

Crystal Run Village, Inc.

“Services for the Integration and Empowerment of People with Disabilities”

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Currents

They call him Shane . . .

Unwrapping an Enigma

*By Deborah Cipollia, LCSW-R
Clinical Coordinator Supervisor*



Shane Holman and Alana Nowak exchange greetings on the night of their Senior Prom.

The young lady walked to the top of the stairs and paused. Full of anticipation, her eyes met his and their smiles illuminated the hallway. She was indeed beautiful. Her dress was sky blue and shimmering. Her hair filled with glittering ribbons that intensified the sparkle in her eyes. He was so handsome and proud, pulling on the sleeves of his tuxedo trying so very hard to maintain his composure and do all of the things that were expected of him. Amidst the cameras flashing, the oohs and aahs of family and friends, she descended the stairs and took his hand. He softly whispered, “You look beautiful.” She replied, “So do you.” This special evening in May was the Senior Prom for Shane Holman and Alana Nowak.

In order to fully appreciate this evening as the onlookers did, you must come to understand how grim the days, weeks and even years were for Shane before this prom ever took place. Shane came to Crystal Run Village, Inc. homeless and in the custody of the State of New York. His childhood and adolescence was filled with despair, mistrust, abuse and neglect. Shane never really knew his dad, and his mom died shortly after his beloved grandfather passed away. He lived with relatives after that; it was clear that no place was to be expected as long-term. For Shane the world was a dismal place.

I first met Shane on a cold winter’s day. Social Workers and Service Coordinators were requesting permanent placement for him within one of the agency’s group homes. He was receiving temporary housing in the Respite House because he had no one and no where else to go. Perhaps it was the expression in his eyes, because from the minute my colleagues and I came face to face with Shane we knew that he should live in a Crystal Run Village residence. We wanted to give him the feeling of stability that being at home with us would bring. We listened intently that day as he rehashed and rehashed his history. His self-advocacy skills have been hard won. *(continued on page 6)*

From the Desk of Jim Lawler

“Celebrate the Possibilities”



**Jim Lawler,
Executive Director**

This year we are using as our theme “Celebrate the Possibilities.” We could have used the word consider instead of celebrate, but that would not capture the spirit of enthusiasm and encouragement that we need to bring to our vocation. We do not celebrate alone. Celebration suggests a party of everyone -- people with disabilities, their families, their partners, government officials and the staff who support them.

We would all acknowledge (if we are honest with ourselves) that change is necessary and, when we make the right choices, empowering, giving us an increased sense of satisfaction. Every one of us wants to sit down at the end of the day and be able to say that, “In my small slice of the world, some good happened and I was a part of it.”

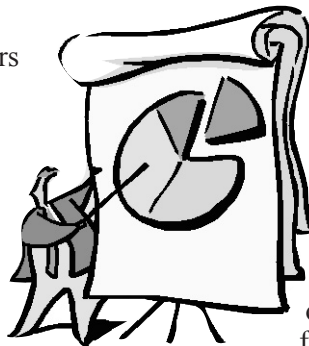
So what are these “Possibilities” we are celebrating? They are probably different for each of us individually, but then there is the collective responsibility to support people in reaching their goals which are unique to them. The idea of person-centered planning was not in my vocabulary 30 years ago. At that time this organization was helping people survive, living on 2 congregate care campuses, one with 96 people and the other with 182. A home with 4-6 people with dedicated staff, 2 vehicles, and significant choice was not on our radar. Large workshops and day treatment programs were the daily norm. There was no small day hab or, particularly, “Without Walls” programs to choose from. It is good to admit that we have made meaningful progress. It happened because people believed the status quo to be unacceptable and state government supported and challenged the field to be creative -- to find better ways to support people.

Where are we going? I can only imagine. What I do know is that there is a final destination. As long as we can continue to say we can do better, as long as we take the time to better understand peoples’ needs, as long as we commit ourselves to greater possibility and, as long as we collectively acknowledge our successes, there will be no end to the celebration.❖

*“It is good
to admit that
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progress.”*

OMRDD Agenda Forecast

Across the state self-advocates, family members of people with developmental disabilities, providers and people concerned with and involved in the intellectual disability system participated in Commissioner Thomas Maul's Public Hearing Draft of the Five Year Comprehensive Plan 2005-2010 for the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD).



Crystal Run Village, Inc. Executive Director Jim Lawler, in his role as an at large board member for the New York State Association of Community and Residential Agencies (NYSACRA), participated as a team presenter of testimony at the Mid-Hudson region hearing. NYSACRA is the largest statewide association of its kind, comprised of over 200 voluntary agencies providing services to persons with mental retardation and developmental disabilities.

Vision and Goals

OMRDD's vision for the next five years will feature continuity in the provision of the highest quality services, while expanding the system's capacity to offer more individualized services to each person and family. This vision will be implemented through pursuit of the major agency initiatives that are planned for the Comprehensive Five-Year Plan period of 2005-2010. These initiatives will help realize a service system for people with developmental disabilities and their families that emphasizes individualization, innovation, and choice, and that leads to quality outcomes. These initiatives are:

- **Participation and Collaboration.** OMRDD will continue to build on its tradition of seeking the participation of stakeholders, and especially parents and individuals with developmental disabilities, in planning for and providing services. In addition, OMRDD will further its work with the Self-Advocacy Association of New York State (SANYS) in realizing our mutual vision for full community participation.
- **NYS-OPTS.** This program is designed to provide a wide array of affordable options that promote inclusion and personal choice.
- **NYS-CARES II.** This program is critical to continuing the success of the original NYS-CARES initiative in providing out-of-home residential services to those from the community who need them.
- **Individualized Supports and Services.** OMRDD will continue to make supports and services more customer designed, directed, and individualized.
- **Workforce.** OMRDD will continue to work for higher wages, a stronger career structure and other elements of a quality work life for the direct support professional workforce. In addition, the Commissioner will establish a direct support professional advisory committee.

Preview of Future Systems Change

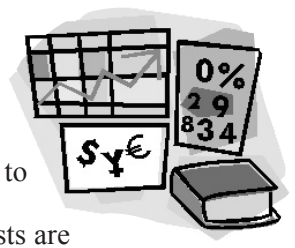
The major OMRDD program initiative during the plan period is NYS-OPTS, a person and family-driven systems change initiative using the Organized Health Care Delivery System model permitted under federal Medicaid regulations. NYS-OPTS will profoundly influence the variety, quantity, and quality of services in the OMRDD system in the future by using contracts that provide highly individualized services to specific service recipients. People with developmental disabilities and their families will shape the design and delivery of the services and supports offered through these contracts, as well as identify the outcomes by which success will be evaluated. The contractors such as Crystal Run Village, Inc., including many of the members of NYSACRA will be the voluntary providers of service. NYS-OPTS is being pursued to increase choice and individualization of services for people with developmental disabilities. Providers will gain the flexibility to customize solutions that will better meet the expectations of their customers.

NYS-OPTS has great potential for positive systems change.

The Guiding Principles for NYS-OPTS, as established by a diversified Steering Committee will direct the selection of pilot project proposals and constitute the standards for evaluating projects. OMRDD began implementing this program in 2004 by utilizing a statewide pilot program. Based on the experiences of these initial pilots, OMRDD will seek to expand successful projects to other parts of the state. Participation is strictly voluntary with consumer satisfaction as a key element in determining its success. The potential impact of NYS-OPTS might be compared with aspects of the HCBS Waiver. During the past decade, OMRDD concentrated on fully using the HCBS Waiver as a vehicle for financing and developing an array of supports and services. This was a major administrative change that had and continues to have a profound effect on the quantity and quality of supports and services that are offered. It enables the delivery of supports and services that are more individualized than in the pre-Waiver days. NYS-OPTS is another big change in administrative systems with the potential to enable OMRDD and its providers to deliver even more individualization in supports and services, consistent with the national direction for individuals with disabilities. ❖

Information taken primarily from the Executive Summary of the Public Hearing Draft of the OMRDD Comprehensive Five-Year Plan for the period of 2005-2010. To view the plan in its entirety go to http://www.omr.state.ny.us/507plan/hp_507_index.jsp

Ten Things to Know about Medicaid



1. Medicaid does the job it was asked to do - and much more.

- Medicaid is one of the most successful and cost-effective programs administered by government.
- It makes a positive difference in the health and long-term care needs of over 53 million of the nation's vulnerable citizens.
- It provides a fiscal stimulus to states and communities. It produces a return of \$2 to \$6 in new economic activity for every state/local dollar invested in Medicaid; it generates nearly 70,000 jobs per state; and it adds to state/local tax bases.
- However, Medicaid is a victim of its own success.
- Medicaid was designed as the safety net health care program for low-income pregnant women, children, people with disabilities and the elderly. Medicaid not only picks up the tab for this safety net program but, it is also now pressed into duty as the nation's single largest source of funding for all long-term care. In addition, some federal and state lawmakers look upon Medicaid as the backbone to address America's 45 million uninsured.

2. Medicaid spending growth has outpaced overall inflation and state revenue growth.

- This is due to high annual cost growth in the broader health care industry and recent difficult years for overall state revenues.
- State revenues finally increased slightly in 2004 by 3.4%; while Medicaid spending growth averaged 9.5%.
- Health care inflation is increasing at two to three times the rate of general inflation.

3. Total Medicaid spending has increased significantly since 2000, but is projected to increase at a much lower rate over the next decade.

- Medicaid spending is projected at \$330 billion in 2005.
- Spending increased on average by 12% in 2001-2002; by about 9.5% in 2003-2004.
- Spending is projected to increase between 7 and 8% over the next decade.
- Drivers include enrollment growth and rapidly rising costs of prescription drugs and hospital care.
- Drivers also include the cost of paying for Medicare premiums and co-payments, and for long-term care and prescription drugs not covered under Medicare for the dually eligible.

4. Medicaid is efficient compared to private health coverage.

- Between 2000-2003, Medicaid per capita growth in the cost of acute care was 6.9%.
- For employer-sponsored health insurance the figure is 12.6%; while the number for all private insurance coverage is 9%.

- Medicaid administrative costs are in the range of 4 to 6% while commercial insurers administrative costs are often well above 10%.

5. Medicaid fills the gaps in Medicare.

- 42% of all Medicaid expenditures are for the 7 million individuals who are also on Medicare (dually eligibles).

6. Most Medicaid beneficiaries are not on welfare.

- More than 75% of those currently on Medicaid are not receiving cash assistance under welfare. This represents a 180 degree reversal in this ratio compared to the 1985 caseload.
- Medicaid was delinked from welfare in 1997 with the major changes made in the welfare law.

7. Medicaid enrollment jumped 40 percent in the past five years.

- Statistical reviews indicate that increasing enrollment accounted for most of the spending growth in recent years.
- State projections indicate a further 5% enrollment growth in 2005.

8. Medicaid has been a major factor in limiting growth in the number of the uninsured.

- Between 2000 and 2003, the number of uninsured increased from 40 million to 45 million.
- During the same period, Medicaid enrollment increased by 9 million enrollees.

9. As measured by enrollment, Medicaid provides health and long-term supports coverage for more individuals than any other program - 53 million Americans:

- 25 million children
- 13 million low-income uninsured adults
- 8 million individuals with disabilities
- 7 million elderly individuals.

10. Measured by expenditures, Medicaid is America's largest single health/long-term supports program.

- Total (federal and state) Medicaid spending is projected to be \$329 billion in 2005 or 2.6% of (GDP) gross domestic product.
- Medicaid accounted for 17% of all U.S. health care spending in 2003.
- Medicaid is the single largest source of funding for long-term care in the U.S.❖

*Note: The above Ten Things to Know About Medicaid in 2005 was written by the Public Policy staff of the American Network of Community Options and Resources (ANCOR). The information used by ANCOR was derived in part from highlights in the National Governors' Association's report Medicaid in 2005: Principles & Proposals for Reform, as well as ANCOR analysis and data from Georgetown Health Policy, Center on Budget Policy and Priorities, and Families USA. ANCOR is a nonprofit trade association representing private providers who provide supports and services to people with disabilities. Find out more about ANCOR at www.ancor.org

Giambi Stats Gauge the Midas Touch

by Gage Johnson



From left to right :
Gage Johnson with his mother, Debbie Major,
brother Jacob and his father, Troy Johnson.



Gage with slugger Jason Giambi.

On July 10, 2005, I went to Yankee Stadium to meet the New York Yankees. I arrived at the Press Gate and a guide, whose name was Ben, gave us a tour around the stadium. Next he took us to the locker room to meet the players. I met 15 players!!! My favorite player is Derek Jeter. Jason Giambi asked me to rub his bat for good luck. I did and he hit a home run that day. Ever since then Giambi has been on fire, hitting 14 home runs in July.

I got a number of souvenirs from the players: a towel and a broken bat from Derek Jeter, and a pair of batting gloves from Bernie Williams. I also received 20 baseballs signed by the Yankees and had my picture taken with them. In closing, you all will be happy to know that the Yankees won 11-9. It was an awesome day. *Gage Johnson receives services through the agency's Service Coordination Department.* ♦



Third Baseman Alex Rodriquez and Gage.



continued from page 1, Unwrapping an Enigma

“There is not anything more on earth that I want than to live with you guys,” Shane said. A sincere connection had been made; our hearts were overcome.

Shane is an exceptional young man. He is a very bright, quick witted guy with a really big heart! In spite of some adjustments to group living, Shane, now happy and content, has found a place to call home at the Tennyson residence. Shane has also captured the affection of his teachers at Clarkstown South High School where his grades have been terrific. His teachers, so delighted with his going to the prom, purchased a bouquet of



Shane shares with pride his accomplishment of graduating from high school.

flowers for Shane to give Alana. A donation from the Crystal Run Village Foundation, Inc. assisted Shane in participating fully in the Senior Year activities at the high school . . . all of which then bring us to back to those stairs and that hallway in Alana’s home.

Alana’s parents, the Nowaks, give new meaning to the phrase “blended family.” They have children of their own; the blending results from them welcoming a number of young people into their home, many who have a disability. Nurturing, harmony, respect, and unity serve to amalgamate this diverse group into a truly unique and loving household. Being a guest at the home of all those young people on this magical occasion of a high school senior prom left me feeling wonderfully inspired.

Well, Shane, what’s new?

Converse with Shane today and he becomes breathless in his enthusiasm to discuss with you what is going on in his world. “I went to the Cheeseburger-Cheeseburger restaurant and ate the ONE POUND CHEESEBURGER and got my picture put on the wall,” he explained. “Isn’t that great? Yes, I ate the whole thing.” He will launch into more serious topics, announcing “I got my diploma.” He will proudly tell you that he is now a CIT (counselor in training) at the Venture Summer Camp. Shane was involved in this program last year. He has a natural ability in working with younger children with disabilities. Perhaps he relates to their struggles, perhaps he sees in them what Crystal Run Village staff see in Shane -- hope, and a future of opportunity.

In spending time with Shane one can see that each day he continues to wrestle with the underlying pain of his past. However, there are moments like the prom that give him hope! “I really like Alana. She is nice and we are good friends,” he will say. “I am happy about this summer because I am doing well and will meet more people at the camp. Do you think I can go shopping and buy some CDs and shirts at the mall? I really want to go out to see a movie this weekend. What do you think?” My answer is that now the world is a very good place for Shane. ❖

News from Crystal Run Village, Inc.		Fall '05 • Volume 14, Issue 1	
		Publisher Crystal Run Village, Inc. 601 Stony Ford Road Middletown, NY 10941 Phone: 845-692-4444 Fax: 845-692-7101 www.crvl.org	
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Future Planning Assures Parents

by I. Jay Safier

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In recent years, as developmentally disabled and mentally ill individuals are being deinstitutionalized and becoming active residents in local communities, the estate planning for parents of these individuals is being given greater focus. This article will review considerations to be addressed when families are seeking advice from a professional about planning for the devolution of their assets when there are one or more beneficiaries deemed to have a permanent disability. Section 7-1.12 (a) (4) of the New York State Estate Powers and Trust Law (EPTL) defines a disabled person as one "... (i) with mental illness, developmental disability or other physical or mental impairment; (ii) whose disability is expected, or does, give rise to a long-term need for specialized health, mental health, developmental disabilities, social or other related services; and (iii) who may need to rely on government benefits or assistance."

The Impact of Capacity and Its Variations

After overcoming the shock, disappointment and attempt to lay blame for having a developmentally disabled child, there are immediate questions that many parents may try to address. In the past 30 years there have been major strides in the diagnosis and treatment of various developmental and psychiatric disabilities so that the answers to these questions are never definitive but must be reassessed every three-to-five years and, therefore, the corresponding estate planning must also be revisited. One question is to determine the child's mental capacity -- his/her ability to make decisions concerning his/her life and whether he/she can function alone in the general society. As an example, can the individual maintain a job, collect a salary and manage his/her own expenses? Based upon the conclusions of the mental health professionals engaged by that person's family it may be determined that if he/she was to be the beneficiary of a sizable sum of money the individual may not have the capacity to properly manage it.

Another consideration to be addressed is whether the disability can be measured definitively or is subject to variations. This refers to whether the illness can be treated

to the degree that, with proper treatment and supervision the person can maintain a stable level of existence. For example, someone suffering from a mental illness may become stabilized if properly supervised and treated on a regular schedule. The degree to which recurrence of the disease is determined to have lessened will impact on the recommendations offered by the professionals involved in the parents' estate planning.

Lastly, the parents are concerned with whether the child, despite the disability, can care for him/herself. This goes beyond the foregoing for it concerns whether the person can live independently (rather than in a group home). The impairment and its impact on the individual's independence must be factored in when doing a proper estate plan.

A Unique Situation

Parents of a disabled child face a dilemma unknown to others. This child receives public assistance [e.g. Social Security Supplemental Income Benefits ("SSI")] as a benefit because of the disability. The estate planner must be alert to the fact that there should not be a direct distribution of the parents' assets to the child in order to avoid losing the SSI benefits. The planner should be aware of the planning device known as a Special Needs Trust ("SNT"). The purpose of this trust is to provide benefits to the beneficiary, the disabled individual, beyond those covered by federal and state benefits. It is a quality of life issue in which the SNT should supplement not supplant the governmental benefits received.

Why the Special Needs Trust is Different

Before reviewing the SNT and its general characteristics, we should review the other alternatives of direct and indirect bequeathing of assets and why these other methods are not as preferable to using the trust. Firstly parents can disinherit the child having a disability. While this action retains the ability to receive the governmental benefits it generally is not appreciated by parents who realize that nothing has been designated to improve the child's quality of life beyond what is received from the governmental programs. Secondly, parents may choose to leave money outright to the disabled child. The federal and/or state governments will use the extent of this amount to offset services formerly covered by SSI and/or Medicaid. Only after the inheritance has been fully exhausted will the governmental benefits resume. Lastly, a method used by some parents is to leave funds to a sibling or another third party with instructions that the money be used for the disabled child. The hope may be that this action will place a moral obligation on this third person to oversee the disabled child. *(continued on page 8)*

continued from page 7, Futures Planning Assures Parents

However, the assets are not segregated and can be available for use by this third party or may be accessed by this individual's creditors if there is a divorce, personal bankruptcy, etc.

The SNT is unlike trusts commonly used in estate planning. The widely held opinion of a trust is that it is used to help the beneficiary maintain a standard of living. Not so with the SNT. In Section 7-1.12(e) of the New York State EPTL there is suggested language to be incorporated into the trust document in order to be sure that it meets the criteria necessary to qualify as an SNT.

*A Special Needs Trust
is one in which funds are drawn upon
only as a secondary source.*

The statute specifically details that a clause should contain verbiage "...that the trust assets be used to supplement, not supplant, impair or diminish, any benefits or assistance of any federal, state, county, city, or other governmental entity for which the beneficiary may otherwise be eligible or which the beneficiary may be receiving." It continues by suggesting that the grantor charge the trustee in the trust agreement by stating, "...it is the grantor's desire that, before expending any amounts from the net income and/or principal of this trust, the trustee consider the availability of all benefits from government or private assistance programs for which the beneficiary may be eligible and that, where appropriate and to the extent possible, the trustee endeavor to maximize the collection of such benefits and to facilitate the distribution of such benefits for the benefit of the beneficiary." It is clear from this language that such a trust is one in which funds are drawn upon only as a secondary source-something not normally found with a traditional trust.

The trust document should make clear that the trust's assets may never be directly accessible by the disabled person. Only the trustee should have exclusive management over the income and principal of the trust. Only the trustee should be permitted to make distributions on behalf of the disabled person and those payments should be made directly to the provider of the services that will benefit the beneficiary.

Examples of the kinds of services covered by the income and assets of an SNT include but are not limited to:

- Entertainment such as attending concerts, ball games, traveling, and vacations
- Payments to a nurse or other attendant to accompany the beneficiary
- Private transportation

- Athletic training and similar services not covered by public programs
- Special medical and dental care beyond coverage by Medicaid

The Two Types of Trusts

There are two basic types of Special Needs Trusts. The first is one created with assets of the disabled person. This is often the case when an award is made to the disabled individual or this person is the beneficiary under another person's will. However, it is not the disabled person who acts as the grantor. Rather, it is a parent, other relative, or a court-appointed guardian that is the grantor. A popular spin on this type of trust is the pooled trust which can only be managed by a not-for-profit organization. Separate sub-accounts are established for each participating SNT (and the respective beneficiary) but all of the funds are pooled for purposes of investment and administration. Management fees are arranged with the organization. Besides managing the assets and making distributions on behalf of the beneficiary, the organization may also act as a personal advocate for the disabled beneficiary during the person's lifetime. At the death of the beneficiary the undistributed assets in the trust may be distributed to Medicaid, as reimbursement for advances made, and the balance may be paid to the remainder beneficiaries. This type of trust is offered by UJA-Federation of New York in conjunction with F.E.G.S., a UJA-Federation network agency, acting as the advocate.

The second type of SNT is one established by a third party (e.g. parents or grandparents). This category of SNT may be funded during the lives of the grantors or at their deaths using cash, life insurance or a combination of assets. Upon the death of the beneficiary the remaining assets are distributed to the designated person(s) listed in the trust agreement/will of the grantor(s). If the document is properly prepared none of the remaining funds will be reimbursed to the state for the previously advanced Medicaid payments. It is important to remember that an SNT is irrevocable. As such, family members might be more apt to fund such a trust through a will rather than during their lifetimes. A knowledgeable estate planning advisor must be aware that a disabled beneficiary is limited by law to the amount of assets he/she can own directly (generally no more than \$2,000). For this reason the third-party SNT is generally created under a will which has a "spill-over" provision of assets into the SNT rather than directly naming the disabled beneficiary as a direct recipient.

Choosing a trustee is another difficult task. Generally parents look first to other siblings or close family members whom they hope can be relied upon to carry out their wishes after they die. However, given the responsibilities of this trust it is *(continued on page 15)*

Donate Your Electronic Trash

It is estimated that there are 110 million cell phones in use in the United States today and, more than 50 million are lying inactive in the drawers of homes and businesses; casualties of society's fast paced techno-upgrading. If you are an average cell phone user, you upgrade your phone every 14-18 months. So, why not donate your old phone to a worthy cause, known to you, and receive a \$40 tax deduction?

The donation of your unwanted cell phones can be money in the bank for the "Searching for Stars" self-advocacy group comprised of people living in houses and supported apartments managed by Crystal Run Village, Inc. The group recently kicked off its recycling fund-raising campaign and the benefits to society of collecting the unused phones are many.

Collected phones will be sent to a non-profit clearinghouse where they are refurbished and reprogrammed for secondary markets and those international markets that are becoming part of the wireless community. Any phones that are not usable for this purpose are programmed for "911" and distributed to homeless shelters, women's shelters, etc. Collected phones that are damaged beyond repair, or simply obsolete, will be recycled along with their batteries in accordance with environmental laws.

The practice of self-advocacy by people with developmental disabilities results in their having control over their own lives through increased knowledge of their rights and a greater understanding of their responsibilities to mankind. The members of Searching for Stars self-advocacy are determined to become more and more involved as citizens in the communities they live in, in ways similar to other civic organizations. Collecting inactive cell phones is one way to do just that. The fundraising endeavor will allow members of the group to meet their financial objectives so they are able to attend educational conventions and also give to others less fortunate.

Send your wireless phones to:

Searching for Stars

9 Landfield Ave., Monticello, NY 12701.

Cordless phones intended for home use are not acceptable. All cellular or PCS hand-carried phones will be accepted. *For more information call Searching for Stars advisors: Diane Gummerson, Judy Card or Kelly Healy at 845-796-4324.* ❖



Searching for Stars Treasurer John Pratt counting monies to be deposited in a bank account the group anticipates opening.



Left to right: Searching for Stars self-advocacy group members Victor Aldamay and Joel Schnee examine the condition of cell phones collected for the group's recycling fund-raising campaign.

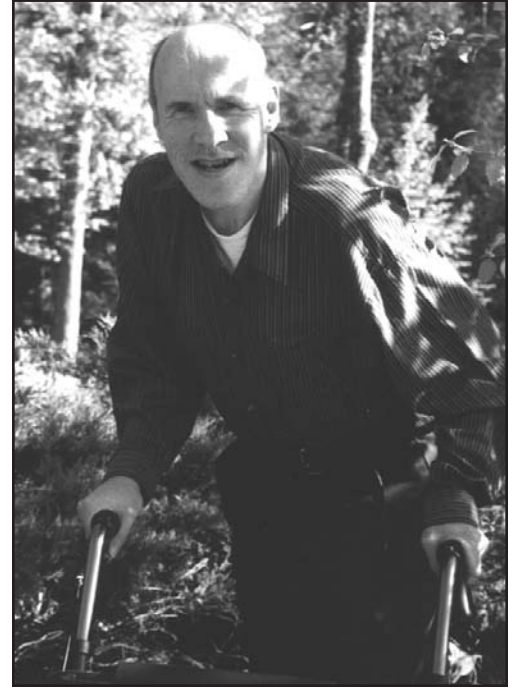
On August 30th Victor Aldamay passed away following complications from surgery. Victor was an original resident of the Sullivan County Campus in South Fallsburg. His enthusiasm for life in the community was inspiring to all who knew him. He was gregarious in his love of America, yet proud of his Puerto Rican heritage. Victor was blessed with a loving brother, Emmanulli who was greatly involved in his life. Victor will be greatly missed by all who knew him.

Influence, Independence, Int

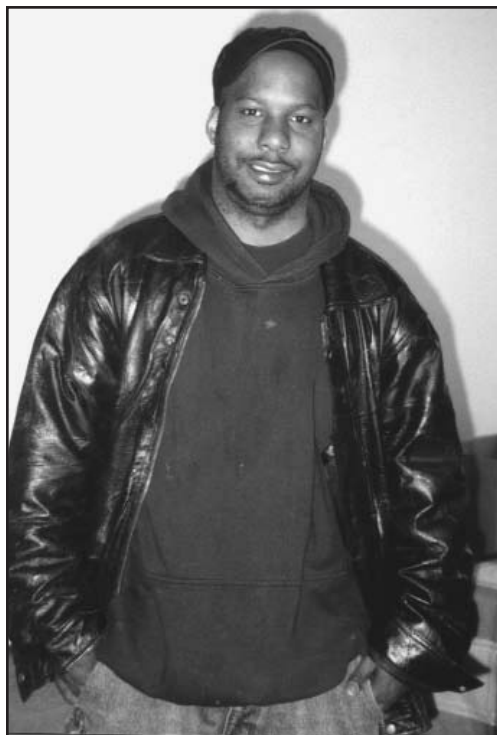
The Power of Self-Determination

At a recent Victim Impact Panel, Allan Kelso, a resident of Nashopa house, spoke to an audience of 85 people arrested for driving while intoxicated. Allan spoke from the perspective of the victim of a drunk driver, having been in a car accident at the age of 4 in which both his parents were killed. The brain injuries received from the accident are said to be the cause of his Cerebral Palsy.

Conversations with the agency’s clinical coordination staff helped Allan, now 43, to realize the extent of his grief and anger from the debilitating circumstances that have handicapped his life. Speaking publicly with the hope of influencing those who may injure others has given Allan peace and a sense of accomplishment.❖



Allan Kelso



Lovett Wilkes

Taking Calculated Risks

Lovett Wilkes is a soft spoken, personable young man in his mid-20s who had been living in the agency’s Walden house for the past five years. This spring Lovett packed his belongings and, with the help of case managers from the agency’s Mental Health Services Program, moved into his own apartment.

Planning for the move was accomplished step by step through setting goals and his meeting or exceeding the fundamentals of being on one’s own. It also took a lot of nerve. Now each day when he arrives home from his job he revels in the quiet of his surroundings and considers the opportunities of greater independence..... perhaps a driver’s license.❖

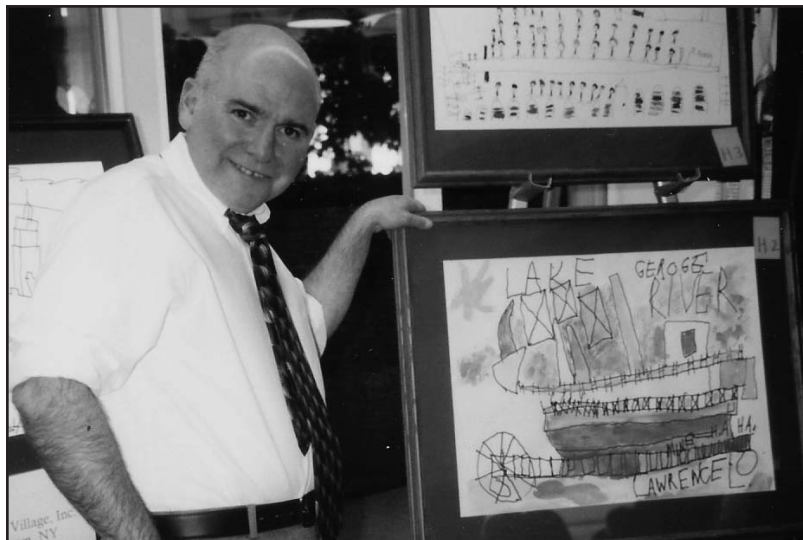
erpretation, Interdependence

Art Expresses Living Community

Residents of Crystal Run Village, Inc. put their unbridled artistic talent to work in hopes of having their artwork selected for use as the program cover design for the 28th Annual New York State Association of Community and Residential Agencies Conference (NYSACRA) held in Lake George this past spring.

While a painting supporting the convention theme “From Community Living to Living Community” was selected from the works created by a resident from a service agency other than Crystal Run Village, the artists felt in no way let down or left out. They were invited to display their artwork at a professionally organized exhibit and reception at the conference, celebrating their talents. The reception provided artists with an opportunity to give and receive feedback, critique and encouragement.

The participating Crystal Run Village, Inc. artists were: Jimmy Conway; Michael Plum; Robert Morrison; Larry Levine; Yosef Zakon; Joan Henderson; Florence Eve; George Ries; Marc Fried and Robert Hogan. ❖



Larry Levine is proud of his creative work
“Boat on Lake George.”

Comfort in Working with Others

Prior to her tender age of 16, Amanda Buck had been loved, forsaken, forgotten, abused, adopted and abandoned. Hurt and anger were her strong reactions to the many conflicts in her past life.

Today, with the support of the staff at Tennyson house and her service coordinator, Amanda has the stability and safety to simply be a teenager. She is a student at Clarkstown South High School and dreams of a career in cosmetology or nursing. As a member of the “Bombers” basketball team Amanda is committed to fair play and gracious in winning or losing. She is all about the glory of the sport and taking part. ❖



Amanda Buck

A Program with a View



By Michael Bodner

What do you get when you combine the talents of the people attending the Open Vistas Day Habilitation Program with energetic and creative staff? You get a showcase of ideas that turn the plain and sterile walls and ceilings into something fun-loving and special.

Utilizing many of the finished arts and crafts projects along with wares from local shops, previously bare ceilings and walls have been transformed into a montage of colors and textures. Each area has a different look that is unique to itself with lots of personality. There's something for everyone who comes to Open Vistas: "artsy" rooms, loud raucous hallways or places and spaces to just relax to the soothing sounds of waterfalls or ambient music. ❖



A flight of fancy.



John Masten (left) tosses one of the famous flying pigs to Michael Bodner.

or When Pigs Fly



Yosef Zakon, a rug hooking in progress.



A fanciful wall of hooked rugs.



Chief architects and visionaries (from left to right, back):
John Masten; Shelly Fabiszak; Diane Pichalski;
Maria Negroni; (on chair) Frank Monaco and Debbie Lyn.



Susan Callaway
catching up on baseball headlines.

Don't stand
in one place . . .
you might get tiled.



FROM EVERY ANGLE
FROM EVERY ANGLE
FROM EVERY ANGLE
FROM EVERY ANGLE
FROM EVERY ANGLE
FROM EVERY ANGLE

insight

Plan for Pre-College Orientation

For the past 15 years, the University at Albany has run a statewide Pre-College Summer Transition Program for high school students who will be receiving sponsorship from the New York State Commission for the Blind and the Visually Handicapped (CBVH) or Vocational Educational Services for Individuals with Disabilities (VESID). This is the only program of its kind in New York State and is attended by students who will be going to colleges across the state, not just the University at Albany.

High school juniors and seniors can attend this seven day intensive orientation to learn about all aspects of transition planning including the college environment, advocacy skills, and their rights and responsibilities as a student with a disability. The program incorporates both experiential and cognitive workshops. Many of the workshop leaders are individuals with disabilities who are now employed as professors, administrators, social workers and other professionals. Peer counselors live in the residence hall with the participants. The orientation is always scheduled the last week of June.

The program to support students with disabilities at the University at Albany is known as Disabled Student Services (DSS). The University at Albany makes it a priority to attract, recruit and retain qualified students with disabilities. The population of students with disabilities has risen from 88 in 1980 to over 400 in 2005. ❖

For more information contact Disabled Student Services at 518-442-5490 or at nbelowich@uamail.albany.edu. or the Hudson Valley Community College Disability Resource Center at 518-629-7154.

Restoring Dignity in Death to Those Designated Different

Make A Difference Day is considered the most encompassing national day of helping others -- a celebration of neighbors helping neighbors. Everyone can participate. Created by USA WEEKEND Magazine, Make A Difference Day is an annual event that takes place on the fourth Saturday of October. This year's event is Saturday, October 22, 2005. In the Mid-Hudson Valley, the 1033 Group will "make a difference" by bringing dignity after death to the thousands of people with intellectual disabilities who died as residents of state schools, developmental centers and hospitals. Through gravesite recovery and clean-up at regional cemeteries, group members will work to identify those buried followed by a commemoration ceremony. The purpose of the cemetery recovery project is to bring dignity after death to people with mental retardation and other developmental disabilities who received services at institutions during a period in our country in which they were routinely confined to isolated and remote institutions.

The 1033 Group is united by a desire to remind society that these individuals did exist. In so doing, the Group intends to keep alive the memory of how they were treated to ensure that other people will never be treated that way again. The aim is to secure a future in which people with developmental disabilities and mental illness are always regarded as persons with rights and dignity inherent to citizens of mankind.

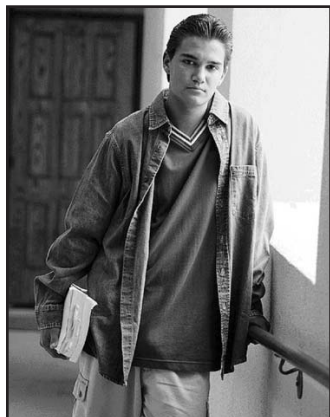
The membership of the 1033 Group represents a cross section of stakeholders within the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) service system. Group participants represent people receiving services from OMRDD, self-advocates, human service staff people, their agencies and associations. The 1033 Group name comes from one of its early recovery projects. While unearthing markers, members came across grave marker number 1033. The sod covering the marker was so impacted that it made a perfect imprint of the number 1033 in the dirt. By fate or coincidence 1033 lends itself to being recognizable as a mirror image. ❖



Unearthed grave marker in the north cemetery of the Wassaic Developmental Center in Dutchess County. It is estimated that combined, the center's two cemeteries are the resting place for 1,200 people.

Learn more about the 1033 Group in the following ways: visit its e-group at <http://groups.yahoo.com/group/dignityafterdeath/>; or e-mail dignityafterdeath@yahoogroups.com, or telephone Tom McCluskey of Poughkeepsie based New Horizons at (845) 473-3000.

A Friend's House Serves Runaway Teens



Do you know a boy in Orange County under the age of 18 who is having problems at home? Is the conflict or neglect such that he just can't live there anymore? Kids who leave home are usually running *from* something, not *to* something. They may believe they have no one to talk to and feel very alone. Unable to deal with their problems, some kids decide to escape by running away. Have you thought of giving advice to a young man in this situation, but just don't know how? The solution is to recommend that he go to "A Friend's House."

"A Friend's House" is a safe place for youth to live while working on finding solutions to their problems. Operated by Emergency Housing Group, Inc., youth are provided with temporary shelter, up to 30 days, and support services with 24 hour supervision by trained professional staff. Parental permission is not required for taking a time-out at A Friend's House and there is no cost.

The program provides a safe, homelike environment, a bed to sleep in, 3 nutritious meals daily, transportation to school, recreational activities, and personal care items along with a lot of support and encouragement. Caring counselors can help individuals sort through problems, reunite with family, or when not possible, find another permanent living arrangement. Aftercare is

another service available to youth who wish additional support upon leaving the "A Friend's House."

A Friend's House, operating since 1992, is fully licensed by New York State and is funded by the Orange County Department of Mental Health, Orange County United Way, New York State Office of Children and Family Services, the Orange County Youth Bureau, Orange County DSS and the United States Department of Health and Human Services. *If you know of a boy that could benefit from some time in a non-threatening environment, have him call 343-0968 for more information. (continued on page 20)*

continued from page 8, Futures Planning Assures Parents

sometimes thought that an institutional trustee would be better. Depending upon the facts and circumstances of a specific case the grantor may choose both. An institution may be sought to handle the financial aspects of the trust (i.e. handling the investing and other financial duties) while an individual is selected to be the personal advocate for the disabled beneficiary. If only an individual is named then a clause should be inserted into the trust agreement allowing for the appointment of an institutional co-trustee if the financial responsibilities become too onerous.

In conclusion the benefits of a Special Needs Trust are the result of enacting laws. Laws, however, may be changed. Given the intention of President Bush to make changes in Social Security it is possible Congress (and the state legislatures) may look again at the inter-relationships of public benefits and the SNT. With that in mind the trust agreement should always provide that the trustee, as a last resort, should be empowered to terminate the trust if legislative guidelines change. ❖

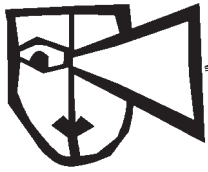
Editor's Notes:

1. The terms "Special Needs Trust" and "Supplemental Needs Trust" are used interchangeably in the literature.
2. This article deals with estate planning for parents that have a disabled child as one of their beneficiaries. A Special Needs Trust may also be used for estate planning between spouses but is beyond the scope of this article.
3. References to state law in this article will be limited to statutes promulgated by New York State.

Jay Safier, CPA, is a principal in the New York accounting firm of Rosen Seymour Shapss Martin & Company LLP, where he is actively involved in advising high net-worth individuals and owners of closely-held businesses on a broad range of corporate, accounting and auditing, tax, estate and business matters. He also actively represents his clients before taxing authorities and has been called upon as an expert witness. Safier is active as a lecturer, contributing editor, past chairman, and current member of various committees of the New York State Society of Certified Public Accountants and the American Institute of Certified Public Accountants. He has been a member of the board of directors of Crystal Run Village, Inc. for 15 years. He can be reached at jsafier@rsmmcpa.com



Jay Safier, CPA



PEOPLE SPOTLIGHT

Litt Elected to Social Work Board

Valerie Litt, MSW, a Clinical Coordinator for Crystal Run Village, Inc. has been elected as the Hudson Valley Division Representative to the Board of Directors of the New York State Chapter of the National Association of Social Workers (NASW). NASW is the largest membership association for professional social workers in the world, with 150,000 members in the United States. In the New York State Chapter alone, there are more than 12,000 members. As a board member, Litt will work to influence the delivery of advanced and innovative services in the field of social work to meet the basic human needs of all people, with particular attention to the empowerment of those who are vulnerable, oppressed and living in poverty.



Valerie Litt

Litt has worked for 26 years in the disability services field where she has held various clinical and administrative positions. She serves on the Board of Directors of the Sullivan County United Way and is a founding board member of the county's Wardrobes for Work program. Her Masters Degree in Social Work is from New York University. ❖



Lisa Wright DeGroot

HR Specialist Hired

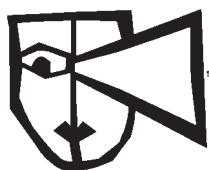
Lisa Wright DeGroot has been hired for the newly created position of Director of Human Resources for the agency. She will be responsible for strengthening the agency's tradition of hiring and training compassionate and competent staff to meet the needs of the individuals receiving services and their families.

According to Crystal Run Village, Inc. Executive Director Jim Lawler, the agency's senior management has recognized that the creation of a centralized Human Resources Department is essential in developing and executing the agency's organizational strategy. Lisa's responsibilities will include: recruiting and retention; education and training; administration of benefits, and policy and procedure.

"Lisa's joining the agency will bring a solid foundation and vitality to our employee relations at a level that has become necessary from our rapid growth," Lawler said. "She brings with her critical knowledge that will benefit staff on all levels and practical knowledge about disability services that will enhance our ability to serve people in our care."

DeGroot has over 19 years of human resource development and management experience in both the public and private sectors, most recently as a director with Jawonio, Inc., in New City, NY. She is a member of the Society for Human Resources Management, Volunteer Agency Personnel Association and Personnel Manager's Association for Rehabilitation Facilities.

DeGroot earned her Bachelor of Arts degree in Interpersonal Communication from Arizona State University at Tempe and a Masters of Science in Human Resource Management from Mercy College in Dobbs Ferry, NY. ❖



PEOPLE SPOTLIGHT



Holly Rich

New Respite Coordinator Welcomes Guests

Holly Rich, a staff person with Crystal Run Village, Inc. for 15 years, has been promoted to the position of Respite House Coordinator. The “free-standing” Respite has been a place as caring and loving as home 365 days a year, for persons with developmental disabilities over the age of 13 since 1988. Rich, along with the members of the respite team, have a complete understanding of how much parents deserve and rely on the program. “Parents and family members know that Respite is a safe place with certified staff that they can trust to leave their loved ones with, in times of emergency, vacation or just a needed break,” Rich said.

Rich is adamant in referring to those served by the respite team as guests, not as consumers. “We welcome our visitors and cater to their needs as if they are guests in an inn,” she said. The team does all it can to understand habits, routines, likes and dislikes, so that everyone enjoys their time there. A stay at the Respite house provides opportunities for people to experience new activities, to interact and form relationships with new people.

Over the years, Rich has held various positions in direct support with the agency. As a staff person on the Middletown Campus during its time of peak occupancy, she witnessed the transition of its many residents to homes in the community and takes great pride in the contributions of all staff in the process. Her varied educational background includes nursing, commercial art, and the liberal arts. ❖

Streamlining the Purchasing Process

Peter Burtis has joined Crystal Run Village, Inc. as purchasing coordinator. Burtis has been spearheading the introduction of a centralized purchasing process for the agency. He has also been busy arranging staff discounts from vendors for goods and services such as: car rentals; carpeting/flooring; vacuum cleaners; security systems; appliances; auto repair, and locksmiths to name a few.

Burtis’ experience includes operations/facilities management, purchasing and systems research and development. He was previously employed by Balchem Corp in Slate Hill and Union Carbide Corp. in Tarrytown. Burtis earned his Bachelor of Science degree from Iona College. ❖



Peter Burtis

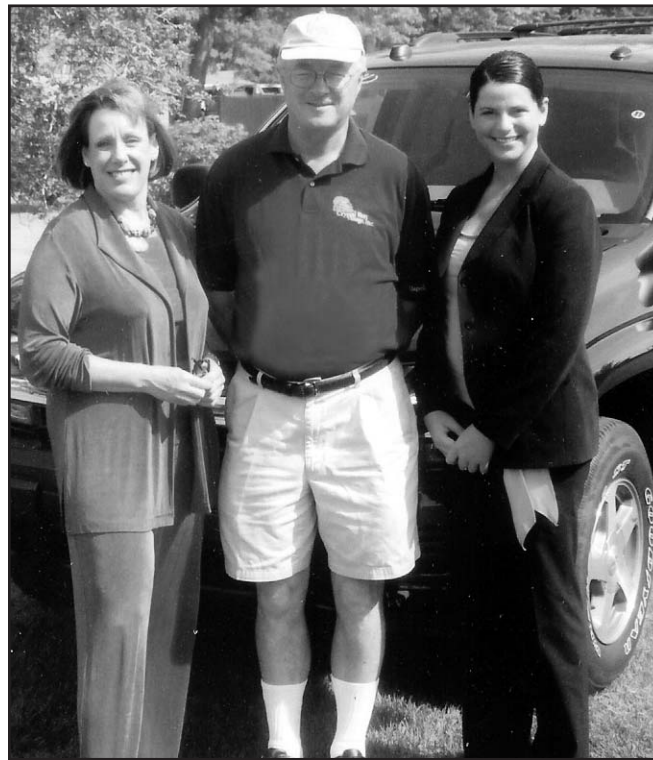
A Cause for Play

Approximately \$18,000 was raised by 124 participating golfers and their sponsoring organizations at the Crystal Run Village Foundation, Inc. Seventh Annual Golf Tournament at the Otterkill Golf and County Club on June 13.

The shotgun start at 10:00 a.m. launched a full day of camaraderie, sunshine and high temperatures. First place honors were awarded to the team comprised of: Al White, White Contracting; Rolf Enquist, Consolidated Risk Management; Doug Braune, a division of Hummer, Corp.; and Garry Brown, Crystal Run Village, Inc. ♦



Dr. Efred Alba claims his prize, a gym bag donated by Gold's Gym.

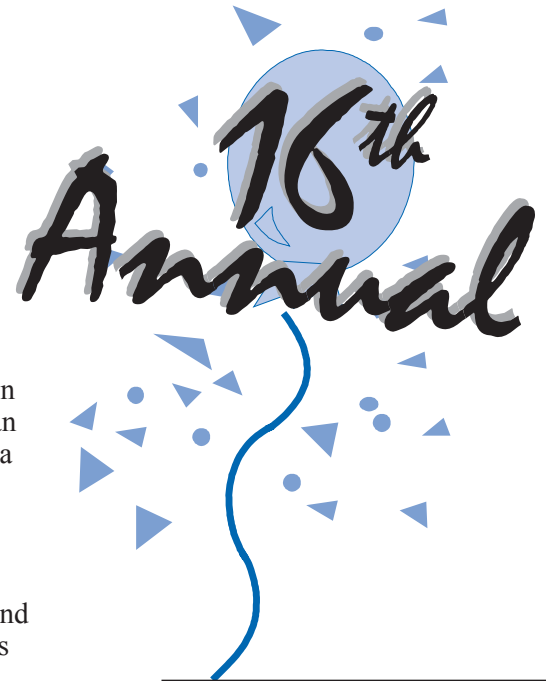


Barbara Bender (left) and Lindsey Chrillo (right) from Enterprise Fleet Services with Executive Director Jim Lawler in front of the SUV donated by Enterprise for the Hole-in-One Contest.

From left to right, back - Crystal Run Village Staff Members: Neil Ryan, Vilma Navarro, Fred Arcidiacono; Kathleen Bushhouse, Michael Bentiviglio (guest), Tom Lorino. Front: Justin Biondollilo and Eileen Taveroni.



Annual Dinner Dance . . . **Celebrating the Possibilities!**



The Crystal Run Village Foundation, Inc. hosted its 16th Annual Dinner Dance Gala on Saturday, March 19 at a new location, the Duck Cedar Inn in Tuxedo, New York. The event attended by approximately 250 people was an acknowledgement of the agency's accomplishments over the past year and a celebration of the future purpose of its staff people and the people served.

In addition to recognizing the agency's good work, the evening was an opportunity for remembering with tender retrospection the passing of a number of people that have called the agency's residential program home and the loss of a beloved co-worker. Many staff people feel a great sense of loss for those taken unexpectedly and for those whose aging bodies could no longer tolerate the history of their disabilities. According to Executive Director Jim Lawler, the willingness of staff to take on new responsibilities and their compassion in assisting the people and their families during such times of great need is deserving of everyone's admiration.

It was also a great privilege for the Crystal Run Village organization to honor Dr. Beth Mount, founder and director of Graphic Futures and Capacity Works, and Chuck Darden, chief executive of the Regional Economic Community Action Program, Inc. (RECAP). Though they travel differing paths in their work, their goals are the same: to strengthen the capacity of those they serve by treating them with respect and equity.

Dr. Beth Mount is a national consultant working with programs throughout the United States to support others to see capacities in people with disabilities. For 30 years, Dr. Mount has worked toward the ideal that every person with a disability can be a valued member of community life. Her efforts demonstrate that communities can support the contributions of people with disabilities, and that organizations such as Crystal Run Village, Inc. can adapt to be more person-centered.

Chuck Darden is a hero in the war on poverty. He has dedicated his personal and professional life to the mission of community action: to change people's lives, to embody the spirit of hope, to improve communities, and to make America a better place to live, by caring about the entire community and by helping people help themselves and each other. Under his leadership RECAP has pioneered many programs, services and activities to meet the ever changing needs of low-income individuals, families and children living in Orange County.

As a fundraiser, the Dinner Dance annually raises approximately \$25,000. Funds from the Crystal Run Village Foundation, Inc. are used to support unfunded community based programs for people with developmental disabilities. The agency's vacation homes on the Jersey Shore and in Lake George were purchased with funds raised through the Foundation. ❖



Dr. Beth Mount



Chuck Darden

