First Things First

Cheryl Marcella, Parent with Marie Awn Floyd
Director of Family Support Services

As caregivers seek supports and advocate for services for their family members with developmental disabilities, they are certain to face the limitations that are a result of the current fiscal environment in New York State. This could likely result in frustration and disappointment.

“It’s important to remember that the cause of your frustration is not about your child because this will impact how you feel about your child. It’s about the system,” Cheryl Marcella, a Wildwood mom, says.

Her son, Ryan, was on board to go into a small group home with a few other young men when development for this particular home was halted by the state. This could have stopped Cheryl in her tracks.

“I really try to look at the positives in our lives and work on helping my son get the services continued on p. 3

Harriet Cornwell, Parent and Advocate

Harriet Cornwell, Parent with Tom Schreck
Director of Communications

Ever since Kevin was born, Harriet Cornwell has been an advocate. It’s not something that before her son was born she spent her life doing and it’s not something that fit real well with her personality, but it is something that eventually came natural to her.

“I consider myself semi-shy. Many people never really spend much time thinking of people with special needs—I know I didn’t, until my son Kevin was born with a developmental disability. At that point I started to educate myself by going to workshops at Wildwood. That’s when I learned it was important to speak up,” Harriet says.

Harriet spent time learning about the need to advocate for her son and to advocate when it came to his supports and services. Kevin is now 36 years-old, and Harriet has never let up.

continued on p. 4
Dear Friends...

The importance of advocacy is frequently a theme of Reaching Out and for good reason. Even in “good times” it is vital for the people we elect to understand the needs of the people and families we serve.

Right now, we are not in “good times.” Programs on which our families have always relied may not be readily available in future years, and wait lists are steadily growing. More than ever before, we live in a time that calls for us to be active and united advocates.

Wildwood was founded in an era when there were very few community-based supports for people with developmental disabilities, and little or no funding. Since then, we have presented ourselves as a united front and worked toward united goals. Along the way, we’ve earned a lot of respect for our efforts, and we’ve accomplished a lot of good things for the people we serve.

However, in this time of great challenge and uncertainty, we can’t rest on our laurels for even one second. And so, I humbly ask for your help. Wildwood’s Government Advocacy Committee has one continuing need that never goes away.

Quite simply, we need your involvement. You don’t have to be a professional lobbyist, a motivational speaker or a great writer. The Committee will guide you, you’ll never be alone and in many cases the greatest contribution that will be asked of you will be to make a phone call, write a letter or send an e-mail. Of course, we always welcome people to join us on visits to our legislators as well.

Wildwood is committed to doing more than just surviving during this difficult period. We are committed to thriving and staying true to our mission. Please send us your e-mail addresses, and we’ll put you right to work!

Thanks in advance for your help. I wish you all a happy and healthy summer.

Sincerely,

Mary Ann Allen, Esq.
Executive Director,
Wildwood Programs

In this issue of Reaching Out we are focusing on the importance of advocacy in the lives of children and adults with developmental disabilities and the critical role of family members in advocacy efforts. The thought of acting as an advocate on behalf of someone else can be somewhat intimidating for many, assuming that it must require a particular set of skills or knowledge. The truth of the matter is that if you are a parent, you have very likely already practiced the skills of advocacy but without labeling it as such.

Advocacy is primarily the act of conveying the knowledge you have about an individual to help others understand what is needed to make that individual’s life successful and meaningful. If you’re a parent you may have had experience helping a new neighbor learn about your child or helped people at the market or at the mall understand your child’s unique needs as you negotiated your way through a crowded store or checkout line. Sometimes a word or two or a nod helps people know what your child needs.

That is advocacy.

It is very likely that you have talked to your child’s teacher or service provider about what approaches are most helpful and about situations that he or she might find frustrating or difficult to navigate… all examples of advocacy that happen on a day-to-day basis.

As a parent it is likely that you’ll need to advocate for your child throughout their life as there is nothing you should take for granted. In so doing you also help your son or daughter learn about advocacy. Your actions will serve as a model for them to become good self advocates so they will be able to independently articulate their wants, needs and desires.

In short, you already know about advocacy even if you don’t call it that. Chances are that you are probably already an expert at it when it comes to your child.

Sincerely,

Ric Walley
Chief Operating Officer,
Wildwood Programs
Self Advocacy
Eileen Marone
Social Worker Family Support Services

Charlene Ralph is a member of Wildwood’s Self Advocacy Group. The group meets once a month and is a member of SANYS, The Self Advocacy Association of New York State. SANYS has a very straightforward mission. It is “an organization run by and for people with developmental disabilities. We help people with developmental disabilities speak up for themselves and others.”

Charlene speaks very positively about what she’s learned from the group. “Self advocacy makes me feel proud of myself. It helps me speak up for myself. It gives me self-confidence. It gives me courage.” Charlene has used her self-advocacy skills in many different areas of her life such as speaking up when co-workers were bothering her at work. Charlene also told me about having the courage to attend rallies at the NYS Capital to protest budget cuts.

“I even had the courage to write a letter to the governor to tell him how we feel. Before I joined the group I never would have had the courage to stick my two cents in with the governor!”

She also talked about the group’s efforts to get the name of the Office of Mental Retardation and Developmental Disabilities changed.

“The word disability is okay, but the “R word” is not okay. It’s insulting”. Charlene’s face lights up when she talks about her self-advocacy efforts. The group has certainly been an important force in her life.

But people can certainly be good self -advocates without participating in a group. Learning to speak up for yourself starts at home. As parents, we often begin teaching self-advocacy skills to each of our children at a young age without even realizing we are doing it. However, when a child has a disability, it takes a much more conscious and persistent effort. It starts when parents help their children realistically understand their strengths and their limitations and when they help them practice making their needs known.

As a Wildwood Social Worker, I remember starting work with a very verbal young man who literally threw things if the subject of getting a job came up. We eventually realized that he was extremely anxious because he thought he would never get a job since he couldn’t fill out a job application independently. If he had been able to state his fear to others he would have been displaying great self-advocacy skills and would have been able to move towards job seeking much sooner. (He eventually got a job and was very successful.) Self-Advocacy takes many forms - speaking up for yourself at school, with your family, on the job and maybe even with the Governor.

Wildwood’s group meets on the second Monday of the month at our office at 1190 Troy-Schenectady Road. Anyone who wants to join can get more information by contacting Michelle Brown at 640-3384 or Sue Hanson at 640-3326.

First Things First
continued from p. 1

and supports that he needs. It’s really important to look at the options that we have in our lives and evaluate them with a good dose of realism.” Cheryl says.

Since Ryan was very young, Cheryl has been a tireless advocate. Her actions haven’t always paid off the way she wanted them to and certainly not as quickly as she has often hoped. Still, she shares her philosophy when it comes to advocating for your child.

“I learned very early on that it is important how you approach each situation. For me, I’ve learned that I need to prioritize and do first things first. I need to be realistic and work on things within my control and it always helps to develop relationships with people and work with them. You have to be willing to be persistent with your phone calls and follow up without forgetting to be polite and kind with whom you deal.”

Though success is never guaranteed, it is important to keep on trying. Like many parents, Cheryl doesn’t have any trouble finding the energy to stay motivated.

“I know why I am here. One of the reasons that I get through is because I believe I was put here for Ryan”.

A HISTORY OF PROGRAMS AND SERVICES

1967 27,000 persons with developmental disabilities living in institutions in New York State. Wildwood Programs is formed when parents did not want the status quo.

1972 Television documentary - written and narrated by TV news journalist Geraldo Rivera - reveals deplorable living conditions at New York’s Willowbrook State School. Parents of 5,000 persons living at Willowbrook State School file suit in federal court over the inhumane living conditions at the facility.

1972 First community residence for persons with developmental disabilities opens in New York State.

1975 May 5 - Willowbrook Consent Decree signed. New York State commits itself to a program of improving community placement for the “Willowbrook class” clients. Shortly thereafter, then Governor Hugh Carey extends similar benefits to all persons served by the OMRDD system.


We need people to advocate for the needs of individuals with neurological impairments and related learning disabilities, attention deficit disorders and autism, and their families, with government leaders and the legislature. No experience or special skill is needed.

We need people to write letters and e-mails, make phone calls and visit elected leaders. We will show you how and you never have to do anything alone. Please join us—there is strength in numbers!

Please contact Kathy Fernald at 836-2312 or at kfernald@wildwood.edu to find out how you can help.

Harriet Cornwell continued from p. 1

“I’ve never been happy assuming something was going to get done when it came to Kevin. I learned to check and double check on the follow through to see that people did what they said they were going to do. We’ve always taken him for second opinions when it came to doctors and things like that. I never took for granted that people would do things the way I would want them done.” Harriet says.

Harriet never believed that Kevin would live outside of her home, but from listening to professionals she knew it would be important for his development to be as independent as possible. An early workshop taught her to not wait to plan for the future.

“Kevin wouldn’t be living in his own home if I hadn’t attended that workshop. I learned that it is important to foster as much independence in your children as possible. I learned that I had to plan far in advance for my child’s needs,” Harriet says.

Though Kevin is now 36 years-old, Harriet hasn’t slowed down when it comes to her advocacy activities. She’s supported Wildwood’s Government Advocacy Committee for over 20 years. Advocacy is something she believes in and something she thinks all parents should value.

“The generation before me really fought to get things going. That generation before us should have medals of honor. They fought hard and pushed.

Maybe today parents see services and take them for granted but they shouldn’t because everything can go away with the stroke of a pen. Everyone can do something even if it just means copying over a letter to send to a representative. There’s something everyone can do.”

Harriet Cornwell

WILDWOOD’S GOVERNMENT ADVOCACY COMMITTEE IS ALWAYS LOOKING FOR PEOPLE TO GET INVOLVED

We need people to advocate for the needs of individuals with neurological impairments and related learning disabilities, attention deficit disorders and autism, and their families, with government leaders and the legislature. No experience or special skill is needed.

We need people to write letters and e-mails, make phone calls and visit elected leaders. We will show you how and you never have to do anything alone. Please join us—there is strength in numbers!

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The Power of the Family Voice in Advocacy

Marie Awn Floyd
Director of Family Support Services

The value of a parent or caregiver’s voice on behalf of a family member with a developmental disability cannot be understated. The leadership of the Office of Mental Retardation and Developmental Disabilities and agencies that are funded by OMRDD listen to the needs that are articulated by families and stakeholders. The vision and needs that have been expressed by families, caregivers and stakeholders have played and continue to play a significant role in shaping the development of services and supports for people with developmental disabilities.

Marilyn and her family have been long advocates on behalf of their daughter who has complex medical and developmental needs. In the mid 1990’s, they were planning for her transition from a school program to adult services but did not see a good fit with the established programs that were available.

It was clear to Marilyn that day treatment programs or supported employment services were not going to give her daughter the opportunities and support that she needed to continue developing skills toward increased independence and pursuing her interests as a young adult.

Coincidentally, a small group of young adults graduating from Wildwood School were in the same position and their families and staff shared the same need to create something new that would promote their growth and support them.

What did they do? As the established alternatives were inappropriate for their young adults, these families focused on working together along with staff and leadership at Wildwood Programs to develop something new. They researched and noted what was emerging in the field as a best practice and pursued it.

These families and staff invested their time and energy into advocating a new services model to key individuals within OMRDD and the New York State Legislature.

Their collaboration resulted in the day support habilitation program for young adults that has become the standard for individualized day habilitation services at Wildwood.

Marilyn thinks it is so important to have the leadership of experienced people who have successfully developed quality supports and services. Mentors share their acquired experience enabling new parents to focus their energies in productive ways.

In addition, Marilyn mentions that it is necessary to know the facts, give accurate information to funders, legislators and staffers and present requests courteously.

Parent advocacy never ends. There will be different needs with each developmental and life stage and new things to be accomplished for your family member with a developmental disability.

would subsequently become a central component of the Individualized Service Plan, case management and other parts of person-centered planning.

1993 May 3 - State Division of Budget approves OMRDD’s “Community Service Expansion Plan” (CSEP), a “new way of doing business” based on person-centered planning.

1993 December - Developmental Center census; 4,730. Just under 27,000 persons living in community residences; nearly 34,500 receiving Family Support Services; almost 46,000 in day services programs; and over 3,450 enrolled in HCBS Waiver. More than 86,400 consumers served.

1996 May - 26,861 consumer enrolled in HCBS Waiver Program, an increase of nearly 25,000 in four years.

1998 July - As of this date there are nearly 31,900 persons living in the community; more than 58,600 receiving day services. About 51,650 receiving family support services. Developmental Center census; just over 2,100 residents. More than 30,000 enrolled in HCBS. Nearly 109,550 consumers served.

1998 August 19 - Governor George E. Pataki announces “NYs-CARES” (NYS Creating Alternatives in Residential Environments and Services) a five-year plan to virtually eliminate the waiting list for out-of-home residential services for people with mental retardation and developmental disabilities.
Free Parent Workshops

The workshops below are both held at Wildwood Programs at 1190 Troy Schenectady Road, Latham, NY 12110. Please RSVP at least one week prior to program date by calling 518-640-3300. For more information, please call Marie Awn Floyd at 518-640-3346.

**HOW TO FILL OUT GUARDIANSHIP FORMS**
When: Tuesday 7/20/10, 6pm-7:30 p.m.
Presenter: Bill Combes
- Commission on Quality of Care and Advocacy for Persons with Disabilities

In this hands-on workshop, Bill Combes will provide copies of blank Guardianship forms on both paper and on a CD. He will go through the forms with you and tell you how to fill them out. Even if you’re not quite ready to file for guardianship, come and learn what the process involves. There will be ample time for questions and answers. The CD also includes an excellent resource guide, “Planning for the Future”.

**STRESS MANAGEMENT**
When: Monday, 8/2/10, 9am-10:30 a.m.
Presenters: Mary Fornabia, CSW
- Parent Network of the Capital Region
Marianne Simon, PhD
- Wildwood Programs Psychologist

Raising a child with a developmental disability can be one of the most stressful experiences a family goes through. Some common stressors include parental guilt, dealing with the perception of others, worry about the future, coping with difficult behaviors, disagreement between parents, increased financial burden and finding competent professional services for your child. This workshop will be presented by Marianne Simon who is a Wildwood Psychologist and Mary Fornabia who is a Social Worker and the mother of a child with a developmental disability. They will provide parents with strategies to better manage stress and improve wellbeing.