

Adults with Classic Autism and Co- occurring Mental Disorders

Final Report

IRB Number: 12-09



Table of Contents

ACKNOWLEDGMENTS.....	3
ABSTRACT.....	4
INTRODUCTION.....	5
METHOD.....	7
Ethics.....	7
Consumers involved in this innovative project.....	7
SAPPA description.....	9
Psychiatric assessment.....	10
SAPPA interview process.....	11
RESULTS.....	12
Demographics.....	12
Co-occurring Diagnoses.....	13
Treatment Options.....	15
CONSUMERS' FEEDBACK.....	15
FOLLOW UP.....	19
SUMMARY AND CONCLUSIONS.....	20
REFERENCES.....	21
APPENDIX 1 – ORS and SRS forms.....	23
APPENDIX 2 – Consent form.....	25
APPENDIX 3 - SAPPA psychiatric assessment (DSM-IV-TR).....	28
APPENDIX 4 – Auxiliary Material (CD-R).....	30

ACKNOWLEDGMENTS

This Mental Health Services Act (MHSA) Innovation Project was funded by the State of California, with Proposition 63, MHSA funds via the Santa Clara County Mental Health (SCCMH) Department for which we are very grateful.

We wish to express our gratitude to Dr. Patrick Bolton (University of London) who kindly allowed us to use his research diagnostic tool the SAPPa for our Innovation clinical endeavor.

Thanks are in order to Dr. Nancy Pena, Director of SCCMH for her support for innovative methods of assessing people with mental health disorders co-occurring with autism, and their treatment. Her direction and feedback on outcome analysis was appreciated. We similarly thank Gabby Olivarez MFT, MBA, Adult Division Director at SCCMH who offered support to us on this Adult Division project, and who has always demonstrated her deep concern for this population.

Victoria Garrison, LCSW SCCMH project manager/liaison dedicated herself fully and with great enthusiasm to our Project, and was proactive in making both overall vision and details come to fruition. She has advocated strongly for people with developmental disabilities and autism, who also have co-occurring mental health disorders in need of treatment.

Finally, internally at Hope Services' Counseling Center, we acknowledge the SCCMH funded team of clinicians who have dedicated their professional training to helping people with co-occurring mental health disorders and developmental disabilities. In particular we would like to thank Dr. Julie Parsons, and Amy Williams, LCSW, for the SAPPa interviews, Anna Fernandez, MFT, Gina Trepagnier, Compliance, and Dr. Susan Knudsen for management input, and Dr. Maurizio Battaglia for data analysis, outcomes and reporting.

Susan Detrick, Ph.D.
Director of Mental Health Services, HOPE Services

ABSTRACT

Background The Santa Clara County Mental Health Department has identified two serious barriers for clients and their families attempting to access the mental health services they need. The first is the State Mental Health Specialty Service guidelines, which apply to county and contracted agency mental health programs, specifically exclude Autism as a qualifying primary diagnosis for reimbursement. The second is the lack of understanding and awareness regarding the challenges faced by individuals with classic autism and co-occurring mental disorders and their families. These two barriers, combined with the absence of a clear protocol for referral and assessment, can make access to services for clients and their families unreasonably difficult.

Aims The Innovation (INN) component is one of five major programs of the Mental Health Services Act (MHSA). INN projects are novel, creative and/or ingenious mental health practices or approaches that contribute to learning rather than primarily focusing on providing a service. The Adults with Classic Autism and Co-Occurring Mental Health Disorders project (INN-03) is an opportunity to study potential assessment tools and referral guidelines. In particular, we investigated whether the Schedule for the Assessment of Psychiatric Problems Associated with Autism (SAPPA) can be an assessment tool in a clinical setting and can assist in diagnosing mental health disorders. The experience gained in this study can help identifying effective treatment options as well.

Method and Results Ninety consumers with Classic Autism and Co-Occurring Mental Health Disorders living in Santa Clara County were identified through referrals from SARC, HOPE (total of 10 existing consumers to assist in determining accuracy of diagnosis), Santa Clara County Mental Health Clinic call center and other mental health agencies and clinics. A semi structured investigator-based interview (SAPPA) was used to assess prevalence and type of episodic disorders. The SAPPA was modified to be consistent with DSM-IV-TR diagnostic criteria. Consumers interviewed using the SAPPA show higher rates of episodic psychiatric disorders than the control group assessed with standard approach: most commonly Impulse Control (23% of consumers), followed by OCD (19%) and Anxiety Disorder (17%). After the assessment, consumers were offered the possibility of choosing between several possible treatments. Medication Management was the most common treatment chosen (36%), followed by Individual Counseling with or without art therapy (19%), Collateral (15%) and Social Skills Group (12%). Caregivers (i.e., staff or family members) had access to Collateral Therapy. Quality of care and consumer satisfaction were measured using two ultra-short surveys: the Outcome Rating Scale (ORS) and the Service Rating Scale (SRS)

Conclusions Our experience indicates that a semi-structured interview guideline may help clinicians to better identify the Co-Occurring Mental Illness and help the consumers and caregivers in choosing the most appropriate treatment plan. The SAPPA survey is rooted in a British academic environment and may need significant revisions to make it consistent with the social and cultural environment of mental health clinics in Santa Clara County. In

particular, we suggest revising the SAPP to make it consistent with the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

INTRODUCTION

Autism spectrum disorders (ASD) are complex, lifelong, neurodevelopmental conditions of largely unknown cause. They are much more common than previously believed, second in frequency only to intellectual disability among the serious developmental disorders. Although a heritable component has been demonstrated in ASD etiology, putative risk genes have yet to be identified. Environmental risk factors may also play a role, perhaps via complex gene-environment interactions, but no specific exposures with significant population effects are known (Newschaffer et al, 2007)

Since no clear biological marker has been identified yet, and the diagnosis of autism is still based on generic criteria reflecting broadly based behavioral manifestations (Young and Brewer, 2002) such as those outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000).

Although some symptoms of autism may show improvement over time, the majority of individuals with autism may need substantial support throughout their lives. Intellectual impairment and the development of mental health problems during adolescence or early adulthood are strong predictors of the long term prognosis and outcome. For people with autism, the poorest long term diagnoses and outcomes are being experienced by those with the severest intellectual impairment and those who develop psychiatric problems: although a minority of adults may achieve relatively high levels of independence, most remain very dependent on their families or other support services; few live alone, have close friends, or permanent employment; communication generally is impaired, and reading and spelling abilities are poor (Howlin et al, 2004). Despite the impact of mental health problems on outcomes in autism, there has been little exploration of mental health problems in persons with autism. In one study on mental health problems and autism, Bradley and Bolton (2006) reported higher levels of emotional and behavioral problems in the group with autism. Bolton and Bradley (2006) differentiate between those disturbances that were long-standing and those that were episodic, and assessed if these disturbances met clinical criteria for psychiatric illness. Episodic psychiatric disorders (such as mood and psychotic disorders) represent some of the most frequently presenting mental health disorders found in the general population. Determining the prevalence of mental health disorders among individuals with autism has implications for service development, treatment and prediction of outcomes.

The Santa Clara County Mental Health Department has identified two serious barriers for clients and their families attempting to access the mental health services they need. The first is the State Mental Health Specialty Service Medical Necessity guidelines, which apply to county and contracted agencies mental health programs, which specifically exclude

Autism as a qualifying primary diagnosis for reimbursement. Second, there appears to be a lack of understanding and awareness regarding individuals with classic autism and co-occurring mental health disorders.

The goal of this Innovation Project (INN-03), funded through California Proposition 63, the Mental Health Services Act (MHSA), is to test and evaluate a supportive assessment tool that would increase access for individuals and expand treatment options. In particular, we investigated whether the Schedule for the Assessment of Psychiatric Problems Associated with Autism (and Other Developmental Disorders) by Bolton and Rutter (1994) could be utilized in a clinical setting and assist in diagnosing co-occurring mental health disorders.

The Schedule for the Assessment of Psychiatric Problems Associated with Autism (SAPPA; Bolton and Rutter, 1994) is a semi-structured investigator-based interview with an informant, and is linked to Research Diagnostic Criteria (RDC) for major psychiatric disorders. The RDC are a collection of psychiatric diagnostic criteria published in the late 1970s. As psychiatric diagnoses widely varied especially between the USA and Europe, the purpose of the criteria was to allow diagnoses to be consistent in psychiatric research. The RDC is important in the history of psychiatric diagnostic criteria as the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) was based on many of the RDC descriptions (Spitzer, 1989). In the US, the RDC have been superseded by the publication of the DSM-IV-TR and the most recent DSM-V. The SAPPA has been used in a number of follow-up studies (Hutton, 1998; Bradley and Bolton, 2006; Hutton et al, 2008) and is still being developed for wider use in research. In its present form it provides a rigorous assessment framework for use by the clinician experienced in the psychiatric assessment of persons with autism and with intellectual disabilities (Bradley and Bolton, 2006). In this project, the original SAPPA psychiatric diagnoses (available at pg. 67 of the SAPPA survey) were adjusted to better reflect the DSM-IV-TR (see Table 1 below, discussion on page 8 and Appendix 3).

Table 1. Adjusted SAPPA psychiatric diagnoses

Original diagnosis based on RDC	Adjusted diagnosis Based on DSM-IV-TR
Manic Disorder Hypomanic Disorder	Bipolar Disorder
	New diagnoses not present in the original SAPPA
	ADHD
	Impulse Control
	PICA

Practice-based evidence requires that practitioners adopt a highly individualized service delivery plan for each patient, acknowledging the patient's goals for treatment, ideas about how change occurs, and view of an effective therapeutic relationship. Outcome assessment measures are ultimately intended to guide clinicians in tailoring treatment and to identify efficient treatment approaches. In this project, outcomes were measured using two ultra-brief surveys: the Outcome Rating Scale (ORS) and the Session Rating Scale (SRS), available on-line from the Heart and Soul Change Project (heartandsoulofchange.com/) – see Appendix 1. The validity and reliability of the Outcome Rating Scale and the Session Rating Scale have been evaluated against existing longer measures, including the Outcome Questionnaire-45, Working Alliance Inventory, Depression Anxiety Stress Scale-21, Quality of Life Scale, Rosenberg Self-Esteem Scale and General Self-efficacy Scale (Campbell and Hemsley, 2009). The use of brief outcome measures in clinical practice involves a simple methodology that can be easily implemented by most services. The simplicity of scoring procedures also leads to measurements that are easily interpreted. The cost of materials is low, which ensures that service providers are able to repeatedly administer the measures without significant cost. The implementation procedures of the scales is also usually simple, meaning that there is minimal training required in the administration, scoring; and interpretation of results (Miller et al., 2003; Campbell and Hemsley, 2009).

METHOD

The study was conducted in several successive stages including:

- (a) identifying the population and inviting them to participate in the study;
- (b) individual assessments of participants to ensure there was a previous diagnosis of autism present in the medical records that confirmed autism;
- (c) psychiatric assessment of consumers using the SAPP interview and the Santa Clara County Mental Health Clinic assessment tool.

Ethics

Parents, caretakers or consumers have all signed informed consent forms prior to participation in the study (see Appendix 2). The Santa Clara County Internal Review Board approved both the consent form and the study.

Consumers involved in this innovative project

Consumers with autism and co-occurring mental health disorders living in Santa Clara County were identified through referrals from SARC, HOPE (total of 10 existing HOPE consumers), other mental health agencies and clinics, and the Santa Clara County Mental Health Call Center. Whites (non-Hispanic) comprised the largest ethnic group (57%), followed by Asians (22%) and Hispanics (17%) – for a total of 96% of total consumers interviewed. This reflects the ethnic composition of the County of Santa Clara, which consisted of Whites (35%), Asians (33%) and Hispanics (27%) totaling 95% of the County population, according to figures from the 2010 US Census (Figure 1).

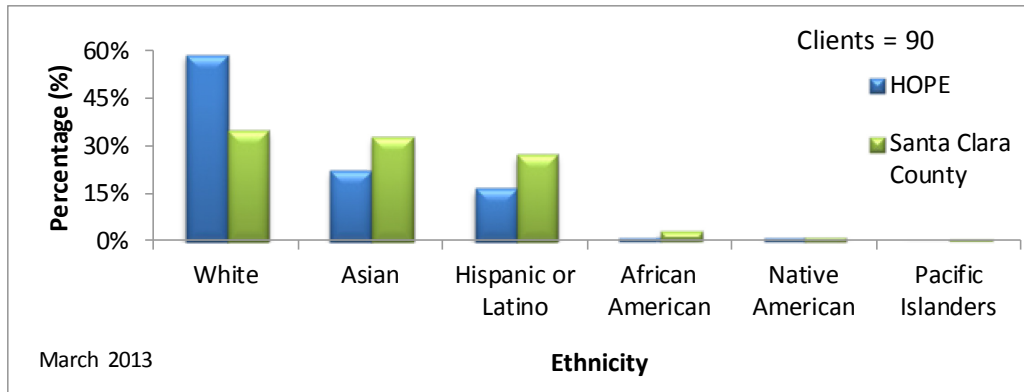


Figure 1. Consumers’ ethnicity (Hope, blue bars), compared against the Santa Clara County’s latest census data (green bars) - source US Census Bureau (available on line at quickfacts.census.gov/qfd/states/06/06085.html).

The average consumer is a young adult male about 28 years of age, living at home with his parents (Figure 2, Figure 3 and Figure 4).

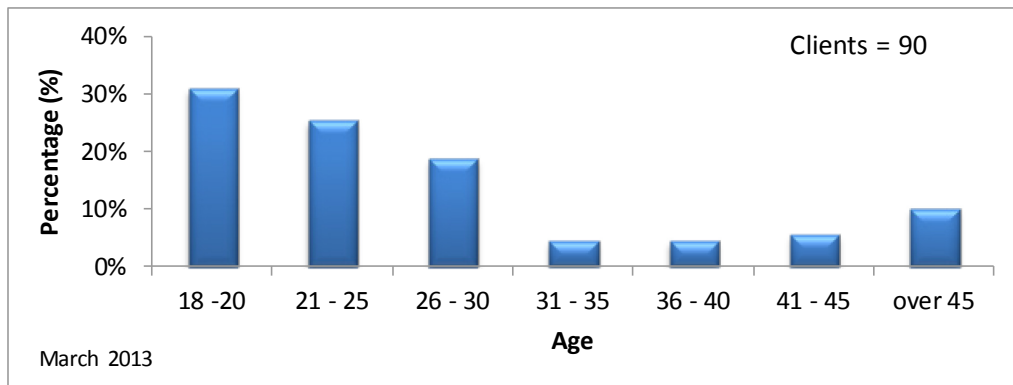


Figure 2. Age distribution of consumers involved in this study. The median age is 22 years, average age 27.6 years, standard deviation 10.6 years – 80% of clients have an age between 18 and 35 years old.

Our data shows a gender ratio (male to female) of 4:1. According to Newschaffer et al (2007), males represent a higher risk group than females. Males are affected with autism spectrum disorders more frequently than are females with an average male-to-female ratio of 4.3:1 (48). The gender ratio is modified substantially by cognitive impairment; among cases without intellectual disability the gender ratio may be more than 5.5:1, whereas among those with intellectual disability the gender ratio may be closer to 2:1.

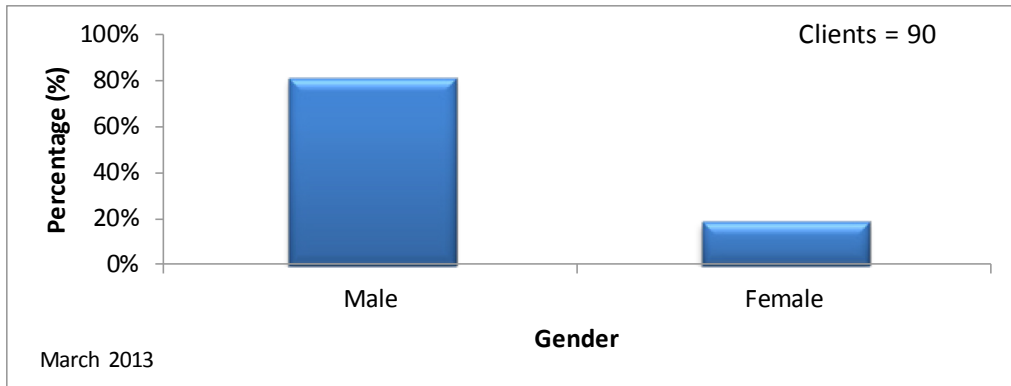


Figure 3. Gender distribution of consumers involved in this study.

While a significant percentage of consumers are living in board/care homes, the majority of the consumers involved in this project are living with the family of origin. Only a nominal percentage is able to live independently (Figure 4).

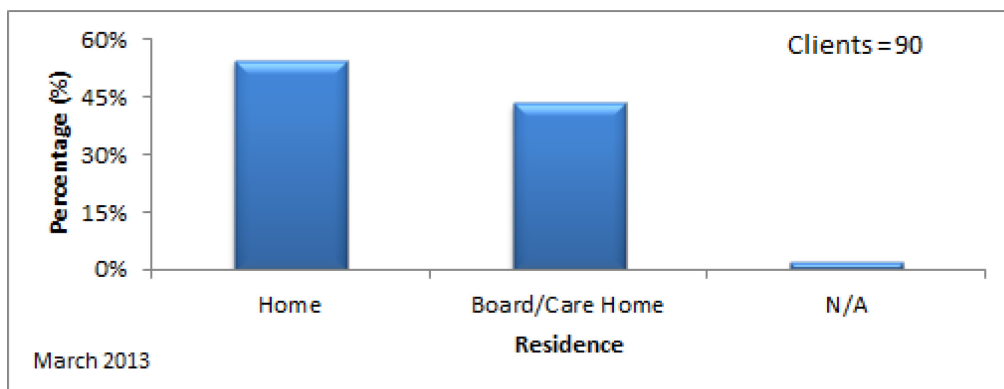


Figure 4. Consumer living arrangements.

SAPPA description

The Schedule for the Assessment of Psychiatric Problems Associated with Autism (and Other Developmental Disorders) (SAPPA; Bolton and Rutter, 1994) is a semi-structured investigator-based interview with an informant. The SAPPA was originally linked to the Research Diagnostic Criteria (RDC) for some major psychiatric disorders but has been modified by the clinical staff of Hope Counseling Center to meet the diagnostic criteria of DSM IV-TR. The SAPPA has been used in several studies (Hutton, 1998) and has been developed for wider use in research. This study is the first to test this instrument in a clinical setting. In its present form it provides a rigorous assessment framework for use by clinicians experienced in the psychiatric assessment of persons with autism and with co-occurring mental health disorders (see Auxiliary Material in CD-R for a copy of SAPPA).

The first part of the SAPPA focuses on identifying episodes of behavioral change against the background of usual baseline behaviors for the individual; the latter include pervasive and

chronic problems that may have been present from an early age (such as self-injurious, hyperkinetic, obsessive, compulsive and other anxiety-type behaviors, tics, stereotypes and other non-specific challenging behaviors). A significant part of the interview is spent, therefore, establishing baseline behaviors for the individual against whom any episode of change in behavior is evaluated (see Bradley and Bolton, 2006).)- It is worth noting that while this approach makes sense in a research setting, it is not likely in a clinical setting (e.g., County mental health services) where baseline behaviors are established except for brand new clients.

Psychiatric assessment

The original criteria based on the Research Diagnostic Criteria (Spitzer, 1989) for an episode of behavior change include:

- (a) either psychotic symptoms (delusions, hallucinations, catatonia, etc.) lasting at least 3 days;
- (b) or a change in behavior outside the range of normal variation for the individual, lasting at least 1 week;
- (c) and definite diminution in level of social functioning as shown by at least two of the following:
 - a. loss of interest in play
 - b. loss of self-care
 - c. loss of social involvement
 - d. loss of initiative
 - e. need for change in supervision and/or placement.

Episodes of changed behavior are explored further to obtain systematic standardized information on symptoms. A symptom is deemed clinically significant if:

- (a) it is outside the range of normal behavior for that individual;
- (b) it intrudes into, or disrupts, the individual's ordinary activities;
- (c) it is of a degree that is not readily controlled by the individual or caregivers;
- (d) it is sufficiently pervasive to extend into at least two activities.

In addition, the duration of each episode is determined, as well as the timing in the context of other circumstances (e.g., life events such as loss, bereavement, medication changes or medical concerns such as seizures) occurring in the person's life. The symptoms during an episode that meet inclusion criteria and the pattern of the episodes are used to establish a psychiatric diagnosis. In the first part of the SAPPa interview, inquiry is also made as to family history of psychiatric illness. The second part of the SAPPa interview deals with behaviors and disorders that do not follow an episodic course (e.g. some self-injurious, hyperkinetic, obsessive, compulsive and other anxiety-type behaviors, tics, stereotypes and other non-specific challenging behaviors).

The diagnoses described in the final assessment schedule of the SAPPa are rooted in the Research Diagnostic Criteria (Spitzer, 1989) and the British clinical and academic environment. The Research Diagnostic Criteria are associated with the DMS-III, from a point

much earlier in time. This may have an impact on mental health clinics in Santa Clara County facing somewhat different cultural and professional challenges than their British counterparts. For these reasons, the clinical staff of Hope Counseling Center decided to modify some of the criteria so that they could better fit the cultural and clinical environment of a mental health clinic in California. For example, practitioners experience in our clinic showed that two criteria used to establish a baseline in behavioral change - (a) either psychotic symptoms (delusions, hallucinations, catatonia, etc.) lasting at least 3 days; (b) or a change in behavior outside the range of normal variation for the individual, lasting at least 1 week (Bradley and Bolton, 2006) – were not appropriate in the clinical setting of Santa Clara County. For example, aggressive behaviors (e.g., fire setting, glass breaking ...) would not be expected to last one week to meet criteria.

Thus psychiatric diagnoses were adjusted to better reflect the DSM-IV-TR (see Appendix 3). We also created a digital version of the SAPPA to make administration of the instrument more efficient; to implement paperless storage and distribution of data (see Auxiliary Material in CD-R for a copy of the digital SAPPA).

Psychiatric disorder is identified as being absent, possible, probable or definite according to SAPPA criteria. Episodic psychiatric disorders identified using the SAPPA interview include mood (manic, hypomanic, depressive), anxiety and psychotic (schizophrenia, schizoaffective, unspecified psychotic) disorders. Disorders with intensity level 2 or above for three prominent symptoms, are referred to as unclassified disorders if the pattern of symptoms is not clearly indicative of a specific DSM-IV-TR diagnosis.

A database of the SAPPA interviews is available in the Auxiliary Material CD-R.

SAPPA interview process

All the SAPPA interviews were administered by licensed clinicians experienced in developmental and psychiatric evaluations. In the first part of the SAPPA interview, inquiry is also made as to family history of psychiatric illness. The second part of the SAPPA interview deals with behaviors and disorders that do not follow an episodic course (e.g. some self-injurious, hyperkinetic, obsessive, compulsive and other anxiety-type behaviors, tics, stereotypies and other non-specific challenging behaviors) - see also Bradley and Bolton (2006). A large percentage of the interviews were completed with information provided by parents (62%) with an average contact of 18.7 years (standard deviation: 12.1 years); 74% of the informants were in contact with the consumers on a daily basis (Figure 5).

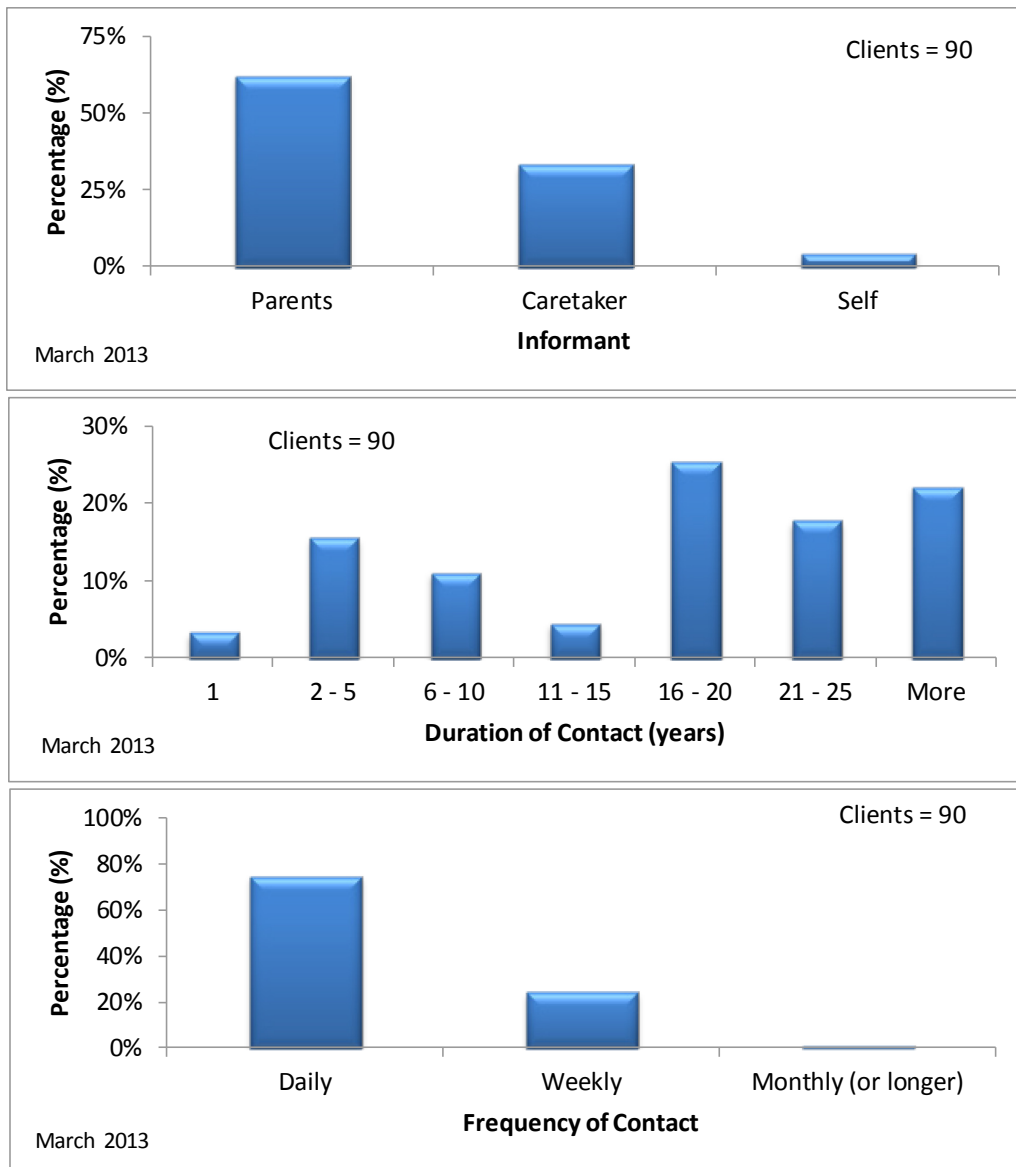


Figure 5. (top) Informant; (middle) Duration of contact; (bottom) Frequency of contact

RESULTS

Demographics

The consumer demographics are shown in Figure 1 – Figure 3. The average consumer involved in the project is young adults male (average age is 27.6 and about 66% of the consumers are within 18 and 30 years old), living at home with his parents (Figure 2 and Figure 3). The consumers’ ethnic distribution follows the ethnicity composition of Santa Clara County (source US Census Bureau). Whites, Asians and Hispanics are the three largest ethnicities represented in the County and in this study (Figure 1).

Co-occurring Diagnoses

The main goal of this project is to test the application of the SAPPA as a support tool for the clinician in the diagnosis of co-occurring disorders within a clinical setting and then suggest treatment options for the client. Please note that (a) the terminology from RDC has been modified by diagnostics present in DSM-IV-TR, (b) the SAPPA allows four different levels of likelihood for a psychiatric disorder (absent, possible, probable or definite). We have presented in this report quantitative data for both definite and probable diagnoses (Figure 6). A definite diagnosis meets all the DSM-IV-TR psychiatric criteria for mental disability; a probable diagnoses does not reach the DSM criteria only because of communication difficulties (e.g., the consumer is not verbal). A complete database is available in the Auxiliary Material CD-R.

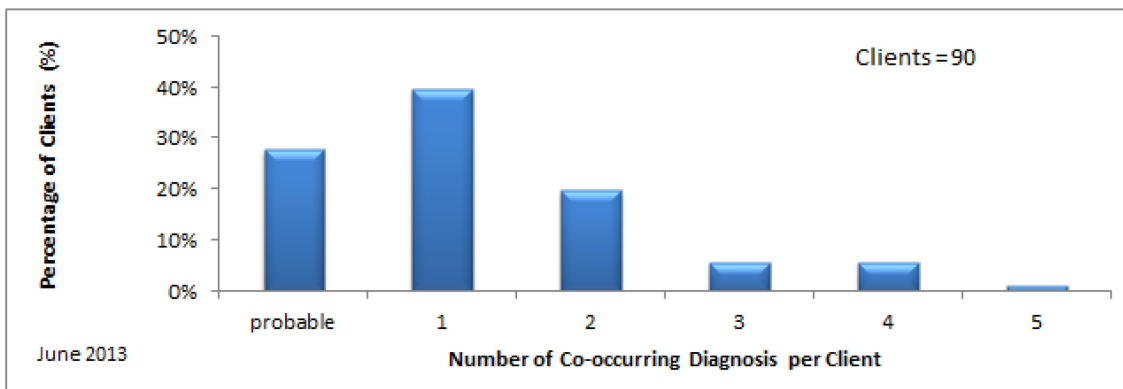


Figure 6. Number of consumers with probable diagnoses and number of co-occurring definite diagnoses

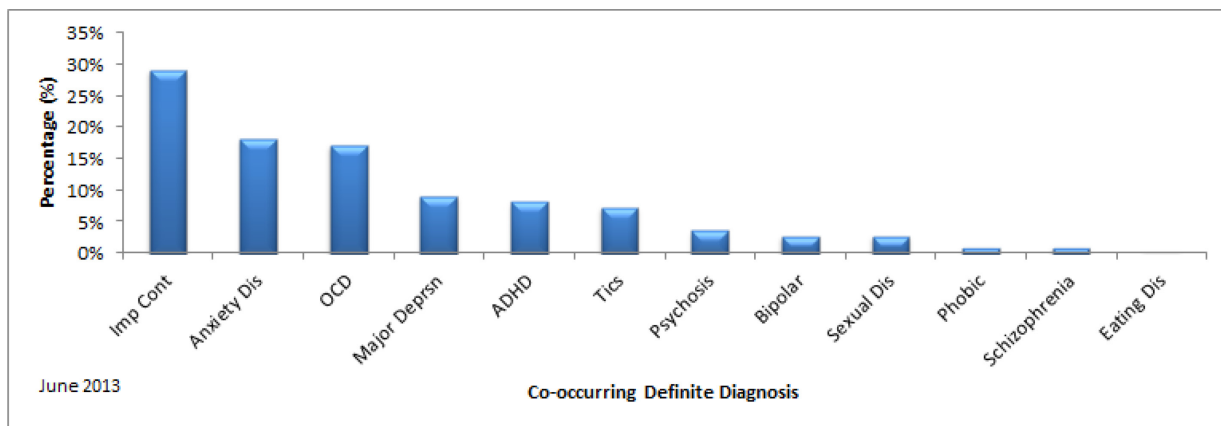


Figure 7. Co-occurring definite diagnoses, based on SAPPA interviews. OCD: Obsessive Compulsive Disorder; Imp Cont: Impulse Control; Anxiety Dis: Anxiety Disorder; Major Deprsn: Major Depressive Illness; ADHD: Attention Deficit Hyperactive Disorder; Bipolar: Bipolar Disorder; Eating Dis: Eating Disorder.

Data from the SAPPA surveys indicate a broad range of definite co-occurring diagnoses (Figure 7). The three more common co-occurring diagnoses (affecting 64% of consumers)

are Impulse Control (29%), followed by Anxiety Disorder (18%) and Obsessive Compulsive Disorder (17%).

Probable diagnoses have been proposed for 28% of consumers. The more common probable co-occurring diagnoses are Impulse Control and Anxiety Disorder (20%), followed by Major Depression and Tics (10%); see Figure 8.

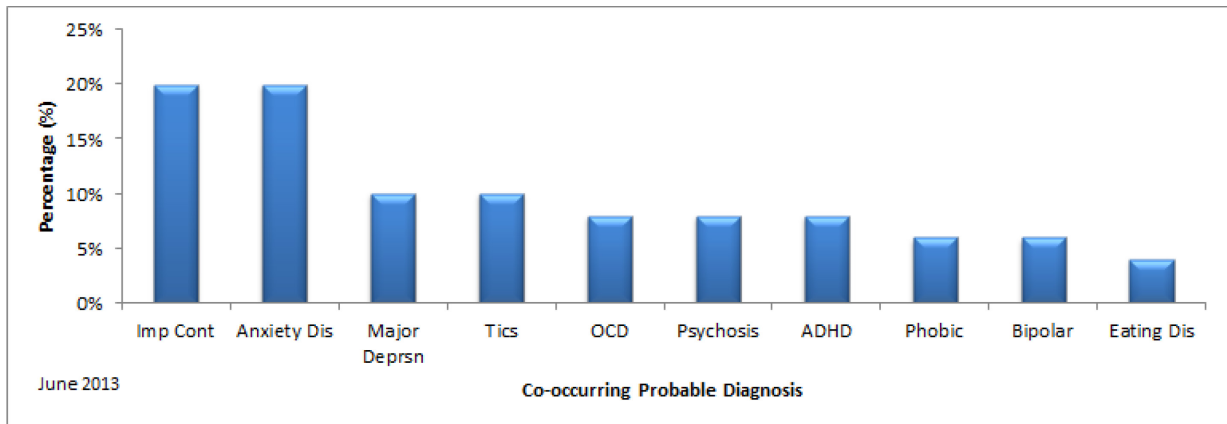


Figure 8. Co-occurring probable diagnoses, based on SAPPA interviews. OCD: Obsessive Compulsive Disorder; Imp Cont: Impulse Control; Anxiety Dis: Anxiety Disorder; Major Deprsn: Major Depressive Illness; ADHD: Attention Deficit Hyperactive Disorder; Bipolar: Bipolar Disorder; Eating Dis: Eating Disorder.

Most of the participants had had multiple cognitive assessments over the years. A comparison between existing and SAPPA psychiatric assessment for the 10 HOPE consumers involved in the study is available in Table 2 below

Table 2. Existing and SAPPA psychiatric assessment for 10 HOPE consumers

Client number (+)	Existing disorder	SAPPA	
		Definite disorder	Probable disorder
1	300.3 Obsessive Compulsive	Obsessive/Compulsive	
33	300.0 Anxiety NOS	Anxiety	Obsessive/Compulsive, Phobia
34	295.70 Schizoaffective	Schizoaffective	Obsessive/Compulsive
39	300.3 Obsessive Compulsive	Obsessive/Compulsive	
40	312.34 Intermittent Explosive	ADHD, Impulse control	Anxiety
61	312.3 Impulse Control NOS	Impulse control, Anxiety	ADHD, Obsessive/Compulsive
65	296.9 Mood NOS	Impulse control	Tics

† This is the same number used in the SAPPA database

Table 2. continued

Client number (†)	Existing disorder	SAPPA	
		Definite disorder	Probable disorder
77	296.33 Major Depression	Major depression	
78	311 Depressive NOS		Major depression
88	312.3 Impulse Control DNOS	Impulse control	Anxiety, Obsessive/Compulsive

† This is the same number used in the SAPPA database

Treatment Options

Consumers evaluated through the project have access to treatment options that fit their individual diagnoses (Figure 9). Caregivers (e.g., family members, case managers, residential care facility staff, legal guardians) and others directly responsible for the wellbeing of the consumer who (i.e., staff or family members) are allowed to collaborate in the development of the consumer’s treatment plan and have access to collateral therapy as well. Medication Management is the most common treatment chosen (36%), followed by Individual Counseling with or without art therapy (19%), Collateral (15%) and Social Skills Group (12%).

The majority (66%) of consumers involved in the SAPPA study have chosen to take advantage of two or more treatment options compared to 42% of the FY 2012 consumers. 4% of consumers involved in the SAPPA study declined any treatment (Figure 9). It is worth noting that Innovation projects are designed for voluntary participation and no person can be denied access solely on voluntary or involuntary status.

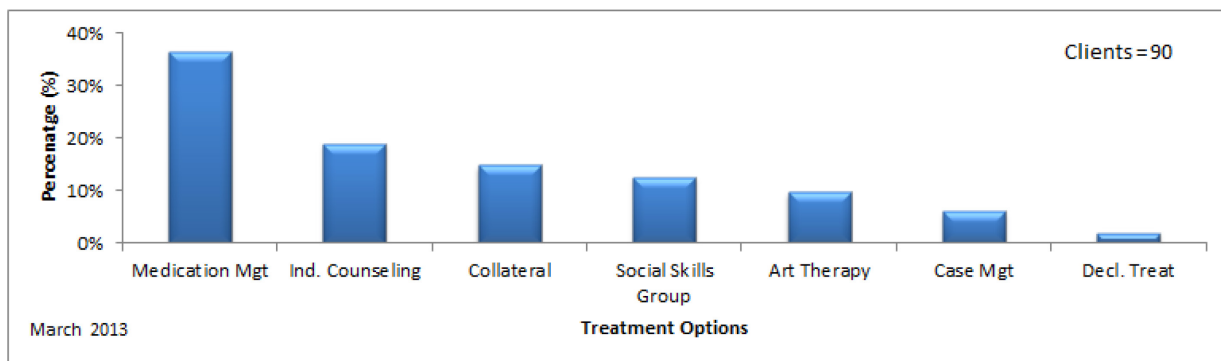


Figure 9. Treatment options. Decl. Treat.: Declined Treatment; Ind. Counseling: Individual Counseling

CONSUMERS' FEEDBACK

The Outcome Rating Scale (ORS) and the Session Rating Scale (SRS) were used to evaluate the outcome of the treatment, and the quality of the services provided. Both ORS and SRS

are available on-line at heartandsoulofchange.com/. ORS and SRS are two ultra-brief outcome assessment measures that involve a simple methodology and can be easily implemented. The cost of materials is low, which ensures that service providers are able to repeatedly administer the surveys without significant cost. Likewise, administration of the surveys is usually a simple procedure that requires minimal training in the processing, scoring and interpretation of results. For example, the ORS assesses the three areas of functioning including individual, relational, and social, but does so in visual analogue format through a set of only four questions that take approximately 1 min to complete.

The validity and reliability of the Outcome Rating Scale (ORS) and the Session Rating Scale (SRS) were evaluated against existing longer measures, including the Outcome Questionnaire-45, Working Alliance Inventory, Depression Anxiety Stress Scale-21, Quality of Life Scale, Rosenberg Self-Esteem Scale and General Self-efficacy Scale. Both the ORS and SRS demonstrated good reliability and concurrent validity with their longer alternatives. The ORS also evidenced significant correlations with measures of self-esteem, self-efficacy, and quality of life. The ORS and SRS offer benefits such as cost-effectiveness, brevity, simple administration, and easy interpretation of results when compared to their lengthy counterparts that substantiated the use of brief outcome assessment measures in psychological practice (Campbell and Hemsley, 2009).

On the ORS scale, social setting is the area where our clients face the stronger challenge (median satisfaction 7 against the 8 – 9 in other areas) – see Figure 10.

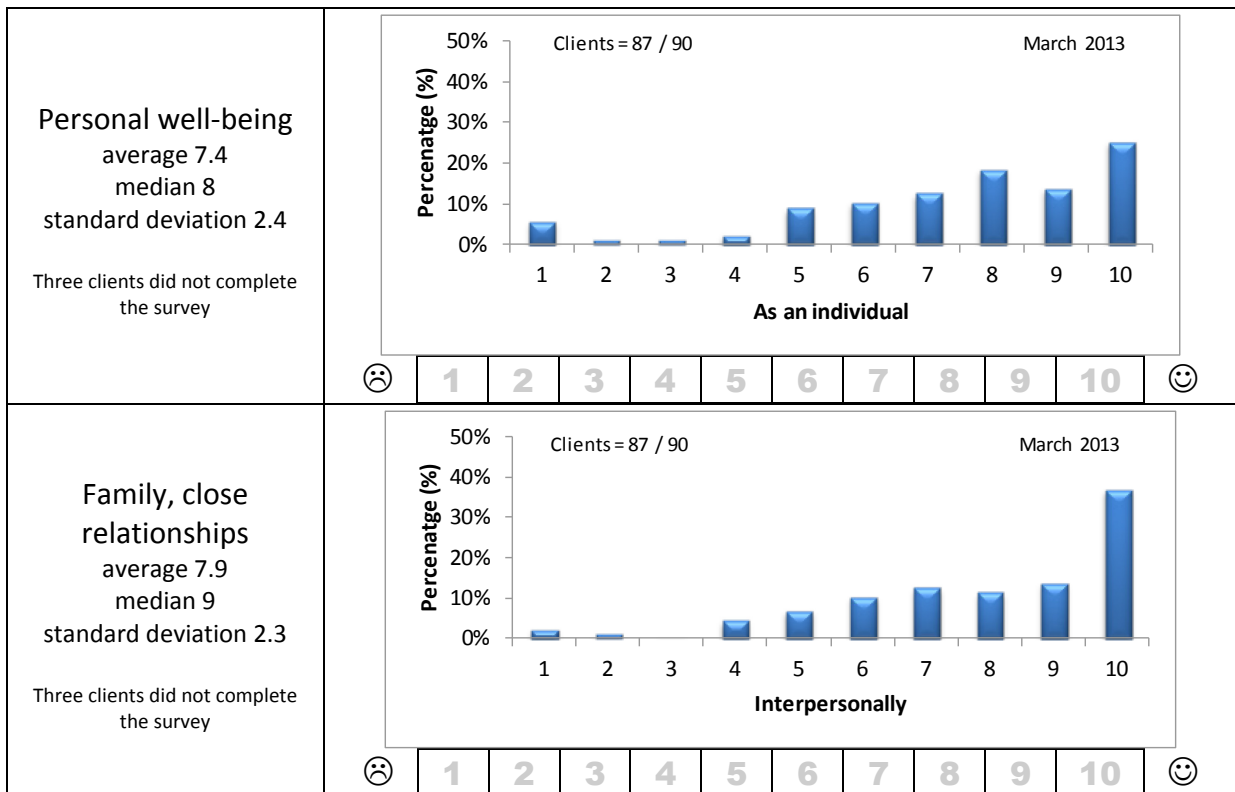


Figure 10. Outcome Rating Scale (ORS) survey results.

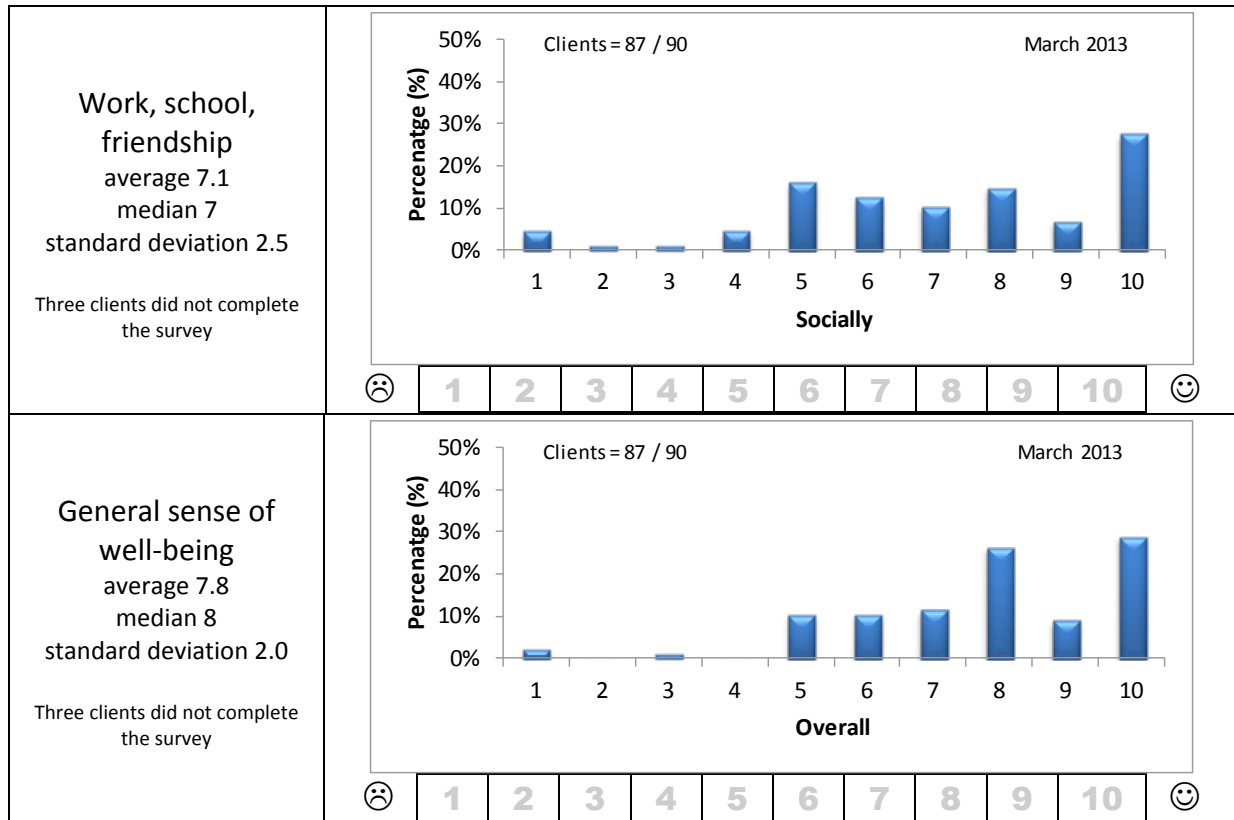
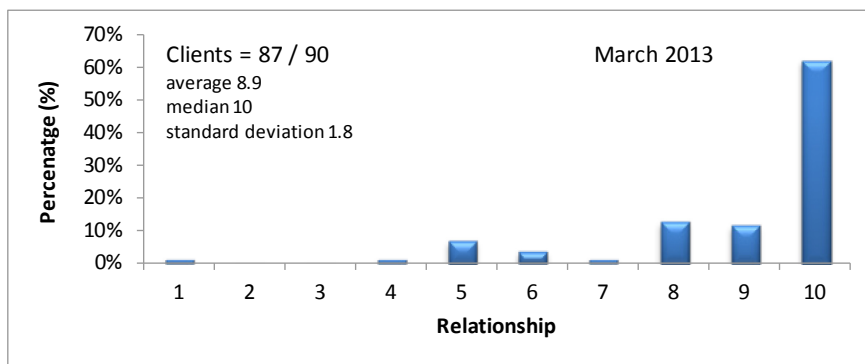


Figure 10 (continued). Outcome Rating Scale (ORS) survey results.

The SRS scale shows that clients express a significant satisfaction in their interaction with the therapist with average scoring between 8.9 and 8.5; approximately 55% of the clients gave the therapist the highest scoring of 40/40 – see Figure 11.

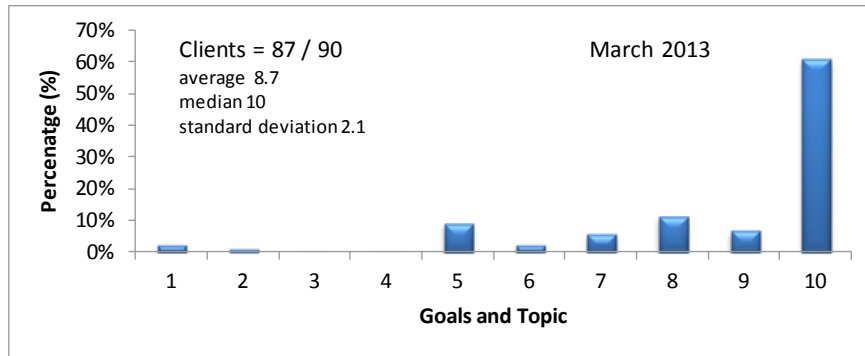


I did not feel heard, understood, and respected.



I felt heard, understood, and respected

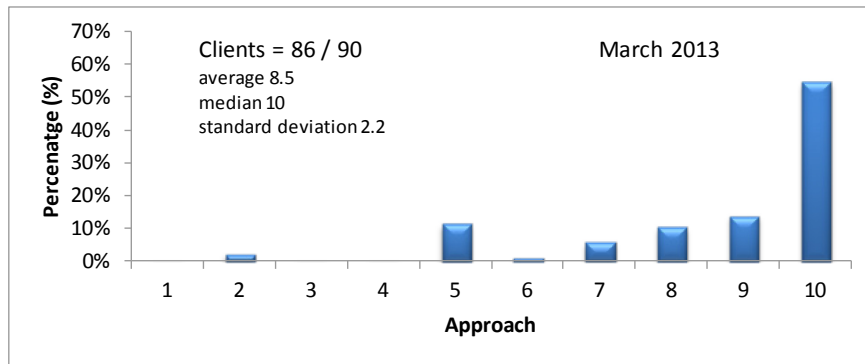
Figure 11. Service Rating Scale (SRS) survey results.



We did not work on or talk about what I wanted to work on and talk about.



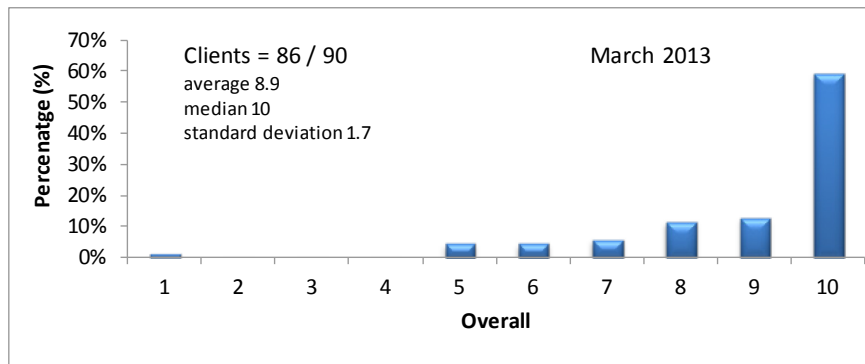
We worked on and talked about what I wanted to work on and talk about.



The therapist's approach is not a good fit for me.



The therapist's approach is a good fit for me.



There was something missing in the session today.



Overall, today's session was right for me.

Figure 11. Service Rating Scale (SRS) survey results (continued). Three clients did not answer the first two questions; four clients did not answer the last two questions

FOLLOW UP

Developing a way to track consumers enrolled in this study will allow Hope and the County of Santa Clara to gather long-term follow-up information, which may contribute to learning appropriate therapy approaches in the future. As such, 11 current consumers were randomly chosen for follow-up and to verify:

- (a) changes in the life of the consumers served (Figure 12)
- (b) changes in the relationship with the therapist (Figure 13)

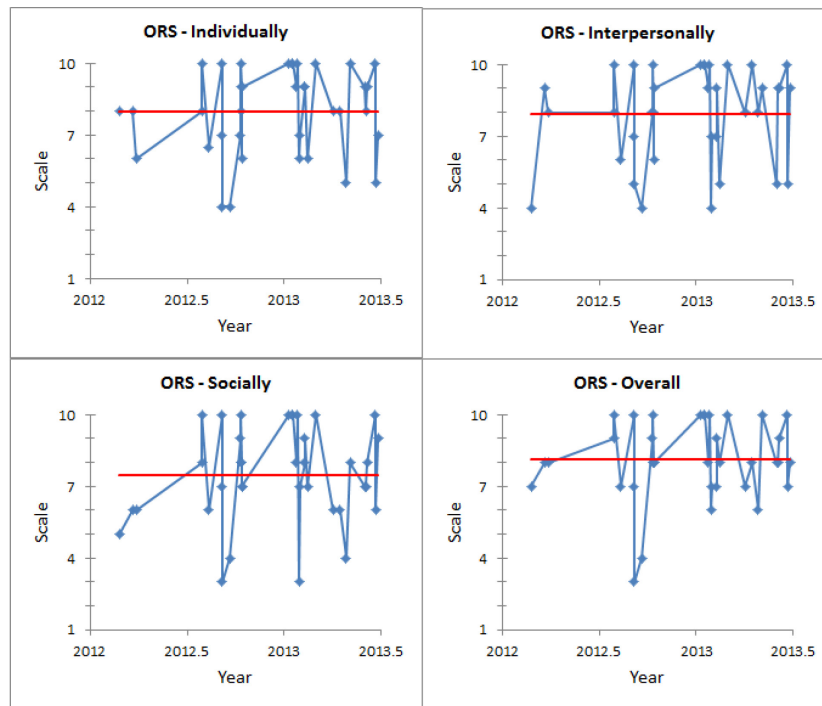


Figure 12. Outcome Rating Scale (ORS) follow up surveys. The red line is the average value of the scale for the each areas assessed. Individually: average = 8.0; Interpersonally: average = 7.9; Socially: average = 7.5; Overall: average = 8.1.

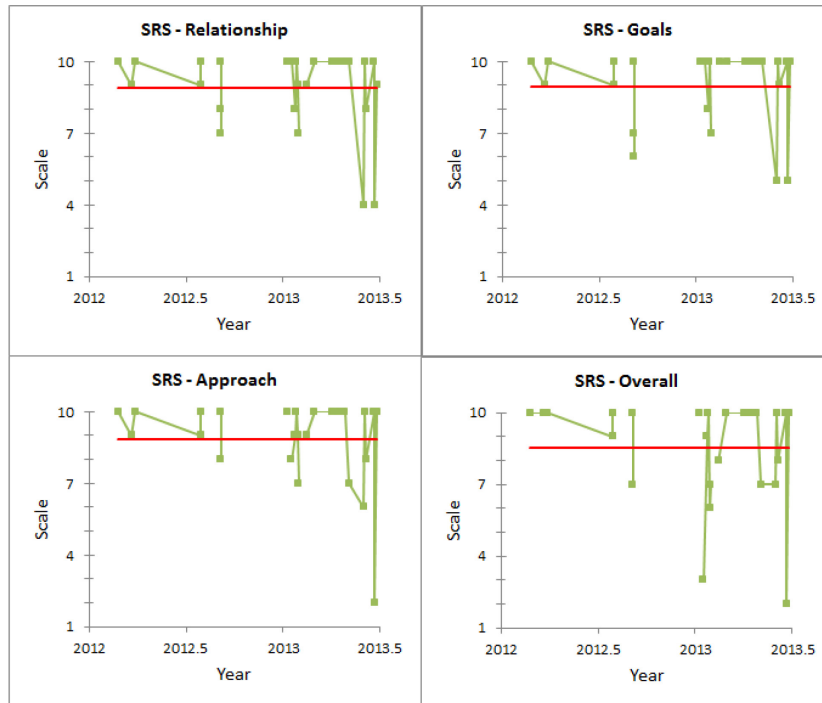


Figure 13. Session Rating Scale (SRS) follow up surveys. The red line is the average value of the scale for the each areas assessed. Relationship: average = 8.9; Goals: average = 8.9; Approach: average = 8.8; Overall: average = 8.5.

It is worth noting that

- (a) the consumers involved in the follow up have been either stable or have experienced some improvement in their lives
- (b) the relationship with therapists has been consistently positive during the whole project with rates scoring between 8.5 and 8.9.

SUMMARY AND CONCLUSIONS

The focus of the present study was the application of the Schedule for the Assessment of Psychiatric Problems Associated with Autism (and Other Developmental Disorders) (SAPPA; Bolton & Rutter, 1994) within a clinical setting to assess the prevalence of episodic psychiatric illnesses and control variables known to impact mental health. This Innovation project is the first study to document the prevalence of psychiatric illnesses associated with autism in an epidemiological sample of ninety individuals in Santa Clara County. Additionally, it is the only Innovation project in California that addressed any issues pertaining to individuals diagnosed with autism. Previous studies using behavioral checklists have described greater emotional and behavioral problems in those with autism and mental health disorders compared with those with mental health alone (e.g., Bradley and Bolton, 2006).

Our experience indicates that a semi-structured interview guideline using information gathered from an Informant/Caregiver may assist clinician to better identify the Co-Occurring Mental Health disorders. In doing so, it possibly will help consumers and caregivers in choosing the most appropriate treatment plan to fit their unique diagnosis. The SAPPA survey is deeply rooted in a British academic environment and may need significant reviews to make it consistent with the social and cultural environment of mental health clinics in Santa Clara County and in the United States. In particular, we suggest reviewing the SAPPA to make it consistent with the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-V). Additionally, it is recommended that an appraisal of SAPPA is conducted to evaluate decreasing the length making it more advantageous for use in a clinical environment.

For example, many factors impact the amount of time necessary to complete an assessment for one consumer. Depending on the number of symptoms you assess for and examiner variability, two assessments needed to be completed. The required Santa Clara County Mental Health (SCCMH) assessment as well as the SAPPA and the time duration in completing both assessments is difficult to determine and is estimated to range from 4.5 to 6 hours, including a records review prior to the actual interview. Given that the SAPPA is a supportive instrument another assessment is required and the management of both is usually blended throughout the interview. Data then is extracted and entered into the database. Moreover, assessment time was contingent on the individual case and the numbers provided do not include completing SCCMH assessment form; Transformational Care Planning (TCP); and Narrative Summary documents that are now also required.

REFERENCES

- American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.). Washington, DC: Author.
- Bradley, E., and Bolton, P. (2006). Episodic psychiatric disorders in teenagers with learning disabilities with and without autism. *The British Journal of Psychiatry*, 189(4), 361-366.
- Bolton, P. F. and M. Rutter (1994). Schedule for Assessment of Psychiatric Problems Associated with Autism (and Other Developmental Disorders) (SAPPA): Informant Version. Cambridge: University of Cambridge; and London: Institute of Psychiatry.
- Campbell, A. and S. Hemsley (2009). Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures. *Clinical Psychologist*, 13, 1-9.

- Howlin, P., Goode, S., Hutton, J., and Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212-229.
- Hutton, J., Goode, S., Murphy, M., Le Couteur, A., and Rutter, M. (2008). New-onset psychiatric disorders in individuals with autism. *Autism*, 12(4), 373-390.
- Hutton, J. (1998). Cognitive decline and new problems arising in association with autism (Doctoral dissertation, Institute of Psychiatry, Kings College London.).
- Miller, S. D., Duncan, B. L., Brown, J., Sparks, J. A., and Claud, D. A. (2003). The outcome rating scale: A preliminary study of the reliability, validity, and feasibility of a brief visual analog measure. *Journal of Brief Therapy*, 2(2), 91-100.
- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... and Windham, G. C. (2007). The epidemiology of autism spectrum disorders*. *Annual Review of Public Health*, 28, 235–258.
- Spitzer RL (1989). Commentary on RDC by Robert Spitzer, *Current Contents*, 32(19), 21.
- Young, R., and Brewer, N. (2002). Diagnosis of autistic disorder: Problems and new directions. *International review of research in mental retardation*, 25, 107-134.

APPENDIX 1 – ORS and SRS forms

Outcome Rating Scale (ORS)

Name _____ Age (Yrs): _____ Sex: M / F
Session # _____ Date: _____
Who is filling out this form? Please check one: Self _____ Other _____
If other, what is your relationship to this person? _____

Looking back over the last week, including today, help us understand how you have been feeling by rating how well you have been doing in the following areas of your life, where marks to the left represent low levels and marks to the right indicate high levels. *If you are filling out this form for another person, please fill out according to how you think he or she is doing.*

Individually (Personal well-being)

	1	2	3	4	5	6	7	8	9	10	
---	---	---	---	---	---	---	---	---	---	----	---

Interpersonally (Family, close relationships)

	1	2	3	4	5	6	7	8	9	10	
---	---	---	---	---	---	---	---	---	---	----	---

Socially (Work, school, friendships)

	1	2	3	4	5	6	7	8	9	10	
---	---	---	---	---	---	---	---	---	---	----	---

Overall (General sense of well-being)

	1	2	3	4	5	6	7	8	9	10	
---	---	---	---	---	---	---	---	---	---	----	---

Modified after The Heart and Soul of Change Project

www.heartandsoulofchange.com

© 2000, Scott D. Miller and Barry L. Duncan

Licensed for individual use only

Session Rating Scale (SRS V.3.0)

Name _____ Age (Yrs): _____
ID# _____ Sex: M / F _____
Session # _____ Date: _____

Please rate today's session by placing a check on the box nearest to the description that best fits your experience.

Relationship

I did not feel heard, understood, and respected.

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

I felt heard, understood, and respected

Goals and Topics

We did not work on or talk about what I wanted to work on and talk about.

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

We worked on and talked about what I wanted to work on and talk about.

Approach or Method

The therapist's approach is not a good fit for me.

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

The therapist's approach is a good fit for me.

Overall

There was something missing in the session today.

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Overall, today's session was right for me.

The Heart and Soul of Change Project

www.heartandsoulofchange.com

© 2002, Scott D. Miller, Barry L. Duncan, & Lynn Johnson

Licensed for individual use only

APPENDIX 2 – Consent form

SUBJECT’S CONSENT FORM

TITLE OF PROJECT:

Adults with Classic Autism and Co-Occurring Mental Health Disorders.

PRINCIPAL INVESTIGATOR:

S. Detrick, PhD, Director, HOPE Counseling Center.

CO-INVESTIGATOR(S)

S. Knudsen, PhD, LMFT. HOPE Counseling Center.

A. Fernandez, MA, LMFT. HOPE Counseling Center.

PURPOSE:

- improve the quality of assessment of individuals with classic autism with a co-occurring mental health disorder in a clinical setting

PROCEDURE:

You and/or your caregiver will be interviewed by one of our clinicians following the Schedule for the Assessment of Psychiatric Problems Associated with Autism and other Developmental Disorders (SAPPA).

RISKS/DISCOMFORTS:

- The research is interview based and involves minimal risk.
- You and/or your caregiver could experience a mild anxiety during the interview as you will be asked to discuss significant behavioral changes related to your disorder

BENEFITS:

- We hope to use the results from this study to improve access to treatment services for clients.
- We cannot and do not guarantee or promise that you will receive any benefits from this study.

CONFIDENTIALITY:

By signing this document you are permitting the Principal Investigator, the Co-Investigators and HOPE to use the personal health information collected about you for research purposes. The information we will use includes the information from the SAPPA Survey and supporting information from your medical records. The information will not be disclosed for a purpose other than the research described in this document unless you have given written permission for the Investigators to do so. Your name will never appear in reports. The research will report information about groups of people, not single individuals.

COSTS:

There will be no charge to you for participating in this study.

SUBJECT/PATIENT RIGHTS:

Your participation is voluntary. Refusal to participate will involve no penalty or loss of benefits and/or services to which you are otherwise entitled. You are free to withdraw your consent and discontinue participation in the project at any time without prejudice to you or effect on your participation in County health programs. To do so send a written revocation of your authorization to Dr Detrick, HOPE Counseling Services, 1555 Parkmoor Ave, San Jose CA 95128.

Any discomforts and inconveniences involved in this research study should have been explained to you. If you have additional questions, you may contact Dr Detrick or one of her associates at (408) 282-0402. If you are not satisfied with the manner in which this study is being conducted, you may contact the Institutional Review Board, which is concerned with protection of volunteers in research projects. Aimee Reedy, current IRB Chairperson, may be reached at (408) 423-0724, or by writing to the Institutional Review Board, c/o Department of Public Health, Research, Planning & Evaluation Division, 3003 Moorpark Avenue, San Jose, CA 95128.

WITNESSING AND SIGNATURES:

Your signature indicates that the nature, demands, risks, and benefits of the project have been explained to you, and that you understand what your participation involves. Furthermore, you understand that you are free to ask questions and withdraw from the project at any time without affecting your health care. You have

been offered a copy of the signed and dated consent form. You hereby voluntarily consent and offer to take part in this study.

(if applicable) I give permission to discuss with my parent(s), legal guardian or primary caregiver(s) my participation in this study: () YES () NO

Signature of Subject

Date Signed

Signature of Witness

Date Signed

Signature of Parent/Legal Guardian

Date Signed

APPENDIX 3 - SAPPA psychiatric assessment (DSM-IV-TR)

SAPPA ORIGINAL PSYCHIATRIC ASSESSMENT (PG. 67)

Page 67

Code 8 for Not Applicable (i.e. No Episode) and 9 for Not Known

OVERALL CODING PSYCHIATRIC ASSESSMENT OF PROBAND

Disturbance/Disorder Present (other than Autism/Developmental Disorder)

0 = No

1 = Yes

2 = More than 1

<u>Type of Disorders</u> (use RDC criterion)	<u>PRESENT</u>	<u>AGE ONSET</u> (years)	<u>DURATION</u> Worst episode	<u>EPISODES</u> (Number)
0 = Absent				
1 = Possible				
2 = Probable or definite but does not reach criteria <u>only</u> because of communication difficulties				
3 = Definite				
8 = N/A because of communication problems				
<u>Affective</u>				
Major Depressive Illness	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Manic Disorder	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hypomanic Disorder	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Anxiety Disorder	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Obsessive/Compulsive</u>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Phobic disorder</u>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Eating disorder (DSM-IV)</u>				
Anorexia	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Bulimia	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Psychosis</u>				
Schizophrenia	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Schizo-affective	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Unspecified	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Tics</u>				
Motor	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Phonic	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Tourettes	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<u>Other Disorders (e.g. sexual etc)</u>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

SAPPA PSYCHIATRIC ASSESSMENT, CONSISTENT WITH DSM-IV-TR , USED IN THIS STUDY

Code **N/A**: Not Applicable (i.e. No Episode) and **N/K** Not Known

**OVERALL CODING
PSYCHIATRIC ASSESSMENT OF PROBAND**

Disturbance/Disorder Present (other than Autism/Developmental Disorder)

0 = No

1 = Yes

2 = More than 1

<u>Type of Dis orders</u>	<u>PRESENT</u>	<u>AGE ONSET</u> (years)	<u>DURATION</u> Worst episode	<u>EPISODES</u> (Number)
---------------------------	----------------	-----------------------------	----------------------------------	-----------------------------

(use DSM-IV-TR criterion)
 0 = Absent; 1 = Possible; 2 Probable or definite but does not reach criteria only because of communication difficulties;
 3 = Definite; N/A because of communication problems

<u>ADHD</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Impulse control disorders</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Affective</u>				
Major Depressive Illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bipolar Disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety Disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Obsessive/Compulsive</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Phobic disorder</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Eating disorder</u>				
PICA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anorexia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bulimia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Psychosis</u>				
Schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Schizo-affective	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unspecified	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Tics</u>				
Motor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phonic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tourettes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Other Disorders</u> (e.g. sexual etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Go to next page

APPENDIX 4 – Auxiliary Material (CD-R)

1. Survey
 - Original SAPPA interview booklet
 - Fillable SAPPA interview booklet
2. Database
 - Excel Database
3. SAPPA interviews
 - PDF copy of 90 SAPPA interviews
4. Ultra-brief surveys
 - PDF copy of ORS and SRS questionnaires
5. Reports
 - PDF copy of monthly reports
 - PDF copy of final report
6. Ethics
 - Consent form