinforcement for appropriate behavior (e.g., praise, touch, or something he/she likes)? [At least once every:]

(1) 15 minutes	(4) workshift
(2) 1 hour	(5) less than once per workshift
(3) 2 hours	
3. How many regular providers would you say ____ had on each shift during the past year?

(1) 1	(4) 4
(2) 2	(5) 5 or more
(3) 3	
4. How much of a typical day would you say ____ is involved in active treatment or activities of interest to him/her?

(1) nearly all (75-100%)	(4) some (10-25%)
(2) most (50-75%)	(5) little or none (0-10%)
(3) much (25-50%)	
5. How would you rate one direct care provider's relationship with ____, from 1 to 5, where the following apply to each number?

(1) very close	(4) distant
(2) close	(5) very distant
(3) neutral	
6. How would you rate the tone or atmosphere set by your cottage supervisor, from 1 to 5, where the following apply to each number?

(1) very positive	(4) negative
(2) positive	(5) very negative
(3) neutral	

Other speculated factors, such as degree of staff adherence to and implementation of behavioral programming, might also be investigated. Verification that one or more of these factors contribute to behavioral success may lay the groundwork for the development of such factors for *all* persons with behavioral programs. Unless we attempt to determine the ingredients to success, assisting persons with challenging behaviors becomes a random hit-and-miss endeavor.

Spreadsheet by Last Name. Appendix K, listing outcome data by client last name (column 1), may prove to be the quickest referencing of information for staff working with or monitoring services provided to persons at LLCPPDD. Staff may wish to remove or make a separate copy of this appendix.

Recommendations

The following recommendations apply to rendering behavioral support services at LLCPPDD but are also directed to my fellow members of the New Mexico Task Force for the Development of a Behavioral Support System for Persons with Developmental Disabilities and Challenging Behaviors.

1. Adopt a Mission Statement. The following mission statement was adopted by the Task Force and appears valid for LLCPPDD and community agencies:

Support the behavioral and emotional well-being of people with developmental disabilities, so that they are included and valued members of their community.

2. How Will “Mission Accomplished” Be Determined? It is all too easy in a large system, whether an institutional facility or a statewide Behavioral Support System (BSS), to plod along with “business as usual,” without determining the efficacy of services or supports rendered. The question is: “For all we are doing for the person, is the person any better off?” Put another way, “Did we make a difference?” Individualized Personal Programs (IPPs) are continually developed for persons with developmental disabilities, articulating target behaviors, goal levels, and target dates by which certain levels of success might be accomplished. I would suggest that “Individualized System Programs” (ISPs) be developed for the missions set out by LLCPPDD as well as the proposed statewide BBS. Given the assumption that a reduction in challenging behavior is desirable and may reflect increased behavioral and emotional well-being, that appropriate behavioral supports may contribute to such an outcome, and that inclusion within the community is desirable, herewith are some ISPs for LLCPPDD and the BSS to consider:

a. By 1/95 at least 50% of persons with developmental disabilities and challenging behaviors will reduce the frequency of their challenging behaviors between their 1993 and 1994 rates by 11% or greater, as reflected in behavioral data.

This was essentially the result achieved at LLCPPDD between 1992 and 1993, though it has already been shown that a considerable difference in success rates resulted when looking at persons who took psychoactive medications (39% success rate) versus those who did not (64% success rate). In order to aspire to such a goal, behavioral data for 1993 and 1994 (or any two comparison years) are needed. Alternatively or additionally, other criteria for assessing supported or improved “*behavioral and emotional well-being*” can be investigated, with ISP goal statements as follows:

b. By 1/95 at least 50% of persons with developmental disabilities and challenging behaviors will demonstrate improvement in their challenging behaviors between 1993 and 1994, as indicated by staff observation.

This would be comparable to the “staff observation” used in this study, where improvement was the combination of level 4 (“better”) and 5 (“much better”) responses provided by staff members.

c. By 1/95 at least 50% of persons with developmental disabilities and challenging behaviors will demonstrate improvement in their challenging behaviors between 1993 and 1994, as indicated by improvement in General Maladaptive Index scores (on the ICAP) of 5 points or greater.

The ICAP is generally administered once a year for all persons at LLCPPDD and may prove to be a less time-consuming measure of efficacy of behavioral outcome than analyzing a year’s worth of behavioral data. Moreover, the GMI scores take intensity as well as frequency into account. The biggest asset, perhaps, is that the GMI score may suggest how close to “normal” the person is functioning (whereas, e.g., a “60% improvement in SIB” does not necessarily indicate how much further a person might ideally aspire). The big down side, however, is that the ICAP respondent’s answers to items comprising the GMI score may be transient estimates that do not reflect a person’s level of behavioral functioning across the entire year, or even an entire month.

d. By 1/95 there will be a 50% reduction in the rates of psychiatric hospitalizations of persons with developmental disabilities and challenging behaviors between 1993 and 1994, as measured by number of hospitalizations and hospitalization days per person.

This would apply to persons already served in the community rather than at LLCPPDD. If, however, a disproportionate number of “at risk” individuals enter the community in a given year, the rate “per person” may go up that year. However, this should be a temporary phenomenon, with subsequent rates per person per year hopefully showing a downward trend to the extent adequate alternative behavioral supports are in place.

e. By 1/95 there will be a 100 mg chlorpromazine equivalent reduction in psychoactive medications received by persons with developmental disabilities and challenging behaviors between 1993 and 1994, as measured by chlorpromazine equivalent levels per person.

A recommendation by Psych Services at LLCPPDD in 1991, to have the quarterly psychiatric consultation conducted in concert with each person’s IDT core team rather than with one nurse for the entire Center, was implemented January 1992.

By year's end, it was demonstrated that there was a 100 mg chlorpromazine equivalent reduction in psychoactive medications. While the denial or reduction of appropriate levels of medication would be unethical, reductions achieved while maintaining the same or improved levels of behavioral and emotional welfare may be a good indicator of behavioral success and independence.

f. By 1/95 persons with developmental disabilities and challenging behaviors will demonstrate their being included and valued members of their community as reflected by an average score at the 50th percentile on the Social Belonging/Community Integration subscale of the Quality of Life (QOL) Questionnaire.

The second part of the mission statement of the BBS addresses persons with developmental disabilities and challenging behaviors "being included and valued members of their community." The QOL Questionnaire for persons with developmental disabilities, published just last year by Robert Schalock and Kenneth Keith, has a subscale which seems perfectly suited to assess this. While an overall QOL score can also be acquired, such a measure would not be responsive to assessing either of the two components in the mission statement, though increasing QOL may be a means to reduce challenging behaviors.

If LLCPPDD or the BSS establish ISPs or measurable goals from the outset, they enhance accountability and quality assurance. The key may be to administrative and clinical supervisors concurring on ways to determine "mission accomplished" and separating such outcome measures from the *means* by which to achieve them.

3. Establish a statewide computer database for behavioral information, along the lines of that established at LLCPPDD, on all persons with developmental disabilities and challenging behaviors.

If a statewide BBS is to be "state of the art" and LLCPPDD a "center for excellence," communication among providers and across agencies and facilities will need to be enhanced. A statewide computer database could provide information:

- to measure progress toward the mission statement
- to determine who is receiving behavioral support services and from whom
- to increase exchange of ideas on successful programs
- to alert supervisors and clinicians to those programs needing possible revision
- to more effectively monitor the use psychoactive medications
- to assist in further research on the ingredients to success
- on specific methods used for various adaptive and challenging behaviors

4. If WTPs are not yielding positive results, get a new plan.

ICF/MR regulations require the IDT to meet if progress on any WTP, behavioral or otherwise, is not demonstrated after 90 days. Such meetings do not always

occur. In fact, a WTP may remain unchanged even when progress may not have been shown over many months. This may be due to a number of speculated factors. However, where clinical supervision and QA-ing are assured, there is a greater likelihood timely program revision will occur. But lack of progress may be due to factors other than the WTP, e.g., medical difficulties, staffing or environmental disruptions, medication changes, lack of adherence to programming methods, etc. If such factors are speculated to have prevented progress, such should be noted and, where possible, addressed. If, however, no factors are speculated to have prevented progress, the WTP needs to be revised: not just the present level of performance and target date but the methodological steps. If not already completed, the program author may need to conduct a behavioral analysis (e.g., functional analysis, ABC, reinforcer survey, etc.) to determine what changes in method are needed.

5. Investigate replacement or supplementation of psychoactive medications with anticonvulsants for more persons.

Psychoactive medications are adjunctively used to assist behavioral programs where success without such medication has not been adequately demonstrated. However, there appears compelling evidence, both in terms of behavioral regression rates and improvement-to-regression ratios, that persons on psychoactive meds fared less well than those off such medications. This may suggest reductions in psychoactive medications (and chlorpromazine equivalents have been reduced since 1992). However, more examples are emerging where the introduction of or dosage increase in preexisting anticonvulsant medications are yielding significant results. While this may suggest changes in psychiatric diagnoses from those of functional to more organic bases, and professionals may have their theoretical differences on this, the more important issue is: What proves to assist the person most? As 61% of behavioral programs supplemented with psychoactive medications were associated with either behavioral regression (37%) or no significant change (24%) between 1992 and 1993, any different treatment regimen showing promise should be vigorously pursued. It is recommended that a person with trends analysis skills thoroughly review *all* B-Med Spreadsheets. Such a person can then discover trends (like those associated with John and Mary Doe in Appendices A and B) which may suggest who may benefit from such medication changes. Any such suggestions, of course, would then be reviewed, accepted, rejected, or modified by the appropriate IDT.

6. Submit proposed changes to Policy 5.5 on the use of psychoactive medications for administrator's and legal counsel's review.

The high turnover of physicians in 1993 was associated with changes by new physicians in the utilization of psychoactive medications, including the process by which they would pursue such changes. This led Diane Nunn, Pat Beery, and the author to review Policy 5.5 and attempt to revamp it so that it was clearer and

more comprehensive. The draft of the proposed changes was completed in Spring 1994 and should be submitted through the appropriate channels. Until and after policy changes are adopted, all new physicians and nurse practitioners need to be fully apprised of the nuances of Policy 5.5.

7. Increase and monitor congruence:

a. Between DSM-III-R defined criteria (symptomology) for diagnoses and actually assigned diagnoses.

Every person receiving psychoactive medication has a psychiatric diagnosis. Such a diagnosis should have documentation by a psychiatrist or psychologist of those DSM-III-R criteria which support the person's present diagnosis.

b. Between symptomology and target of behavioral programming.

Symptomology (such as depressed mood, disinterest in activities, significant weight change, and insomnia or hypersomnia, which may support a diagnosis of a major depressive syndrome) should be consistent with the target of behavioral programming. In this example, the symptomology of a major depressive syndrome should be consistent with the focus of behavioral programming.

c. Between the WTP target behavior and acquired behavioral data.

While it may seem obvious that behavioral data acquired should be consistent with the stated WTP target behavior, monitoring or QAing of WTPs increases the likelihood of such consistency.

d. Between diagnoses and medications.

Medication should be driven by the diagnosis and conform to current standards of practice. The use of psychoactive medication with the developmentally disabled, particularly with persons without verbal expressive language skills and who may be neurologically impaired, is a highly specialized skill. Obtaining, retaining, and independently monitoring such skilled staff is a challenge in itself. The turnover of medical staff at LLCPPDD, particularly between 1993 and 1994, has been high. Not until medical staffing is more consistent, and an independent monitor obtained, will the likelihood of greater congruence between diagnoses and medications occur.

e. Between medications and behavioral outcome.

Congruence between medications and behavioral outcome at LLCPPDD was increased and monitored with the advent of quarterly core team reviews with the consulting psychiatrist beginning in 1992 and with the inception of the B-Med Spreadsheet in fall of 1993. It appears both processes are better than either alone in assuring that the efficacy of medications will be more carefully monitored.

8. Where challenging behaviors appear at a low frequency, add intensity level.

Arguably, data collection might standardly include both frequency *and* intensity of behavior, regardless of frequency. Alternatively, frequency alone could be obtained until such point as a low frequency is obtained, after which the justification for retaining data collection lies in the intensity level of the behavior. Where the latter course is chosen, it is recommended that intensity level be required when the rate of behavior is: (a) at or below 0.10 times per workshift (8 times per month) on Format A, (b) at or below 10% of observation periods on Format B, or (c) at or above 90% of observation periods on Format C.

9. Establish a standardized taxonomy of behavioral categories.

Developing a standardized taxonomy of behavioral categories will contribute to both clearer communication among professionals and, with the establishment of a computerized database, easier and more accurate access to programs of interest to other professionals.

10. Eliminate unnecessary data collection (e.g., night workshifts).

Data collection should be as infrequent and unobtrusive to care provision as possible to while still affording a means by which to accurately assess progress. If a person engages in as many occurrences of the target behavior on odd days as on even days of the month, data collection need not occur every day. Similarly, if night workshift data collection yields a rate of behavior that is virtually zero, its inclusion only serves to artificially suppress the overall (cross-workshift) rate, does not lead to any different conclusion about program progress, and might therefore be discontinued. Lastly, if the behavioral rate in one domain (e.g., work setting) virtually always predicts the behavioral rate in another setting (e.g., residential setting), the absolute levels in either setting may not matter and data from just one setting may then be sufficient to determine progress. Providers need to focus on the provision of services while still acquiring sufficient information to convey whether programmatic changes are needed.

11. Obtain more clues for success in BOF's Behavior Comments.

The Behavior Comments section is where qualitative information, such as successful interventions, can be recorded by staff. This section has to date been variably addressed by staff, yet may prove to be the biggest help in uncovering keys to success. Psychologists and psych techs need to more consistently train and monitor the use of the Behavior Comments section.

12. Simplify the WTP from 13 to 4 sections: (1) Goal statement, (2) Methodology, (3) Data collection, and (4) Contact persons.

The goal, the means by which to achieve the goal, the way to determine goal progress, and the person or people to contact for assistance with the WTP are the

necessary and sufficient parts of a WTP. This will help streamline the WTP writing process for the author, and the WTP will be more readily integrated by the provider. Other components, such as present level of performance, rationale, etc., may be articulated in a person's annual update and may serve only as distracting information for the provider implementing the program.

13. Maintain at LLCPPDD and establish statewide a means to independently QA all behavioral programs for adequacy of goal statement, methodology, and means of data collection.

In January 1992, the duties of the lead psychologist expanded to include the QAing of all behavioral programs. While the positive behavioral outcomes achieved between 1992 and 1993 are most likely the result of hard work rendered by direct care providers, the QAing of programs in 1992 may have contributed to stronger programs for providers to follow. QAing can lead not simply to a clarification of language but, at its best, to fine tuning the method with slight modifications or to significant changes when called for. On a statewide basis, the BSS program director's duties might include sampling WTPs from all agencies on an ongoing basis for QAing.

14. Maintain at LLCPPDD and establish statewide the use of the Behavior Observation Form (BOF) to help standardize and improve both positive and maladaptive behavioral data collection.

Standardization of data collection across the facility at LLCPPDD through use of the BOF has strengthened the meaningfulness and utility of information gathered. It has allowed for a significant increase in the validity of comparisons across time periods (e.g., year to year), workshifts (e.g., AM vs. PM vs. Day Program), and cottage locations to occur. As a person moves from institution to community and between community agencies, a standard means of behavioral data collection can help determine if a person is faring better in one location than another. It allows for the comparison of "apples vs. apples" and more meaningful dialogue between agencies around the state. Unless a statewide standardization of behavioral data collection is in place, determination of the efficacy of the BBS in achieving its stated mission to support the behavioral well-being of persons with developmental disabilities and challenging behaviors may not be possible.

15. Maintain at LLCPPDD and establish statewide a means to monitor progress on all behavioral programs.

The means to monitor progress on all behavioral programs at LLCPPDD contained in this report may serve as a model for the proposed statewide BSS. This will allow for determining if the goals stated in the mission statement were achieved. Even with the relatively few variables entered on the current spreadsheets, it is possible to determine the following important findings:

- How are persons overall faring behaviorally now vs. last year?

- Which persons are benefitting most?
- Which programs are associated with the greatest success levels?
- Which programs are associated with the greatest regression levels?
- Which authors' programs appear associated with greatest success levels?
- Which residential locations are associated with greatest success levels?
- Who is authoring and receiving programs for each type of targeted behavior?
- How are persons on and off medications faring?

Organizing behavioral information in this way can contribute to unifying the BSS and the tasks it hopes to accomplish.

16. Change the focus of Reliability Checks from data to provider's implementation and knowledge of behavioral programs.

With staff's anecdotal observation already serving as a check against behavioral data anomalies, the time required to do reliability checks on behavioral data would appear to be a misallocation of human resources. However, such time devoted to reliability checks on the provider's implementation and knowledge of behavioral program may be a very prudent use of time. If the thrust of potential improvement hinges upon how staff are instructed to implement behavioral supports, for the reduction in maladaptive and increase in adaptive behaviors, then it is incumbent upon program authors to monitor the implementation of their programs. Where low frequency maladaptive behavior may preclude random observation of providers' interventions, it would *not* preclude direct observation of providers' *preventive* and positive support measures. Moreover, without adequate monitoring of program implementation, any conclusions drawn on the efficacy of behavioral programming are quite speculative. Improvement could have nothing to do with program methods if staff are disregarding the WTP and relying on other approaches.

17. Maintain at LLCPPDD and establish statewide the use of the Behavior-Medication (B-Med) Spreadsheet.

With the potential serious, and in some cases even life-threatening, side-effects of psychoactive medications, there needs to be clear evidence of such medication's efficacy, and such efficacy should be reflected in more than anecdotal reports that a person is "doing better." As such medications are to be used only as an adjunct to existing behavioral programs, and as such programs require behavioral data to monitor progress, it follows that the efficacy of such medications should similarly be determined by such behavioral data in concert with anecdotal reports. The B-Med Spreadsheet consolidates and allows the reviewer to succinctly see the history of medication use, interactions, other impinging factors, and the associated behavioral outcomes. The B-Med Spreadsheet, with its trend analyses allowed for the delineation of the apparent efficacy of anticonvulsant medications in lieu of or in conjunction with psychoactive medications (see Appendices A and B). Drs. Charles Woodhouse, Mark Wesselman, and Joseph Cardillo of the

Human Rights Committee advocated that persons transferred from LLCPDD to the community have their B-Med Spreadsheets provided to the receiving physician in order to get a clearer picture of the psychoactive (and anticonvulsant) medication history and its associated behavioral consequences. The B-Med Spreadsheet used by the BSS on a statewide basis, with a system of monitoring, perhaps by the BSS program manager, may help lead the way to systematically uncovering the most and least effective medication regimens for various presenting problems. The maintenance of such a program will require a relatively small core group of specially skilled persons in behavioral data collection, trend analyses, and medication effects. A psychological technician, psychologist, and psychiatrist (or psychopharmacologist) might form such a team.

18. Psychological Evaluations:

a. With the exception of annual updates for persons with challenging behaviors, eliminate all other required psychological evaluations and replace with evaluations on a referral-basis only.

This would be consistent with the principle of “normalization” (most people do not get annual or even quintennial psychological “check ups”) and would free up psychologists to devote their energies to more pressing enterprises such as assisting persons with challenging behaviors and the staff who support them.

b. Revamp the component parts of evaluations such that only information with the potential to contribute to recommendations will be included.

It may be difficult to determine a priori what information will potentially contribute to recommendations. However, areas of speech, language, motor skills, and education may be better left to specialists in those fields. If evaluations are limited to (a) annual updates on persons with current behavior programs, or (b) those on a referral-basis, it is likely the questions raised will be, in the former case: “How has this person done in the past year and how can we better meet their needs in the year ahead?” or, in the latter case, “How can we best meet the behavioral needs of this person?” These are the questions which should drive the content of evaluations rather than a fixed boiler plate of domains, the content of which is often unresponsive to these questions.

c. Emphasize the expansion and specificity of recommendations.

The most impressive array of evaluation content becomes very unimpressive if it culminates in a paucity of recommendations. The most important aspect of a psychological report is its recommendations. The psychologist is effectively saying, “Given all that I have reviewed, here is what I advise you do to enhance this person’s life.” Failing such action- and results-oriented advice, the report remains a stagnant piece of paper with little real meaning to the person evaluated.

The best evaluations are those, then, whose recommendations, when followed, made a difference for that person.

19. Resume “brainstorming” sessions, as advocated by the LLCPPDD administrator, by the IDTs on persons deemed to have the most challenging behaviors. (List of persons previously distributed.)

20. Determine the ingredients to success by pursuing an investigation or survey of factors which may have contributed to success.

All the data collected and evaluations written amount to little if we fail to learn from our successes as well as from our failures. We have a wealth of information collected here just “itching” to be further investigated. I am not aware of another facility-wide study on behavioral outcome with persons with developmental disabilities and challenging behaviors. However, we have an opportunity to make an even more meaningful contribution to the people we serve as well as to the profession we practice if we can begin to unravel the most central question: “What did we do made a difference?” (See proposed survey, page 18.) As already stated, “Unless we attempt to determine the ingredients to success, assisting persons with challenging behaviors becomes a random hit-and-miss endeavor.” We should obligate ourselves to do better than that.

21. Obtain, retain, and nurture in-state human resources. The evolution of training and expertise of professionals serving persons with developmental disabilities and challenging behaviors nationally and within New Mexico has been a gradual one. LLCPPDD, however, has committed substantial resources in recent years to beefing up its contingent of such professionals, with substantive gains resulting for persons served. As persons are transitioned into the community, the use of these professionals to serve them might be similarly transitioned. The effective use of out-of-state resources is acknowledged, but the ongoing care for and enhancement of the lives of New Mexicans will rest in the hands of New Mexicans. Obtaining, retaining, and nurturing in-state human resources may prove to be the best long-range strategy in assuring continuity of effective services for persons with developmental disabilities and challenging behaviors.