



# Tri-Counties Regional Center Autism Services Survey 2007

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## Executive Summary





## Executive Summary

In 2007 Tri-Counties Regional Center (TCRC) conducted a study on Autism Services in support of the *Strategic and Performance Plan 2007 - 2009* and the regional center's mission of providing services and supports to people with developmental disabilities. The Autism Services Survey supports TCRC's vision and mission by gathering information from families of children with autism about the effectiveness of services provided and providing insight on the full spectrum of services families receive from both the regional center system and the education system.

Specifically, this survey gathers feedback on the utilization, efficacy and program standards for the autism services purchased by TCRC and provided by a number of independent providers. The study seeks to:

- Determine the degree to which parents of children with autism feel they are helped by purchased in-home behavioral services;
- The initial and current concerns, problems, and benefits of parents receiving in-home behavioral services for their child with autism; and
- Measure the effectiveness of complementary support services from the family perspective.

This survey also gathers information on medication, information, family support services and overall regional center services specific to individuals with autism and the families of those individuals.

*Population.* The population was defined as families meeting four criteria: 1) individuals served by TCRC, 2) having an active status with the regional center, 3) having a flag for Autism in the Client Master File and 4) between the ages of 3 and 22.

*Sample.* With a qualified population of 1,208 individuals with autism between the ages of 3 and 22 and a target of 296 completed surveys, Kinetic Flow included the entire population in the sample to participate in the survey. While calls are made randomly, every family has an equal opportunity to participate in the survey.

*Questionnaire.* While Kinetic Flow provided some guidance, the survey instrument was designed substantially by TCRC's stakeholders. Questionnaire design was a multi-year process, beginning in 2004, with contributors to the final questionnaire including TCRC's executive staff and managers, the Service Review Committee, Consumer Services Committee, the Autism Task Force – the Diagnosis and Treatment Task Force Sub Group, Services and Supports Task Force Sub Group, the Clinical team and members of the Autism Society of America (ASA).

*Data Collection.* TCRC mailed pre-notification letters to each family to familiarize respondents with the survey effort. Interviews were conducted in both English and Spanish. Telephone interviews were conducted between October 25<sup>th</sup> and November 6<sup>th</sup>. In total, 1,443 calls were made with 299 families participating. The final confidence interval was 95.15%.



**Executive Summary continued...**

*Findings.* According to families, TCRC currently provides in-home behavioral services to 35% of children with autism and their families; 22% state that they have never received in-home behavioral services. For families currently receiving in-home behavioral services, the most commonly addressed goals are:

- Compliance, Following Directions (83%)
- In-home Skills, Manners (75%)
- Peer Social Skills (65%)
- Requesting (65%)
- Shared Attention (64%)

Overall, 94% of families experience “some” (47%) or “major” (47%) progress on their child’s goals and 70.5% feel the number of hours of in-home direct intervention received from a behavioral specialist is sufficient.

The specific types of in-home behavioral services and their effectiveness are summarized below. Overall, families rated the effectiveness of these programs between “Good” and “Excellent”, with the highest score being provided for Relationship Development Interaction (3.71). Also important, Pivotal Response Training was rated “Truly Outstanding” by 18% of respondents.

Service	% Receiving Service	Efficacy Mean Score*
Relationship Development Interaction	23%	3.71
Pivotal Response Training	42%	3.44
Floortime	30%	3.42
Discreet Trial Training (DTT)	40%	3.38
Social Skills	47%	3.21

\* Efficacy Mean Scores provided on a 1-5 Scale, where 1=Poor and 5=Truly Outstanding.

Overall, families rate the in-home behavioral services they receive between “Good” and “Excellent” (3.43) at making them feel empowered. Also worthy of note:

- Service Need – families want monthly meetings with a parent-trainer (53%).
- Service Need – 60% of families who received in-home behavioral supports in the past, feel their child should receive these services to address Peer Social Skills (66%) and Compliance, Following Directions (56%).
- Information - parents are most interested in understanding autism (93%), as well as information on traditional therapies (50%).
- Supplemental therapies – 28% of children are being treated with prescribed medications, while 33% are taking vitamins. Overall, families have rated supplemental therapies as “partially successful” (62%), with 23% feeling the treatment is “completely successful”.

A detailed discussion of the results of this study is found in the full report.



Tri-Counties Regional Center  
Autism Services Survey 2007

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Report on Autism Services Survey 2007





## Background

The State of California contracts with Tri-Counties Regional Center (TCRC) to provide supports and services for approximately 12,000 children and adults with developmental disabilities living in San Luis Obispo, Santa Barbara and Ventura Counties. These services cover the life span of individuals, from early assessment and intervention for infants and children through the residential, employment, service and medical needs of adults and seniors.

As stated in TCRC's *Strategic and Performance Plan 2007 - 2009*, one of TCRC's focus areas is Autism. TCRC wants to achieve "innovative and age-appropriate services reflecting best clinical practices are available to meet the needs of persons with Autism and their families." Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Autism knows no racial, ethnic, social boundaries, family income, lifestyle, or educational levels and can affect any child and any family.

Autism is increasingly common, affecting an estimated 1 in 150 births in 2007 according to the Centers for Disease Control Prevention. Roughly translated, this means as many as 1.5 million Americans are believed to have some form of autism. And this number is on the rise. Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10% to 17% per year. At this rate, the prevalence of autism could reach 4 million Americans in the next decade. In California, autism is the only CDER (Client Development Evaluation Reports) category that shows an overall increase as a percentage of the population, from 5.8% in December 1995 to 16.2% in December 2005<sup>1</sup>.

To support the desired outcome of TCRC's *Strategic and Performance Plan*, one of TCRC's outcome measures is a specialized Autism Survey which, in part, measures how well TCRC provides information about services and supports to families to meet the needs of their child with autism.

Tri-Counties Regional Center partnered with Kinetic Flow to design, develop, and administer the survey, analyze the results and report on findings. Kinetic Flow is an independent research and consulting firm specializing in serving health and human services organizations. With over 30 years of combined person-centered research experience and 12 years of combined experience in satisfaction research with individual regional centers, Kinetic Flow has developed valid, stable means of assessing the quality and benefit for services and supports for people with developmental disabilities and their families.

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<sup>1</sup> Department of Developmental Services, *Factbook*, Ninth Edition, June 2007, p. 14.



## Purpose & Objectives

TCRC's vision is for persons with developmental disabilities live fully and safely as active and independent members of their community. To achieve this vision, TCRC's mission is to provide person and family centered planning, services and supports for individuals with developmental disabilities to maximize opportunities and choices for living, working, learning, and recreating in the community.

The Autism Services Survey supports TCRC's vision and mission by gathering information from families of children with autism about the effectiveness of services provided and understanding the full spectrum of services families receive.

The overall objectives for the data and analysis gathered from this effort are:

- Support TCRC's strategic planning process;
- Understand the service goals and priorities of families with a child with autism;
- Provide insight for resource allocation; and
- Provide an overall picture of autism services.

Specifically, this survey gathers feedback on the utilization, efficacy and program standards for the autism services purchased by TCRC and provided by a number of independent providers. The study seeks to:

- Determine the degree to which parents of children with autism feel they are helped by purchased in-home behavioral services;
- The initial and current concerns, problems, and benefits of parents receiving in-home behavioral services for a child with autism; and
- Measure the effectiveness of complementary support services from the family perspective.

This survey also gathers information on medication, information, family support services and overall regional center services specific to individuals with autism and the families of those individuals.

*When fully utilized, this feedback can help the organization take the next steps in strategic planning, improve the information and resources available for families with children with autism and improve communication with the end result of creating services and supports which have a greater impact on the quality of life for the people they serve.*

This report summarizes the detailed data gathered by Kinetic Flow as part of the Tri-Counties Regional Center Autism Services Survey 2007. The information contained in this report is an accurate and valid snapshot of how families of children with autism perceive the services of and their relationship with the regional center.



## Methodology

People with developmental disabilities and their families are the reason the regional center exists. With the growing rate of autism, service and support needs specific to autism are increasing and changing, creating unique challenges for the regional center. The methodological process for this study focuses on exploring and understanding the service goals and priorities in order to provide an accurate and thorough picture through the eyes, experiences and words of the people TCRC serves.

*Population.* The population was defined as families meeting four criteria:

1. Individuals served by TCRC,
2. Having an active status (Status Code 2) with the regional center,
3. Having a flag for Autism and,
4. Individuals with autism being between the ages of 3 and 22.

Based on records provided by TCRC in October 2007, the total population meeting the criteria was 1,272. Kinetic Flow cleaned the data and removed 64 records with invalid telephone numbers, leaving 1,208 qualified families and individuals. Based on the population of 1,272 Kinetic Flow targeted 296 completed surveys in order to achieve a 95% confidence interval and 5% margin of error.

Overall, approximately 90.1% of families indicate that their primary language is English, approximately 8.8% speak Spanish with an additional 10 languages representing the remaining 1.1% of the population (see Demographic Summary on the next page).

*Sample.* With a qualified population of 1,208 families of individuals with autism between the ages of 3 and 22 and a target of 296 completed surveys, Kinetic Flow included the entire population in the sample to participate in the survey. While calls are made randomly, every family has an equal opportunity to participate in the survey.

*Questionnaire.* While Kinetic Flow provided some guidance, the survey instrument was designed substantially by TCRC's stakeholders. Questionnaire design was a multi-year process, beginning in 2004, with contributors to the final questionnaire including TCRC's executive staff and managers, the Service Review Committee, Consumer Services Committee, the Autism Task Force – the Diagnosis and Treatment Task Force Sub Group, Services and Supports Task Force Sub Group, the Clinical team and members of the Autism Society of America (ASA).

The questionnaire was designed as a “deep-dive” study to be used once every few years, rather than on a comparative, annual basis. In total the questionnaire contains 58 questions in four general categories – In-Home Behavioral Services, Additional Autism Services, Medication, and Overall Satisfaction.



Methodology  
continued...

Demographic Summary

	Sample/Population	
	Count	%
<b>Age Group</b>		
3-18 Years	1,096	90.7%
18-22 Years	112	9.3%
Total	1,208	100.0%
<b>Primary Language</b>		
Arabic	2	0.2%
All Other Languages	2	0.2%
Cantonese Chinese	2	0.2%
English	1,089	90.1%
French	1	0.1%
Hindi	1	0.1%
Hebrew	1	0.1%
Japanese	1	0.1%
Korean	1	0.1%
Spanish	106	8.8%
Tagalog	1	0.1%
Vietnamese	1	0.1%
Total	1,208	100.0%
<b>Ethnicity</b>		
African-American	16	1.3%
Asian Indian	3	0.2%
Chinese	8	0.7%
Filipino	16	1.3%
Japanese	2	0.2%
Korean	3	0.2%
Laotian	1	0.1%
Mult.Cultural	54	4.5%
Native American	2	0.2%
Other	17	1.4%
Other Asian	16	1.3%
Other Pacific Islander	3	0.2%
Russian	2	0.2%
Samoan	2	0.2%
Spanish/Latin	248	20.5%
Unknown	204	16.9%
Vietnamese	2	0.2%
White	609	50.4%
Total	1,208	100.0%





**Methodology  
continued...**

Section 1 - In-Home Behavioral Services – consists of 34 questions separated into three sub-sections:

- 1A – Currently Receives In-Home Behavioral Services,
- 1B – Previously Received In-Home Behavioral Services, and
- 1C – Never Received In-Home Behavioral Services.

Participants are only asked to respond to those questions relevant to their experience with In-Home Behavioral Services. A variety of response scales are used in this section, including Yes/No, multiple response selection, 5-point rating scale, short answer and open end.

Section 2 – Additional Autism Services – contains six questions asking participants about services they receive through school programs and Early Start. Response options in this section are either Yes/No or multiple response selection with one open end.

Section 3 – Medication – contains four questions asking participants about the effectiveness of any medication or supplements their child uses. Similar to Section 2, the response options are Yes/No, short answer and multiple response selection.

Section 4 - Overall Satisfaction – contains 13 questions. This section of the survey is predominantly based on TCRC’s annual *Services and Supports Study*. Respondents to Autism Services Survey were not asked to participate in the 2007 Services and Supports Study which was in progress concurrently, however, by including some of the same questions, families have the opportunity to provide feedback on TCRC in a general way. While a variety of response option types are used, nine of the questions use the 5-point response scale where 1 = Poor, 2 = Just OK, 3 = Good, 4 = Excellent, 5 = Truly Outstanding. In addition, there is one Yes/No, one multiple response option, and two open end questions.

<b>Autism Services – Questionnaire Overview</b>	
Section 1	In-Home Behavioral Services A. Currently Receives B. Previously Received C. Never Received
Section 2	Additional Autism Services
Section 3	Medication
Section 4	Overall Satisfaction



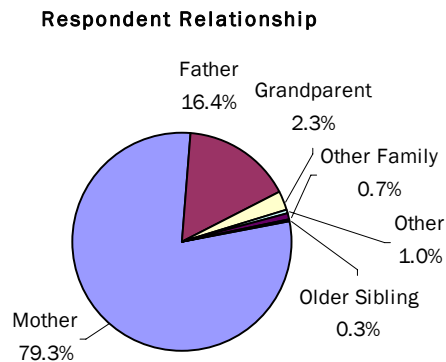
**Data Collection.** TCRC mailed pre-notification letters to each family to familiarize respondents with the survey effort. This served to bolster the response rate, as well as foster confidence in the legitimacy of the effort and increase the overall perception of TCRC.

Interviews were conducted by telephone, allowing the survey to reach a large number of individuals and families without screening for language, literacy, or correct mailing address. Kinetic Flow provided orientation and training to the professional interview team to ensure full understanding of the questionnaire itself. Several call monitoring sessions ensured that quality and process remained consistent. Interviews were conducted in both English and Spanish. The telephone effort began on October 25<sup>th</sup> and closed November 6<sup>th</sup>. In total, 1,443 calls were made with 299 individuals and families participating, which exceeded the 296 targeted completed interviews by three. As a result, the confidence interval is slightly higher than targeted at 95.15% and the margin of error was slightly lower - 4.99%. The final cooperation rate was 80%<sup>2</sup>. A total of 37 individuals declined to participate.

## Findings

### Respondent Demographics

A total of 299 respondents participated in the survey. The typical respondent was the mother of a 6 to 12 year old child with autism living in the family home. Mothers were the respondents in nearly 80% interviews with fathers the next most frequent respondents, approximately 16% of the time. The remaining respondents were family members – grandparents, aunts and older siblings.

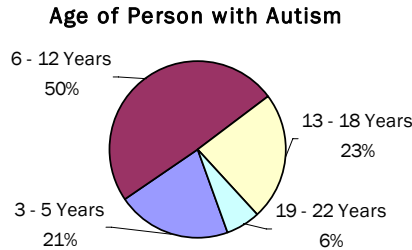


<sup>2</sup> For comparison purposes, national norms for telephone surveys typically have a 53.2% cooperation rate. TCRC, and most regional centers, tend to have substantially higher cooperation rates than the national norm.

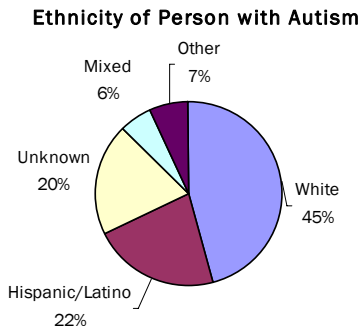


Findings  
*continued...*

The parameters established by TCRC for this survey specifically limited respondents to parents and family members. People with autism were not eligible respondents. Since over 93% of the family members with autism are under the age of 18, there were few cases when the person with autism asked to speak directly with the interviewer but was not able to.



Individuals and families responding to this study were approximately 45.5% White, 22.4% Hispanic/Latino, 19.7% Unknown in the Client Master File, 5.7% Mixed and 6.7% other. Surveys were conducted in both English and Spanish with 27 individuals choosing Spanish. Of the 272 interviews conducted in English, the Client Master File indicated a primary language of Chinese for two respondents and Vietnamese for one respondent.



The vast majority of people with autism included in this survey live with a parent or relative in the family home (97.7%). Other individuals live in group homes – four people in a CCF (4-6 beds), one in a CCF (1-3 beds) and one in an ICF/DD-H (7-15) beds. One other person with autism was residing with the California Youth Authority.



Findings continued...

Section 1: In-Home Behavioral Services

Question 1 asks which services families currently receive through TCRC. Less than half of all respondents receive in-home respite (41%) and in-home behavioral services (37%), which were the most commonly received services. Less than 20% of respondents received other services listed.

Q2 then asks if the family is currently receiving in-home behavioral services, received them in the past or never received these services. In summary, families reported

- Currently receives in-home behavioral services 35% (105 families)
- Received services in the past, not currently 43% (127 families)
- Never received in-home behavioral services 22% ( 64 families)

The family's response to this question determined the next questions asked (Section 1A or 1B or 1C).

Section 1A: Currently Receiving In-Home Behavioral Services - The top five goals for these 105 families included:

Q5. Behavioral Goals Addressed by In-Home Services	% Goal of Service*
1. Compliance, Following Directions	83%
2. In-home Skills, Manners	75%
3. Peer Social Skills	65%
4. Requesting	65%
5. Shared Attention	64%

\* Note: Respondents may select more than one response option - percentages do not add up to 100%

*"In home training - it's been very helpful and fun."*

In general, between 24% and 44% of families responded that these goals had been met or completed with a maximum of one-percent of families discontinuing the goal. In general for the majority of respondents, these goals are in progress with progress being described in Q11 as either "some" (47%) or "major progress" (47%).

The most commonly discontinued goals are Toilet Training (6%), Self-Care/Hygiene (4%), and Chores/Activities of Daily Living (4%). For those respondents who did discontinue these or other goals, 57% tried an alternative method (Q10), particularly change reinforcement (50%), prior to discontinuing work on the goals.

For questions 12 and 13, regardless of the number of hours of in-home direct intervention received from a behavioral specialist, most families feel the time is sufficient, although a substantially higher percentage (86%) felt that 20+ hours was sufficient than only 50% receiving zero hours.



Findings continued...

"I need to find a service to help him become more social...I want him to interact with other kids his age. I want something away from school."

Parent-training was the topic of Questions 14 and 15. The majority of respondents (56%) receive zero hours of parent-training with only 31% feeling that this is sufficient. An additional 36% of families receive between one and ten hours of parent-training with 81% feeling that this amount of time is sufficient. The remaining 8% of families receive over ten hours of training and overall 67% feel the time is sufficient.

Questions 17 through 22 ask families to rate various additional services they receive on a 5-point scale where 5.0 = Truly Outstanding, 4.0 = Excellent, 3.0 = Good, 2.0 = Just Ok and 1.0 = Poor. A mean score is calculated for each service using this scale. None of the respondents felt the services received were "poor". Of the 105 families currently receiving services, 42 families are receiving one of the services below and 46 families are receiving two or more of the services. The following table provides an overview of the service, the percentage of respondents who use the service and the mean score for effectiveness of the service. Services are ranked by effective mean score - highest to lowest.

Service	% Receiving Service*	Mean Score
Other**	10%	4.14
Relationship Development Interaction	23%	3.71
Pivotal Response Training	42%	3.44
Floortime	30%	3.42
Discreet Trial Training (DTT)	40%	3.38
Social Skills	47%	3.21

\* Note: Respondents may select more than one response option - percentages do not add up to 100%

\*\* Note: "Other" reflects the experience of less than 10 people. Data should be used for directional purposes only.

For "Other" respondents cited behavior therapies, language and play as effective. **Even excluding "Other"(which was selected by a minimal number of respondents), there is an inverse relationship between the percentage of people receiving services and the perceived effectiveness of the service.** Overall (Q23), families rated the in-home behavioral services they receive between "Good" and "Excellent" with a mean score of 3.43.

In addition to in-home behavioral services, parents would like to receive:

Q24. Additional Resources to be an Effective Parent	% *
Monthly meeting with parent trainer	53%
Support group for parent/caregiver	43%
Individual counseling	43%
Monthly meetings with other families	38%
Other	16%

\* Note: Respondents may select more than one response option - percentages do not add up to 100%



Findings continued...

When asked to specify "Other", responses included:

- Communication
- Coordination with the school
- Direct training
- Attendance at conferences
- Recreational/social and outdoor activities
- More information
- More therapy

Section 1B: Previously Received In-Home Behavioral Services – The 127 families responding to section 1B received in-home behavioral services at some time in the past, however, were not receiving services at the time of interview. Based on the responses to Q25, 60% of families had received services within the prior year, 30% received services one to three years prior and 10% received service three years or more prior.

Approximately 60% of respondents felt that their child should receive services now (Q26). The top goals which these families feel need to be addressed included:

Q27. Behavioral Goals which Need to be Addressed	%*
1. Peer Social Skills	66%
2. Compliance, Following Directions	56%
3. In-home Skills, Manners	46%
4. Chores, Activities of Daily Living	37%
5. Initiation	28%
6. Shared Attention	28%

\* Note: Respondents may select more than one response option – percentages do not add up to 100%

“(Need something to teach teenage boys about dating and peer pressure in school.”

In general, between 23% and 59% of families responded that these goals had been addressed while receiving in-home behavioral services (Q28). Further, between 25% and 56% indicated that the goal had been met or completed (Q29) while receiving services and between 8% and 25% had discontinued the goal while receiving services (Q30). In general for the majority of respondents, these goals were in progress with progress being described in Q31 as either “some” (49%) or “major progress” (33%) while receiving in-home behavioral services.

Question 32 asks families about additional therapies and interventions they received. The following table provides an overview of the service and the percentage of respondents who received the service. Services are ranked by most to least received.



Findings continued...

"I (would) like him to be able to go play basketball. I want to get the Relationship Development Intervention and transition services."

Q32. In-home Behavioral Services, Therapies, Interventions Received	% Receiving Service*
Social Skills	60%
Floortime	33%
Relationship Development Interaction	31%
Pivotal Response Training	27%
Other	23%
Discreet Trial Training (DTT)	17%

\*Note: Respondents may select more than one response option - percentages do not add up to 100%

For "Other" respondents cited behavior programs, play therapy, safety training, toilet training, and community involvement.

In Q33, families were asked to provide an overall rating of the in-home behavioral support services they received in terms of making the family feel empowered or able to work more effectively with their child. The rating was based on a 5-point scale where 5.0 = Truly Outstanding, 4.0 = Excellent, 3.0 = Good, 2.0 = Just Ok and 1.0 = Poor. Using this scale, a mean score of 3.24 was calculated with 36% rating services as Truly Outstanding or Excellent, 44% rating services as Good, 11% as Just OK and 8% rating services as Poor.

Section 1C: Never Received In-Home Behavioral Services - The people responding to section 1C received in-home behavioral services neither currently nor in the past. Of the families responding to this section, 30% felt their child should receive services at this time (Q34). Families responding "Yes" to Q34 were asked which specific behavior goals they felt needed to be addressed. The following table summarizes the top responses.

Q35. Behavioral Goals which Need to be Addressed	%*
1. Peer Social Skills	67%
2. Self-Care, Hygiene	67%
3. Chores, Activities of Daily Living	61%
4. Compliance, Following Directions	50%
5. In-home Skills, Manners	50%

\* Note: Respondents may select more than one response option - percentages do not add up to 100%

Section 2: Additional Autism Services

Section 2 looks at what other services, aside from in-home behavioral services, families are receiving, particularly services received through schools. The following table provides an overview of the additional services children receive ranked from most to least.



Findings continued...

Q36. Child has Received Services through...	%*
1. Special Education IEP	82%
2. Pre-School	51%
3. Special Day Class	43%
4. Inclusion	38%
5. Early Start	30%
6. Private School, grades K-12	8%

\* Note: Respondents may select more than one response option – percentages do not add up to 100%

Less than half of families responded that their behavioral specialist works with the school to create continuity in the child’s program (Q37).

Of the 299 families who responded to Q38, approximately 83.6% have children who are receiving other specialized designated services in school including speech and language, occupational therapy, adaptive physical education, counseling, behavioral plan and supports, social skills, instructional aides, and/or physical therapy. Sixty-six percent feel the amount of time their child receives support services in school is adequate (Q39). Of the 34% who feel the school support services are inadequate, most families feel their child needs more support (Q40) in social skills (64%) and speech and language (58%).

Over half (55%) of respondents state there are services and supports that they would like that they are not already receiving (Q41). The specific services and support that families would like are detailed in their own words in the Appendix – Open-End Responses to Q41a. Of particular interest are speech and occupational therapy, social skills and recreational opportunities.

*“I’d like to see him have a play buddy. He has never had one.”*

**Section 3: Medication**

Of the 298 people who responded to the types of medication used to treat their child (Q42), 138 indicated none of the medications or supplements listed were being used, while an additional 89 responded that one of the options was used and 71 families indicated that two or more types of medications and/or supplements are used.

Q42. Medication/Supplements for Treating Autism	# Respondents	% Respondents*
None	138	46%
One medication/supplement	89	30%
Two or more medications/supplements	71	24%





**Findings  
continued...**

*“They gave us hope meeting the needs we ask.”*

*“The Service Coordinator kept getting shifted and there was no continuity for the services. The changes caused interruption in services...”*

Among those families that use medications and supplements for their child, the most commonly used are vitamins (33%) and prescribed medication (28%). Overall, 85% of families responded that the medications and/or supplements they use are either partially or completely successful for managing troublesome behavior (Q43).

Most children (92%) do not experience any adverse reactions to their treatments (Q44). For those that do experience adverse reactions, the most common reactions were weight issues (gain or loss), loss of appetite, and becoming more emotional or irritable.

**Section 4: Overall Satisfaction**

The final section of the survey asked families about their information needs and overall satisfaction with the regional center. Questions 48 and 49 asked families if they had ever looked for information on autism and specifically what type of information they were looking for. Overall 89% of respondents had looked for information on autism, autism related therapies and supports and services. The following table ranks the specific type of information in which families were interested.

Q49. Information Looked For	%*
1. Definition of autism, diagnosis, behaviors	93%
2. Traditional therapies	50%
3. References for specialists	37%
4. “Non-traditional” therapies	35%
5. Support groups, local organizations	34%
6. Other	25%
7. Advocacy groups	23%
8. Adult or transition services	13%

\* Note: Respondents may select more than one response option – percentages do not add up to 100%

Based on the open-end responses, information continues to be in high demand. The families’ responses to “Other” are detailed in the Appendix – Open-End Responses for Q49. In general, people were looking for dietary information, behavior information, medical and general information.

For comparison purposes, nine of the questions in this section were the same as questions for TCRC’s annual Services and Supports Survey. The response scale used is the 5-point scale where 5.0 = Truly Outstanding, 4.0 = Excellent, 3.0 = Good, 2.0 = Just Ok and 1.0 = Poor.

TCRC’s annual Services and Supports Survey provides insight on the overall population served by TCRC, as well as looking at results by age group, ethnicity and by regional center team or office. The Autism Service Survey provides a unique opportunity to view



**Findings  
continued...**

some of the same ratings by diagnosis, to understand if the service needs for the growing segment of the population with autism feels that services are being met by TCRC as effectively as those with needs for mental retardation, epilepsy, Down syndrome and other developmental disabilities. The table below provides a summary of the questions, the mean for the Autism Services Survey and the mean from TCRC's CY2006 Services and Supports Survey. In general, while most responses fell within the 3.0 or "Good" range, families with a child with autism are less satisfied with services and supports provided by TCRC than the overall population.

*"They help us learn to live as a family and understand why we do things."*

Question	Mean for Autism Survey	Mean for Services & Supports Survey	Difference
Q46. Service Coordinator	3.27	3.68	-0.41
Q47. Comfort level with staff	3.28	3.41	-0.13
Q50. Providing information	2.97	3.31	-0.34
Q51. Progress towards IPP goals	3.16	3.14	0.02
Q52. IPP addresses important things	3.20	3.46	-0.26
Q53. IPP addresses needs and wants	3.14	3.40	-0.26
Q54. Choice of Services	2.94	3.14	-0.20
Q55. Overall services & supports	3.15	3.41	-0.26
Q56. Impact of regional center on life	3.39	3.51	-0.12

While the progress toward the IPP goals is comparable for individuals with autism and the "general" TCRC population, satisfaction with information and services is significantly lower on most aspects and indicates a different level of comfort with staff and overall impact of the regional center.

Additional detail on each of the findings discussed is available in the Survey Results by Question and Appendix sections of this report.



## Report Summary

While Kinetic Flow does not have the clinical expertise to recommend action steps based on the results of this study, there are trends and conclusions which Tri-Counties Regional Center may want to consider with regards to the Strategic and Performance Plan 2007-2009 and in establishing policies and programs to better meet the needs of people with autism and their families.

One of the three primary objectives of the study is to understand the degree to which parents of children with autism feel they are helped by purchased in-home behavioral services:

- ✓ 94% of families currently receiving in-home behavioral services describe the progress made on the goals addressed as either “some” or “major”
- ✓ 70.5% of families currently receiving in-home behavioral services feel that the number of direct intervention hours received each week is sufficient
- ✓ Overall 60% of families currently receiving parent-training feel that the number of hours received each week is sufficient
- ✓ While only 23% of families are receiving Relationship Development Interaction, 71% of those families rate its effectiveness as Excellent or Truly Outstanding with an additional 18% indicating Good

The second objective of the Autism Services Survey was to identify the initial and current concerns, problems, and benefits of parents receiving in-home behavioral services for a child with autism:

- ✓ With regards to information, parents are most interested in understanding the definition of autism, the diagnosis, related behaviors and symptoms (93%), as well as information on traditional therapies (50%)
- ✓ In order to be an effective parent, respondents are looking for a minimum of a monthly meeting with a parent-trainer (53%). Currently 56% of the 299 respondents receiving in-home behavioral services receive zero parent-training hours with 69% feeling that this is an insufficient level of support
- ✓ As a concern, 60% of families who previously received in-home behavioral services feel their child should receive services at this time

The third and final objective of the study was to measure the effectiveness of complementary support services from the family perspective:

- ✓ 71% of the families responding indicated that their child with autism receives speech and language services in school, however 58% responded that the amount of time is inadequate
- ✓ Similarly, 33% are receiving social skills services, however 64% indicated that the amount of time is inadequate
- ✓ 53.7% of respondents indicated that their child is treated with medications or supplements with 85% stating that the treatments are either partially or completely successful for managing troublesome behavior



The data clearly demonstrates that autism related services and supports provided by Tri-Counties Regional Center have a significant impact on the individuals and families they serve. However, the data also demonstrates that families believe there is room for improvement in the provision and effectiveness of services and supports. As the number of children affected by autism continues to grow, the task for TCRC management is to prioritize the needs of families and to collaborate with other provider agencies, such as the school system, to provide a seamless and comprehensive network of supports. The end goal of these efforts, in alignment with TCRC's mission is to ensure that the child's abilities are fully developed so that they can participate as active and independent members of their community.