MR/DD NURSES ASSOCIATION

Mentally Retarded - Developmentally Disabled

VOL. I - Issue 2 - June 1985

WHAT'S HAPPENING OUT THERE?

Are you involved with any new projects lately at your program? If so, we'd like to hear about them. We can all benefit from your experience. Information that you may think is insignificant may be the piece of information that another nurse is searching for...so please share!

One of my new projects was developing and implementing a new Self-Medication Task Analysis Sheet. Our Client Coordinator, Trish Stangle, who has experience in developing programs for use in the classrooms, assisted me with this new form for the nursing department and we're very pleased with the outcome. If anyone is working on a similar project, and would like a copy, please let me know!

Our membership is growing! the newsletter is a reality! There's no stopping us! As I mentioned at our last meeting, I'm in the process of organizing a seminar for nurses working in various settings with MR/DD individuals, with a target date of October.

Various companies have indicated a desire to display their products at the Seminar and would like to assist with the cost of the project. Several people have indicated that they would be available to speak at the Seminar, but we're still in need of speakers. If you have anyone in mind, please write me.

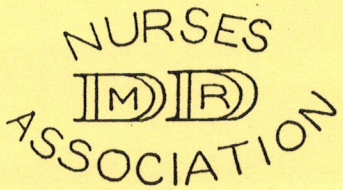
Hopefully, the plans will be finalized and can be presented in our next newsletter. We'll be seeking CEN's for the Seminar also.

A **big thank you** to all our program directors who have been so supportive of our efforts over the past few months. **We appreciate your support. Thank you so much!**

See you in June!

Susan Welsh, RN
President

Sample Logo



ABOUT YOUR PRESIDENT

Sue Welsh is a native of Glens Falls, New York. She graduated with an Associate Degree in Nursing in 1978 from Adirondack Community College.

Prior to her employment with the Saratoga ARC, Sue was a Neonatal Intensive Care Nurse at St. Peter's Hospital in Albany. Earlier in her career at St. Peter's she worked as a charge nurse on a 44-bed surgical unit.

Sue currently resides in Saratoga with her three children, Christopher, Kirsten and Nicole.

Her favorite leisure time activities are canoeing, hiking, and aerobic exercise.

She believes that nurses working with mentally retarded and developmentally disabled individuals are "pioneers," and hopes that this Association will pave the way for other support networks and new curriculum in nursing programs for the nurses.

ITEMS FOR THE NEXT NEWSLETTER

Ulster ARC/DTP will host the next meeting of MR/DD Nurses Association on June 10th, 1985, from 12 - 3. Bring a brown bag lunch - a beverage and dessert will be provided. **Please RSVP by Thursday, June 6th to Beth Summers, RN - 331-4300, ext. 75.**

AGENDA FOR NEXT MEETING

Reports from President, Vice President, Secretary, Treasurer and Regional Representatives
By-Laws Committee will present proposed by-laws for approval
Report from Newsletter Committee
Resource Materials (Display)
Open Discussion (Problem-Solving?)
Day Treatment Providers Panel for Rochester 9/85
Vote on Logo choice

Sample Logo

AGENCY NEWS - Montgomery Co.

An outreach/referral program was developed to establish formal contact with local school districts and Committee on the Handicapped representatives. This program will provide a smoother transition from the school curriculum to Chapter programs for developmentally disabled students as they approach adulthood. It will also serve to educate the school district and parents regarding the variety of services available to their handicapped child in our community.

A major event during 1984 was the start of construction of the addition to the 5-S facility in October. The project is running well ahead of schedule and should be ready for occupancy by mid-March, 1985.

A Medicaid-funded Continuing Treatment Program was established to enhance services to the psychiatrically disabled population at Liberty Enterprises.

Liberty Enterprises' recreation program offered an expanded curriculum of activities to children and adults during 1984. The program will make a concerted effort to involve more handicapped individuals in the program during the upcoming year.

REPORT OF THE LAST MEETING IN BRIEF

3/11/85 at Saratoga ARC

We all enjoyed our bag lunch and exchange of ideas, meeting new people and renewing acquaintances.

12:30 - Sue Welsh, President called meeting to order.

1. Old Business: LPN's are welcome in our Association and we do have some already on the "active members list."
2. Treasurer's Report read and approved.
3. V.P. and Historian need articles for recording that anyone may have since we formed our Association, such as news items, etc.
4. Regional Representatives had poor response from newspaper ads. It was noted that person-to-person rewards were better.
5. Volunteers for By—Law Committee requested for 4/12/85 at Pittstown.
6. Newsletter will print all "Logos" and a vote will be taken at June meeting.
7. Newsletter Report: Criticisms of format, length of articles and wasted space will be addressed in next issue. Plagerism is also a concern.
8. October Seminar is in planning stage.

   Next issue to be out before June meeting and will include the agenda.
9. Correspondence: Secretary will send all Regional Representatives minutes of each meeting.

The next meeting will be June 10, 1985 at Ulster Co. ARC, Kingston, New York.

Hostess: Beth Summers and will include time to address problems anyone may have.

BY-LAWS

"Committee" met 4/12/85 at Pittstown and three people were present to do both newsletter and by-laws. We worked on both from 9:00 a.m. to 1:00 p.m. and took a tour at lunch.

At the next meeting in Kingston, we hope everyone will have input on several questions that arose for the organization. We must think ahead to when we will be encompassing a larger geographic area and membership, and also a possibility of having to disorganize. Hope to see more on next Committee!

FROM THE PEN OF THE P.T. (Archille Godbout) MS LPT QMRP

SENIORS NEED STRUCTURED PROGRAMMING

As our senior citizen population progressively grows larger and larger, so does the need to provide structured, more creative forms of recreational and therapeutic programming. One idea which has taken on increased popularity and interest is the senior exercise group.

The philosophy generally of the senior exercise group is to provide a structured recreational program and, at the same time, offer a program which is geared to improve or maintain the client's fitness. This may sound simple enough, however, after taking into consideration each client individually based on their age, degree of developmental disability relative to physical involvement an cognitive receptive capabilities and possible systemic involvement, the process becomes somewhat more complicated. As a result, a formal method of screening seniors for the exercise group has been adapted. The screening process relies on the coordinated efforts of both the nursing and physical therapy staff. Initially, all pertinent historical information is reviewed. This is important because of the lack of diagnostic consistency throughout a client's life. Often times information relating to pre-existing heart conditions or problems is rediscovered after having found older medical records.

In addition to the historical medical review, a formal screening is then conducted with each client individually using a form adapted to meet the needs of the screening process.

Interestingly enough, and as a result of conducting a number of these screenings, it was found that the seniors generally fall into a high risk group for potential cardiovascular problems. The EKG studies have been very helpful in confirming the various types of involvement that pre-exist in these clients. A yearly EKG is required in most instances with a copy of the test results maintained in the client's medical files. No client is allowed to participate in the senior exercise group without the proper screening proces first being performed. In addition, the primary physician as well as the cardiologist, if indicated, must review and approve both the screening assessment and the exercise protocol before the client is allowed to participate.

After the age predicated heart rate is determined, the training stimulus and exercise target zone can be identified. These are calculated using Karvonen's Training Stimulus Formula.

Although we don't monitor exercise pulse on a regular basis during the exercise program, we nevertheless have some baseline data on each client which we can refer to if it is felt a client is overexerting themselves.

SENIOR EXERCISE SCREENING ASSESSMENT

Name: _____ Age: _____
Diagnosis: _____ DOB: _____
Date: _____ Primary Physician: _____
Height: _____ _____
Resting Pulse: _____ Weight: _____
Resting Blood Pressure: Resting Respiratory Rate:
_____ _____

Age Predicted Exercise Heart Rate: _____
Age Predicted Exercise Target Zone: _____
Medications: _____

Cognitive Capabilities:
Receptive:
Expressive:
Behavioral Activities: _____
Adaptive Aids: _____

Systemic Review: Precautions and Limitations:
Cardiopulmonary:
Musculoskeletal:
Neuromuscular:

Exercise Criteria to be used:
Request for E.K.G. _____
Yes No

Comments

_____
Physician Review & Approval Date

_____
Physical Therapist Date

_____
Registered Nurse Date

All the information collected on the senior exercise screening assessment contributes to a profile needed o determine the specific needs of that client for the program. For instance, if either a behavioral problem exists or if a client has a specific physical disability, then the need for a staff member to work one-on-one with that client during the exercise session is identified.

It is unrealistic to consider total specificity of exercise for each client individually participating in a group session, however, certain components and parameters of exercise become essential when discussing the senior population. Flexibility and range of motion activities are the first group of exercises to be performed. These act as warm-up exercises and include activities moving the extremities or trunk through the various planes of movement. Breathing exercises which are taught as diaphragmatic, are integrated throughout all the different phases of the exercise program. Breathing in through the nose and out through pursed lips is taught to each client and encouraged for efficiency of air exchange. The next group of exercises have their emphasis on general muscular strengthening. Here exercise theraband (a latex rubber material of various strengths) is used. Upon stretching this material, tension is built up in the muscle creating an isotonic response. The material is of a nature whereby very mild exertion is needed to produce an exercise movement. All large muscle groups are exercised using this method.

The last group of exercises have their focus on relaxation. Breathing is emphasized here with proper timing of movements. Environmental controls such as turning down the room lights and requiring silence with the exception of very low relaxing music is employed. The program lasts approximately 30-45 minutes and is conducted three times per week. It should be noted that formal goal plans and objectives are easily drafted for this program.

In conclusion, I have outlined a senior exercise program which can be utilized effectively both from a recreational and therapeutic sense. The program requires the expertise of both the nursing and therapeutic staff of an agency to assure both proper client screening and staff in-service training be provided. The exercise program focuses on parameters to include, but not limited to, flexbility and range of motion, breathing exercises, muscular strengthening, and relaxation exercises.

PRADER-WILLI SYNDROME

A birth defect of unknown origin, Prader-Willi Syndrome is not inherited, nor is it caused by brain damage or prenatal trauma. The infant with Prader-Willi generally displays the following characteristics:

Low birth weight (most have reduced movement in the womb).
Hypotomia (poor muscle tone), lack of ability to control head and limbs, weak cry.
Poor sucking reflex.
Poor appetite.
Walking at about 30 months.
Talking in short sentences at about 3 1/2 years.

In addition, there is usually some degree of mental retardation, with an I.Q. in the seventies, although some persons may function at a higher or lower level.

Between the ages of one and four change occurs in the person with Prader-Willi. The child who would not eat now becomes dominated by an insatiable and unselective desire for food. This uncontrollable appetite and emotional outbursts are the two key manifestations of Prader-Willi Syndrome. In adults, other significant characteristics include:

Short stature (average height 5 feet).
Small tapering, puffy-looking hands and feet.
Lack of muscle tone.
Underdeveloped genitals or incomplete sexual development.
Picking at sores or insect bites.
Diminished sense of pain.

There is some evidence that there is some correlation between a defect in the fifteenth chromosome and the occurrence of Prader-Willi Syndrome. If not controlled, the insatiable desire for food causes obesity and, in some cases, early death from heart or respiratory problems. The person with Prader-Willi will eat items most people consider unappetizing - pet food, spoiled food, frozen food, food from garbage cans.

People who have been diagnosed early and have been given adequate support can function quite well. A team approach utilizing medical, nutritional, physical, vocational and behavioral disciplines in a controlled residential setting does work. Residential services are currently under development in New York State, but better early diagnosis and awareness among professionals is a primary need right now, as are better family supports for people whose children are living at home.

A conference on Prader-Willi Syndrome will be held at Howard Johnson Windsor - Lock, Connecticut, on June 20, 21, & 22. Fee $20 for members, $27 for non-members.

For more information, contact: Duncan Whiteside, Director, Resource Center for Developmental Disabilities, 30 East 29th Street, New York, New York 10016. Phone (212) 889-5760.

MEET YOUR VICE PRESIDENT

Claire R. Ludwin, R.N. (widow)
Graduate of St. Mary's Hospital School of Nursing, Amsterdam, New York
Medical-Surgical, general duty, nursing, part-time since graduation
Montgomery County ARC 3 years and Board of Directors of Montgomery County Lifeline (Corresponding Secretary)
New member Montgomery County Planning Board
Former C.C.D. instructor 7 years.
St. Stanislaus Parish.
Lector - St. Stanislaus Parish.
Enjoys working in garden.
Enjoys traveling (our travel).
One son.

RESOURCES

Mary Giles, Director HSE
Russell Sage College
140 N. Scotland Avenue
Albany, New York 12208
(518) 445-1728

She is more than willing to gather information for us on any subject and do a Seminar via her facility.

If you have any suggestions, please let me know or write or call Mary Giles. I suggested: Sturge-Weber & neurological diseases - Prader-Willi - Hep B - Down's Syndrome (mosaic).

Please let's hear what you want or need!!!