

Keep My Family Close

A place where family members and caregivers of children in YCS Sawtelle programs can find support, understanding and helpful information



New Health Insurance Benefits for Children with Developmental Challenges

Page 4

Enter our holiday raffle to win one of three TD gift cards

See page 5 for details

Celebrating the holidays can be tricky when your child has special needs. A parent shares her advice and the one key word that can help you make this year's holidays special.

Page 9

Parent Satisfaction Survey results are in

Page 2



Photos guaranteed to make you smile!

What did a Recent Parent Satisfaction Survey Reveal about The YCS Sawtelle Residential Services?

The YCS Research Department conducted two Parent/Caregiver Consumer Satisfaction Surveys in October 2012 and April of 2013. The cumulative results of these surveys was published this summer. While the results are encouraging, the number of families who participated was underwhelming. We hope that as parents become more comfortable with staff, the number of survey participants will grow.

Sawtelle Homes and Residences Parents said... *

86% of parents said they would recommend the program to others

76% of parents said they depend on YCS to be there when needed

71% of parents said they had input into developing their child's HP goals

64% of parents said the treatment team understands their child's needs

* 22 parents/caregivers participated in these surveys

Have you received your YCS Sawtelle In-Home Parent Satisfaction Survey in the mail?

The surveys were mailed to all the parents receiving in-home services in October. Please return the forms as soon as possible. Your input gives our Sawtelle team the information needed to re-evaluate what is working and what needs to be improved.

If you did not receive your survey, please tell your behavioral assistant or e mail Jennifer Saraiva at jsaraiva@ycs.org



Keep My Family Close Sawtelle Edition

Autumn 2013

Message from YCS President Mom and Son in video	3
ASD Health Insurance coverage Enter our raffle to win	4
In the Community	5
Autumn Fun Letter from a grateful mom	6
Finding new hope at a Sawtelle Home Meet Student of the Year	7
Advice on navigating the holidays with your child	8-9
Good Reads and Resources	10



Want to know what your children are eating at the residences?

*Knowing how tricky it is to get any child to eat healthy foods,
YCS nutritionists design hearty, tasty menus.*

To encourage our residents to adopt a healthy lifestyle, our nutritionists plan meals with a wide variety of fiber-rich fresh fruits, vegetables, whole grains and lean meats.

Our home cooked meals support a heart healthy diet that relies on seasonings and herbs rather than salt in preparing delicious menus that exceed federal and state regulations.

We have seasonal, four week cycles that reflect favorites with ethnic and cultural selections. During the fall and winter, there are lots of soups, stews and stir-fries while the spring and summer meals emphasize robust salads and local produce. Every meal contains four components; meat/protein alternative, grains, vegetables/salad, and fruit as well as a glass of milk or water.

We pair the hearty menu with a nutrition education program that encourages residents to enjoy individualized portions and encourages daily physical activity. Our focus on nourishing food and regular fitness as vital components in the treatment process that provides optimal care for every resident.

By Jodi Godfrey, MS RD, YCS Dietician and Emily Callen, Dietetic Intern

Welcome to the first YCS Sawtelle edition of *Keep My Family Close*

A publication designed to support the parents and caregivers
of children in Sawtelle Residences, In-Home Care and Specialized Foster Care

*You've developed the
strength of a draft horse
While holding on the
delicacy of a daffodil...
you are the [parent]
protector, advocate of a
child with a disability.*

Lori Borgman

Like all new endeavors, this pilot Sawtelle edition of *Keep My Family Close* is a work in progress. It is our attempt at reaching out to all the parents and caregivers of children with intellectual and developmental disabilities. This newsletter is and can only become more meaningful with your input.

In this issue, we address some very important issues that affect every family. Foremost, is the article on health insurance coverage for children diagnosed with Autism Spectrum Disorder and other developmental disabilities. You may be surprised to find that all health insurance companies under state law are required to provide coverage for a range of services (see page 4).

Who else but a parent of a child with ASD and disruptive behaviors is better suited to share advice on navigating through the holidays and creating happy memories. We hope you can glean some insight from this parent to parent advice.

At YCS, we are committed to giving all our children and teens the opportunity to be a part of their communities as much as possible. Carolyn Roth, the parent of a child at Sawtelle Lawnridge, shares how difficult it was for her to place her son in a residential program, and now how gratifying it is for her to see him enjoying time with his peers and socializing in the community.

We look forward to your feedback on this inaugural Sawtelle edition of *Keep My Family Close* and promise to announce the raffle winners in our next edition.

Best wishes for a safe and joyous holiday.

Richard Mingoia
YCS President and CEO

Message from the President



***Keep My Family Close
Sawtelle Edition***

is produced by
YCS

235 Main Street
Hackensack, NJ 076041
www.ycs.org

President/CEO
Richard Mingoia

Editorial Advisor
William Waller

Writer/designer
Janis Nicolosi-Endo
jnendo@ycs.org

© 2013 YCS Systems, Inc.
All rights reserved.
May not be reproduced without
the written permission of YCS.



**A Sawtelle Mom takes us into her home and talks
about the help she and her son receive from the YCS
In-Home Behavioral Support Team**

More than 100 guests at the YCS Annual Meeting got a glimpse into the challenges and triumphs Dianna Chipkin faces every day as she cares for her son Daniel with the support of Sawtelle Behaviorist Jackie Maddi and Behavioral Assistant Lonnie Wallace, Jr.

Did You Know

The NJ Autism Insurance Law requires health insurance companies to cover various services and therapies for ASD and other developmental disabilities

On August 13, 2009, the NJ legislature passed The New Jersey Autism Insurance Law (P.L.2009, c.115). This groundbreaking law makes it possible for parents to access health insurance benefits for various therapies and in-home ABA services for children with ASD and other developmental disabilities. The coverage officially became effective on February 9, 2010.

However, while this was great news, there appears to be some drawbacks to implementing the law. Although ASD is a widespread problem affecting 1 out of 88 children in New Jersey, unlike other health problems (such as breast cancer), the insurance companies have done very little to advertise these relatively new health benefits. Also, in some cases, insurance companies are treating these services as an out of network expense which requires larger co-pays - thus, discouraging families from participating.

“We encourage all of our families to have a conversation with their insurance providers to find out what their options are so they can decide the best outcome for their child,” says Richard Mingoia, YCS President and CEO. “We are committed to working with families and providers to this end.”

Which autism services are required to be covered by the law? *

- ◆ Coverage for expenses incurred in screening and diagnosing autism or another developmental disability
- ◆ Applied Behavior Analysis
- ◆ Occupational therapy
- ◆ Physical therapy
- ◆ Speech therapy

Coverage for Applied Behavior Analysis is limited to individuals with autism under 21 years of age and is subject to a maximum benefit of \$36,000/year. There are no age or annual dollar limits on other benefits.

The types of insurance plans covered

- ◆ State Employee Health Plans
- ◆ Individual Plans
- ◆ Fully insured large group plans
- ◆ Fully insured small group plans

* Adapted from Autism Speaks website

Could you use a little extra cash to shop for the holidays?

YCS may be able to help
Enter our holiday raffle to win
one of three \$50 TD gift cards

It's easy

Just send us an e mail and put “Sawtelle Newsletter raffle” in the subject line

No Email? Then give us a call at 201-678-1312 x 134
and ask for Janis. We'll enter your name for you.

Deadline: December 20, 2013





All Smiles! - Three year-old Abigail visits her mom Christina for Family & Friends Day.

Friends and Family Day

Family and friends of the residents at two Sawtelle homes in Paterson gathered for a summer barbeque and a birthday celebration for one of the residents.

YCS instituted Friends and Family Days to bring families together in a relaxed environment where they could reconnect and strengthen their relationships. Speak to your child's clinician to get the date for the next event at his or her Sawtelle Home.

Daniel's family did not have to walk alone at the Gloucester County Autism Walk

Teens wore hand painted shirts and carried signs to let everyone know that they were walking on behalf of nine year-old Daniel Baldveieso, at the Gloucester County Autism Walk. In support of the Baldveieso family, YCS sponsored a table at the event and provided walkers with mementos and literature about Sawtelle Autism services.



Glenn and Delma Baldveieso with their son Daniel and supporters at the GCSSEF Autism Walk.

Shawn's hoop skills helps his team win the silver at the NJ Special Olympics Spring Festival

Eighteen year-old Sean, got into the game with less than a minute to go; he sunk a three point shot and the YCS team won the game. Although Sean was the only player from Sawtelle on the YCS team, he was not deterred from doing his best and showing his teammates that he cared.

"Sean loves basketball and being on the team," says his coach Romel Herron. "He's a team player and supports his teammates on and off the court."

We want to congratulate Sean and we look forward to cheering him on at the games next year.



Enjoying all the festivities that Autumn offers



Family members join their children and staff on an outing to Battlefield Orchard, where they picked apples and searched the fields for the best pumpkins



Taquan dressed up as his favorite food for a Halloween party



Students at the Sawtelle Learning Center get ready for a scavenger hunt for Halloween goodies that they made in class

A Mother shares her gratitude and new found hope in a letter to YCS

Julia Shriver-Muse's adult daughter has a long history of elopement that has caused her much anguish and fear for her daughter's well-being. After being transitioned into a Sawtelle Home, her daughter again eloped. With a concerted effort by all the staff at the home, they were able to locate Ms. Shriver-Muse's daughter after 12 days and safely returned her to the residence. In a impassioned letter to YCS, Ms. Shriver Muse expresses her gratitude to the staff and in particular Sawtelle Home administrator, Rayletta Garrison.

This is the first time that anyone has gone to the lengths that Rayletta has to get my daughter home....I am humbled and grateful that I, after 15 years, do not have to bear this burden alone. Ms. Rayletta is my hero... She has assured me that I am not alone. She will walk with me through this. She will pray with me. She will be a voice when I can't speak. She will fight with me for my daughter.

We hope you find the inaugural YCS Sawtelle edition issue of **Keep My Family Close** helpful. It is a work in progress and can only get better with your feedback.

Do you have any suggestions or topics you'd like to see covered in future issues?

Would you like to serve on the newsletter's editorial board?

We look forward to your call!

William Waller
Parent Satisfaction Committee Chair
973-985-1422
wwaller@ycs.org

Finding hope in unexpected places



Sixteen months ago, when David transitioned from Trinitas Hospital into a YCS Sawtelle Home, his mother Carolyn Roth described her son as being physically ill and very sad. According to Carolyn, his autism was exacerbated by frequent seizures, depression and erratic behavior (including self-injury and aggression). Today, Carolyn says her 17 year-old son is happy.

"I am just a mom who loves her son and is struggling to accept the fact that I needed to ask for help. When I see how much progress David is making, I am so proud to be his mom."...Carolyn Roth

"He loves his new school [The Sawtelle Learning Center in Montclair] and is able to participate in weekly community outings."

Carolyn Roth drives one hour from her home in Freehold every Wednesday evening to visit her son David at the Sawtelle Home in Lawn Ridge. According to Carolyn, she and her son have some quality time during the middle of the week in addition to the family's regular visit every Sunday. She also gets to talk with the mother of another resident who also visits.

"It really helps as a mom to be able to talk with other parents who have had to make the same very difficult choice [to place their child in a home]. Being able to share her concerns with other parents and to have the support of the YCS staff is comforting.

Carolyn finds David to be more social; he makes more eye contact, and is becoming more verbal. "He's learning how to play basketball and wants to learn how to ride a bicycle," says the proud mom, adding, "The YCS Staff, at home and school, provide a warm, nurturing and safe environment for David to live and learn."

Carolyn explains that when David lived at home he was isolated and had very limited social interaction because of his disabilities and challenging behaviors. Their town did not have the types of services that would give David the opportunity to interact socially with his peers.

Since David has been at the Sawtelle Home she has watched him become more confident. "He's out from under my wing and becoming more independent."

Congratulations to Freddie Sumner and his Family



Frederick Sumner, from the YCS Sawtelle Home in Blackwood, was honored on October 16th as **Student of the Year** at Bankbridge Development Center. Freddie was selected for his strong work ethic and leadership skills that exhibited as a volunteer employee at Pizza Hut. The skills he acquired on his job carried over into his performance in the classroom and really impressed both his job coach and his teacher.

Are you looking forward to the holiday?

One Mom's thoughts on celebrating with her special child

Here come the holidays! For many parents with children, teens or young adults with special needs, the thought of holiday celebrations and socializing with loved ones and friends can feel more like a task than a joy. For many children with ASD and developmental or intellectual disabilities the holidays can be confusing. Disruptions in their daily routines and unfamiliar faces, sounds, food, can be overwhelming. Parents face the double burden of trying to manage their child's behavior and the awkward situations that arise with company.



So if we know how difficult it is to participate in family gatherings during the holidays then why on earth do we put ourselves through it?

It's important to remember that there really are lots of good reasons to celebrate with our child:

- We do love these people and want them to know, accept and love our child.
- It's a chance to visit with relatives we don't often get to see.
- We have fond memories of holiday events from when we were kids and don't want our kids to miss out.
- We want our child to feel part of a larger support network called family.

No matter how many times you've tried to explain the special needs of your special child, those who only see you a few times a year, often just don't get it. They mean well. They do love you. They want to include everyone who they think should be around the holiday table. They may even try to make adjustments to their idea of the perfect celebration, but often they do not understand you and your child's challenges. So, they often have unrealistic expectations for your child's behavior and ideas about what you can do about it.

Key Message to Remember

Don't apologize for yourself or your child

Whatever happens, your child is probably doing the very best he or she can. So are you. There is no need to apologize for your child's limited ability to manage the chaos of a big family get together. It comes with the territory of being who he or she is.

Equally important, there is no need to apologize if you need to take time out or keep the visit brief in order to keep your child stable and happy. The people who love you and your child will understand. For that, we can give thanks.



A Foster Parent shares the insights she has gained through being present with her child

Janet Robinson has been a YCS specialized foster parent for more than five years. Two adolescents who have been in her care have developmental challenges. One 14 year-old girl who transitioned into her home was very uncomfortable in social situations. "I have a large extended family and in the beginning, every time we got together for a social event, she carried on so that we would have to leave," recalls Robinson. She explains that her daughter's behavior was a product of her anxiety; fear of not understanding what people were talking about and the embarrassment of saying the wrong thing and looking foolish.

"I built up my daughter's confidence by being present." They have lots of conversations and talk back and forth until her daughter understands whatever is confusing her. My daughter may have special needs but she knows when she is being treated different from others...this is very hurtful." Ms. Robinson makes an effort to treat all her children equally. "My goal for my daughter is to help her to continue to gain the social skills she needs to live independently."

How can we keep ourselves sane and capture moments of joy at family holiday events?

Veteran parents are almost unanimous in their advice: *Plan, Plan, Plan!*

◆ **Plan to have help**

If at all possible, don't go it alone: If you do have a spouse or partner, plan together so you can operate as a team. If you don't, enlist the relative who is the most supportive or recruit a friend who doesn't have their own family plans to go along.

◆ **Plan to capture at least one important moment**

Identify what is the most important thing you want out of the day. Many special needs kids are on their best behavior for the first part of a visit. If there is someone you want to be sure to talk to, that's the time to make sure it happens. Tell everyone how much you have enjoyed seeing them at the beginning of the visit in case you have to abruptly leave. At least you will have shared one moment that you can take with you.

◆ **Plan for unwelcome family dynamics**

A guest will probably try to corner you into a painful conversation. Think about the likely scenarios and develop a few key lines to divert these probably well-meaning but unhelpful folks. It is never helpful to debate, argue, or try to introduce new information when at a family event. Just find a way to graciously acknowledge their concern and then turn the conversation to another topic or excuse yourself.

◆ **Plan for your child's inevitable melt-down**

Any change in routine can drive special needs kids over the edge. No matter how well you plan or how hard you try, the day is going to be difficult at times. Talk with the host family ahead of time about whether there can be a room where you and your child can take a time out, if you need to. Bring along whatever soothes your child and simply excuse yourselves for a while. If the event is at your house, it's a good idea to make your child's room off-limits so at least that space can stay familiar and friendly for your child.

◆ **Plan the food**

Have prepared or bring with you the food that your child is most comfortable with. Special kids don't care if the holiday meal is gourmet. Most of them get upset when the food is unfamiliar or when they are pressured to "try" something. By keeping a dish of that food next to them at the table, "she was happily occupied while the rest of us ate turkey."

◆ **Plan an escape**

Let the hosting family know ahead of time that you may have to opt out of dessert (or even dinner) but that it's better to go before things reach crisis proportions. The best plans don't always work. Sometimes a time-out to calm down is enough for you and your child to regroup. Sometimes it's simply not. Trying to tough it out just isn't worth it for anyone. If you're with a partner, one of you collects whatever stuff needs to be collected and the other deals with the child. Alone? Leave the stuff and just get out of there while everyone is still smiling.

Advice on both pages is excerpted from
www.psychcentral.com

By Marie Hartwell-Walker, Ed.D a parent of a special needs child

Good Reads and Resources

Tending the Family Heart Through the Holidays

by Marie Hartwell-Walker Ed.D.

Psych Central publishes e-books on parenting and mental health topics. *Tending the Family Heart Through the Holidays* by Marie Hartwell-Walker Ed.D. is a book designed to help the parents of children with special needs successfully navigate the holidays with their families.

This collection of 31 essays and articles written over the years provides you with down-to-earth tips and strategies that you can use today to help improve your family time this holiday season.

This “e” book it's available for downloading **for just \$0.99 at Amazon.com or BN .com**. Both sites allow you to download free software that enables you to read the book on your computer, or a multitude of other devices, including the Amazon Kindle e-reader, the Barnes & Noble nook e-reader, and on free iPad and iPhone apps published by both companies.

An Online Resource

The mission of the **U.S .Autism and Aspergers Association (USAAA)** is “to provide the opportunity for everyone living with autism spectrum disorders to achieve their fullest potential, by enriching the autism community with education, training, accessible resources, and partnerships with local and national projects.” USAAA offers a free online weekly newsletter that contains all the latest information about ASD. It is easy to read and is supplemented with informative and encouraging insights by persons affected by autism, parents, and caregivers.

Visit usaaa.org parents/caregivers link to sign-up for their “e” newsletter.

The YCS Family/Guardian Handbook

This resource, for parents and caregivers with a child in a Sawtelle residence, is an easy to read and comprehensive look at all the services that are provided for your child, and the procedures that provide your child with the best care and protection.

If you don't have a copy of the handbook, please contact your child's clinician.

YCS Mission

To partner with at-risk and special needs children, youth and young adults to build happier, healthier more hopeful lives within families and communities.

www.ycs.org



Just One Big Family

All the children, staff and families in the YCS Southern Region shared a joyous Thanksgiving dinner and then took to the dance floor to show off their best moves! Special thanks to Kohl's volunteers for helping out serving the buffet. This holiday tradition is one that all the children and families look forward to each year. It's a chance for everyone to see old friends and make some new ones too.