Fit Families Group Visits

Promoting Physical Activity for Kids with Spina Bifida

How to launch a monthly physical activity program with kids and families at your spina bifida center

This manual is dedicated to
Dr. Gregory Liptak
in gratitude for his integrity, compassion,
and devotion to teaching and patient care.

Contents

Welcome to Group Visits!

The Fit Families Group Visit Program is a collaboration between the medical team at the Spina Bifida Center in Syracuse, New York, and faculty and students from SUNY Cortland's Department of Adapted Physical Education and the Syracuse University Department of Exercise Physiology.

We get together once per month for an evening of fun physical activities, wheelchair sports, medical care, information sharing, mentoring and friendship. Kids with spina bifida of all ages, and their parents and siblings are invited to attend. Friends from the neighborhood, teachers, and therapists from school are also welcome to join us. We help children with spina bifida to lead active lifestyles and to become involved with adapted sports and recreation in their local communities. Our focus is on fitness, families, and community participation.

We wrote this manual in order to help other spina bifida centers learn how to launch a group visit program. It is a "how-to" guide for bringing professionals in the field of adapted physical education into the interdisciplinary team at a regional Spina Bifida Center. This manual can also be used as a reference for teachers, therapists, and interested others who believe in our vision for high quality physical education and community access to adapted sports and physical recreation for all children with spina bifida.

What is a "Group Visit"?

Group visits are best described as an extended doctor's visit where medical as well as educational, social and psychological concerns can be dealt with effectively. At a group visit, 5-15 patients with a common medical condition meet together on a regular basis under the guidance of a medical team. These visits are voluntary and are meant to supplement, rather than replace, the traditional medical encounter. Group visits are similar to support groups in many ways, but differ in that medical care is included in each session. This provides a mechanism for insurance reimbursement and facilitates the integration of medical care with psychological support and social services. Most group visit programs meet on a monthly basis for a set number of total visits. In addition to doctors and nurses, the health care team at a group visit may also include health educators, nutritionists, and counselors. Group visits are especially valuable for conditions that require patients to initiate and sustain life-style changes. The group format allows patients to share tips and to provide emotional support for one another as they learn – together - how to live with a medical condition. For example, at a group visit program for patients with diabetes, participants learn how to monitor their glucose level, eat a healthy diet, recognize warning signs that require emergency care, and prevent complications that are associated with diabetes. The group visit model of care dates back to 1990 when a physician named John Scott, M.D., of Kaiser Permanente Denver, developed what was then called a "Cooperative Health Care Clinic" for older patients with chronic conditions such as heart failure and high blood pressure. These patients, who were frequently hospitalized or seen in the emergency room, were brought together on a regular basis by Dr. Scott in order to monitor their health and to share practical tips for managing chronic conditions. Dr. Scott found that patients who participated in his program led healthier lives and required less frequent inpatient care than those who received traditional medical care. At about the same time that Dr. Scott's "Cooperative Health Care Clinic" was developed, a Navaho Nation clinic for patients with diabetes also successfully piloted a group visit program. Studies of these and similar initiatives have shown improved clinical outcomes, increased patient satisfaction, increased ability to address psychosocial issues, increased independence and functional abilities, and decreased medical costs.[1] Group visits have been successfully launched for diverse conditions such as asthma, schizophrenia, and heart failure. In fact the group visit is considered "standard of care" by insurers for some chronic conditions, such as diabetes.[2]

The overarching context for group visits is summarized by Ed Wagner's "Chronic Care Model".[3]

The Chronic Care Model identifies the essential elements of a health care system that encourages high-quality chronic disease care. These elements are the community, the health system, self-management support, delivery system design (such as Group Visits), decision support and clinical information systems. The goal is to foster productive interactions between informed patients who take an active part in their care and providers who are prepared to focus on prevention and health promotion. More information is available on the Improving Chronic Illness Care website: http://www.improvingchroniccare.org/. The Group Health Research Institute in Seattle Washington and the American Academy of Family Physicians also maintain helpful websites with information about the group visit model of care: http://www.grouphealthresearch.org/aboutus/aboutghri.html

http://www.transformed.com/resources/group_visits.cfm.

As noted previously, group visits that focus on diabetes care are well-established and serve as a model for group visit initiatives for other chronic conditions, such as spina bifida. We were grateful to have had the opportunity to observe a diabetes group visit program in Rochester, New York, before we launched our spina bifida group visit program. Here is what we learned:

A Visit is Worth A Thousand Words

The Diabetes Group Visit we observed was held at a storefront health clinic in a strip mall in Rochester, New York. The clinic was located in the neighborhood where the patients lived. Visits were scheduled once monthly during an early morning time that was convenient for the patients. Although many of the patients might otherwise miss scheduled appointments, their attendance at the group visit program was reliable. When we asked several of the patients why this might be, they said that they were able to come on a regular basis because they had decided as a group on a time and day of the week that was "do-able." All of the patients lived in the neighborhood. Several mentioned that they were able to come on a regular basis because transportation was "not a problem." One patient said he attended on a regular basis "because there's no waiting room." The group noted that their sessions always started and ended promptly.
What we learned: Schedule group visits at a time and location convenient to patients.

Coffee was served and the atmosphere was welcoming and informal. The group visit took place around a large conference table with 12 patients sitting in a circle facing one another. As patients arrived, blood pressure and finger sticks were obtained by a nurse who went around the table. Patients were in charge of recording and tracking vital signs and laboratory results in their own charts. Patients reviewed their charts together as a group, and commented on improved trends in blood sugar, A1C levels, cholesterol, weight and blood pressure. Next a physician assistant presented a brief 10-minute talk about preventing diabetic ulcers. Most of the discussion thereafter was among the patients themselves. The group shared practical tips based on personal experience. If information was incomplete or inaccurate, the nurse or physician assistant would chime in, but otherwise the discussion was led by the patients themselves. It was clear that the health care team was there in a supportive role, to facilitate discussion. When we discussed this observation with the health care team later that day, the physician assistant mentioned that it typically took 3-4 meetings for a group to "gel". He noted that patients' A1C levels improved shortly after this threshold had been met.
What we learned: Patient involvement is key. The group should "run itself."

The physician assistant wrapped up the meeting by reviewing what the group had learned that day. He also summed up the session topics that had been discussed to date and reminded the group about the topic for the next Group Visit meeting. The upcoming group visit topic was nutrition and the session itself would consist of a trip to the grocery store next door to the clinic. The group visit ended as it began, by having patients review their vital signs and blood work and discuss their goals for improvement for the next session.
What we learned: Reiterate and reinforce topics from each group visit session so that patients understand that the goal is to change their health habits. A tracking sheet to monitor progress keeps patients' health goals in focus. Sharing health goals with the group makes the patients accountable to themselves and to one another!

Toward the end of the hour-long group visit session, the physician assistant wrote script refills for several of the patients. If a more detailed discussion was needed about a medication or a health concern, a separate follow-up appointment was scheduled on the spot. The physician assistant dictated a brief note in the chart for each of the patients who attended the group visit session. The health team also made it a point to sit down together for a debriefing session to share impressions of group dynamics, analyze themes that were discussed that day, and strategize ways to improve the group visit for the next session.
What we learned: Group visits complement (but do not replace) traditional medical care. Make it clear that individual health issues that require extensive discussion should be addressed at a separate visit. Document group visits encounters in the medical chart, just as you would a traditional medical encounter. A debriefing session with the health care team is helpful.

We decided to launch a group visit program at our spina bifida center because we felt that traditional annual comprehensive care visits at our Center did not allow us to adequately address common ongoing chronic health concerns, such as incontinence and pressure sores. In particular, we were concerned about obesity rates among our patients. A chart review study analyzed by Dr. John Foley and published in 2008 documented high obesity rates at our center.[4] We launched the Fit Families Group Visit program in order to combat this preventable secondary condition.

References
1 Jaber R, BraksmajerA, Trilling J. Group visits for chronic illness care: models, benefits andchallenges. Fam Pract Manag. 2006Jan;13(1):37-40.

2 Diabetes management in ahealth maintenance organization. Efficacy of care management using clustervisits. Sadur CN, Moline N, Costa M, Michalik D, Mendlowitz D, Roller S, WatsonR, Swain BE, Selby JV, Javorski WC Diabetes Care. 1999 Dec; 22(12):2011-7.

3 Wagner EH, Austin BT, VonKorff M. Organizing Care for Patients with Chronic Illness. Milbank Q.74(4)511-44.1996.

4 Dosa NP, Foley JT, EckrichM, Woodall-Ruff D, Liptak GS. ObesityAcross the Lifespan Among Individuals with Spina Bifida Disability andRehabilitation, Volume 30, Issue 25 (2008) pages 1-7.

Joann Armstrong

Our Story

Group visits at our spina bifida center began with a vision. In 2006, Dr. Greg Liptak gave us the idea to launch a pilot program. He had recently come to Syracuse to be division director at the Center for Development, Behavior, and Genetics at SUNY Upstate Medical University. As one of the leaders in the field of spina bifida care, he was aware of the obesity epidemic and the importance of preventing secondary health conditions. At one of our division meetings Dr. Liptak handed out an article about the group visit model of care, and made the understated comment that group visits held great promise for our patients with developmental disabilities.

At around the same time our spina bifida team established a connection with Dr. Timothy Davis at SUNY Cortland Department of Adapted Physical Education. Tim and his graduate students offered an excellent annual "Adapted Sports Adventure Camp" that many of our patients attended. We approached Tim about doing an adapted sports program on a monthly basis, as part of an ongoing group visit program. Tim liked the idea and suggested that we include his colleagues at SUNY Cortland, Dr. John Foley and Dr. Luis Columna. John was already working with us on a chart review study of obesity rates at our Spina Bifida Center.[1] In addition, all of us were already working together on an educational DVD about adapted sports for children with vision impairment and blindness.[2] We liked the idea of expanding this collaboration to a group visit program. Dr. Liptak identified a local funding opportunity, wrote a grant, and we were on our way!

Our first group visit program was launched in 2006. It was geared to children with vision impairment and blindness. We planned this with parents and several local teachers for the visually impaired. Our focus group sessions with these stakeholders established that visits would work best if they were held in the evening, and if education teams were invited to attend. It was a huge success! The year-long program allowed us to meet basically all of the local teachers for the vision impaired. The group visits were highlighted at a local conference for vision educators. We were also invited to talk about our project at national meetings for teachers of the visually impaired, social workers, professionals in adapted physical education and at the American Academy of Cerebral Palsy and Developmental Medicine. Unfortunately funding for the group visit program ended after one year.

Luckily, our social worker at the Spina Bifida Center of Central New York, Kim Garver, was able to write an internal grant to the Upstate Advocates to adapt the group visit model for our patients with spina bifida. Our second year experience proved that we were onto something good! A local adapted sports club joined us as peer mentors. We also brought in leaders from the spina bifida community, including Joann Armstrong from the Greater Rochester Area Spina Bifida Association. Joann is a para athlete, coach for the Rochester Rookies wheelchair basketball team, and a dear friend to all of us. She was the invited speaker for our very first spina bifida group visit.

Other invited speakers that second year were local athletes and people involved with a variety of adapted sports programs, including bow hunting, curling, and sled hockey!

Our experiences during the second year underscored the importance of patient and parent involvement when launching a group visit program. Kim Garver started a quarterly spina bifida newsletter to disseminate information about group visits. She asked parents to help come up with a name for our newsletter: "High expectations. No limitations." A letter written by Ben L., about his son's experience with the group visit program was published in the newsletter. The letter below about Caleb (age 9) helped crystallize what we're doing, and why.

As a Parent, more than anything else, I want my child to be happy. I want him to enjoy every moment. I want him to work hard and get a sense of accomplishment when he finishes something challenging. I want him to be the best that he can be, and to be proud of who he is, always. I want him to see that he is loved, I want him to see that he is important, I want him to see that he matters, and I want him to see that he has no limits.

In order for him to see these things he first has to see who he is. He has to sort out the feelings of isolation and being different, he has to realize that he is not the first, nor will he be the last, to fight this fight . How do I show a child that he is not alone when I don't have all of the answers? How can I comfort the insecurities, when I have no idea what he is going through? How can I make my son feel like he is not alone when everyone he knows walks from place to place and stopped wearing pull ups three years ago. How do you tell a caterpillar that someday it will be a butterfly?

The answer is: you don't. You show a caterpillar other caterpillars, and let them find their own way together. This is what Upstate's spina bifida clinic is trying to do, in conjunction with the adapted physical education department of SUNY Cortland. Together, once a month, on a Wednesday night at the Institute for Human Performance, they host a meeting where families from the clinic come together. Children of all ages, and ranges of physical abilities, come together and play games with each other and the staff from both the clinic and SUNY Cortland. These games are designed to be fun, to provide exercise, to improve self esteem and ultimately boost the child's confidence.

While the children are playing and making new friends, they realize, whether they know it or not, that they are not alone. They see, and hear, what other kids can and have done and the limits that they may have perceived, or their parents may have perceived, seem to fade into the background. And what is left is what was there all along; your beautiful child with so much potential and nothing to hold them back, but their imagination.

The children are not the only ones to benefit from these meetings. The parents get to speak to other parents who have gone through some of the exact same situations they are going through. They learn from each other, find out what works and doesn't work and know that they are not alone in some of the feelings they feel and some of the struggles they have each and every day. The clinic provides a different presenter every month. Some may share personal experiences about growing up with spina bifida, some may show parents how to advocate for themselves, some may share success stories and show parents that the only limits their children have are the ones the parents set for them.

Parent involvement was key to getting "buy-in" of hospital administrators. Ben L.'s letter helped get us a meeting with the president of our university. Our group (spina bifida team, adapted physical educators, local wheelchair sports organizations, and parents) discussed next steps for sustaining the group visit program. This brainstorming session resulted in a billing system to make the group visit program self-sustaining. It also led to an initiative to integrate service learning for physical therapy students on our campus with the group visit program. We were featured in our hospital's community outreach magazine and included in Upstate's annual fund-raising camping. The support of hospital administrators was key to further development of our Fit Families group visit program.

The next year we were very lucky to be the recipients of a sizeable donation from a local musician with spina bifida who wanted to celebrate his 60th birthday in a special way! Mr. Mike Casale, a bass player, brought in the national recording band, Orleans, to do a benefit concert with Mike at the Dinosaur Barbeque Club in downtown Syracuse. On behalf of the children with spina bifida in our community, we were very grateful to receive a sizable donation for the group visit program from Mike's excellent benefit concert! That year we also received a generous donation from the Women's Auxiliary of the American Legion in Mattydale, New York. Their connection? One of the leaders of this organization has a grandson who was born with spina bifida.

Mike Casale playing his bass at the benefit concert for our spina bifida center that he organized. (Dinosaur Bar-B-Que, Syracuse, NY)

During the third year Dr. Luis Columna was able to bring in grant support for our group visit program from the Dana and Christopher Reeve Foundation. This funding has allowed us to share our program with other spina bifida centers via an educational DVD and this manual, which is available also in Spanish language translation http://www.upstate.edu/gch/providers/search_result.php?department_id=57). Dr. Columna has presented the group visit model to colleagues in Venezuela, Colombia and Puerto Rico.

During our third year, our social worker, Kim Garver, published a chapter on the group visit model of care in a social work textbook.[3] We also shared our group visit model at national conferences for social workers, for health care professionals and for professionals in adapted physical education. Finally, during our third year we launched a sibling mentor program. Several college students who have siblings with developmental disabilities shadowed us during the Summer months. These interns helped us to develop this manual. Their input is much appreciated. We wish them well as they pursue further studies and careers in the field of developmental disabilities.

Now entering our fourth year, our grants have allowed us to bring in expert speakers from other spina bifida centers. This year Dr. Andy Zabel from the Kennedy Krieger Institute talked via webcam about psychoeducational supports for kids with spina bifida, and Dr. Brad Dicciano flew in from the University of Pittsburgh to talk to our parents about mobility and adaptive technology. We are now exploring how to incorporate into our group visits materials available via Spina Bifida University:

http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.6281735/k.9041/SB_University.htm

and on the Spina Bifida Association website:
http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642297/k.5F7C/Spina_Bifida_Association.htm

We have also expanded our project to include research initiatives led by Dr. John Foley in collaboration with Dr. Kevin Heffernan from the Department of Exercise Physiology at Syracuse University. Anne Marie Abt, PT, faculty at SUNY Upstate Medical University's Program in Physical Therapy, and Dr. Cathy MacDonald, faculty in Adapted Physical Education at SUNY Cortland have also joined our team. Input and in-kind support from GenMove USA, is also very much appreciated. We are very happy to be able this year to share our group visit handbook at the Second Spina Bifida World Congress. Our goal is to bring the group visit model of care to as many people as possible.

1 Dosa NP, Foley JT, Eckrich M, Woodall-Ruff D, LiptakGS. Obesity Across the LifespanAmong Individuals with Spina Bifida Disability and Rehabilitation, Volume 30,Issue 25 (2008) pages 1-7.

2 Cleary D, Dosa NP, Foley JT, LiebermanL. Liptak GS, MacBlane M, WelchT. Sport Opportunities and Activities for Children with Visual Impairments. Instructional DVD, published October2008 (available upon request by calling 315-464-7561) and on the Internet at http://www.campabilitiesbrockport.org/Camp-Video.html.

3 Garver KL, Spina Bifida and Physical Activity:Group Centered Care in Social Work in Health Settings: Practice in Context, third edition, Kerson TS, McCoyd, JLM, et. al. Routledge Books, NewYork: 2010.

Getting Started

Now that you know a little bit about our experience with launching group visits, we would like to give you several concrete suggestions for getting started in your own community.

Tip #1: *Observe an established group visit program.*

As with anything new, getting started can be a challenge. The mentality, "we've always done it this way", can seem mountainous to overcome when a clinic is trying to make changes that will benefit patients and families. Enthusiasm can go a long way. Visiting another facility that already has a group program can foster this enthusiasm as well as increase support and momentum. You are very welcome to contact our Spina Bifida Center if you would like to observe our group visit program in action. We also have a DVD about our program that we would be happy to send to you. We can be reached at 315-464-6395.

Tip # 2: *Review the medical literature and web resources for group visits.*

Once we decided to launch a Group Visit program at our Spina Bifida Center we learned as much as we could about this model of care. We reviewed the medical literature on Group Visits. We also identified several excellent websites with resources and practical information about launching a group visit program. (See below).

Tip # 3: *Reach out to professionals in the field of physical education, adapted physical education and adapted sports in your community.*

TransforMED Web Portal, American Academy of Family Medicine
Group Visit Resources:
http://www.transformed.com/resources/group_visits.cfm

Group Visit Starter Kit, Improving Chronic Illness Care Resources:
http://www.improvingchroniccare.org/index.php?p=Critical_Tools&s=162

Family Medicine Digital Resource Library
Competency Base Curriculum for Group Visits
http://fmdrl.org/group/index.cfm?event=c.showWikiPage&pageId=322

The medical team at our spina bifidacenter would be unable to conduct group visits without the support of adapted physical education professionals from SUNY Cortland and Syracuse University. Similarly the adapted physical education professionals appreciate the availability of medical professionals for questions that patients and families have that go beyond sports and equipment. This collaboration has allowed each profession to learn from the other professions and to share what they are learning with each other in order to strengthen the group experience. Identifying key individuals in your community who have expertise in and a passion for adapted physical education is a critical first step to launching a group visit program. Patients and families may already have this information. If there is a physical education program at a local college, that would also be a logical contact point. The National Consortium on Physical Education and Recreation for individuals with disabilities maintains a directory of college and graduate programs in adapted physical education. We suggest that you search their database to identify a college program and potential service-learning volunteers in your area: http://www.ncperid.org/directory.htm. We also suggest that you ask your physical and occupational therapists to help you to network with adapted physical education professionals and athletes in your area. Finally, it may be helpful also to contact Dr.Timothy Davis, who is the chair for the Adapted Physical Education NationalStandards program at **607-753-4969**. Other national organizations that can help you locate qualified adapted physical education professionals in your area are listed on the following page:

National Organizations for Adapted Physical Education Professionals:

APENS: Adapted Physical Education National Standards
http://www.apens.org/

AAPHERD: Association of the American Alliance for Health, Physical Education, Recreation, and Dance http://www.aahperd.org/

24 Acorns: Adaptping community-based obesity reducing national strategies
http://www.24acorns.org/

NAPSE: National Organization for Sports and Physical Education
http://www.aahperd.org/naspe/

NCPAD: National Center on Physical Activity and Disability
http://www.ncpad.org/

NCPERID: National Consortium for Physical Education and Recreation for Individuals with Disabilities:
http://www.ncperid.org/

PE Central: Website for health and education professionals http://www.pecentral.org/

Tip #4: ***Seek the support of administrators and health leaders.***

Initiating a group visit requires some planning and coordination. Thankfully, many other providers have already tested the idea, and materials are available to assist. Make sure that you have support from the clinical and administrative leaders at your site. Discuss how you will evaluate outcomes for a group visit program (see Appendix F). Because group visits are an excellent service-learning opportunity for students, it may also be helpful to meet with leaders who support the education mission at your institution. Private insurance companies and Accountable Care Organizations may also be interested in supporting a group visit initiative.

Tip #5: ***Determine a measurement plan that works for your site and population.***

Patient and provider satisfaction, physical activity, participation, goal attainment, and achievement on clinical standards of care and utilization are commonly used outcome measures. Appendix F in this manual lists the outcome measures that we use at our Center. An excellent general overview of program evaluation procedures that was developed by the American Academy of Pediatrics, Evaluating Your Community Based Program Parts 1 and 2 (2008), is available on the Internet at: http://www.aap.org/commpeds/htpcp/EvalGuide1.pdf

Tip #6: ***Write a small local grant to get started. Starting small and staying local are key to success.***

We suggest that you seek $500 to $1500 to pay for meals and guest speakers. A little goes a long way, and staying local with funding requests builds community support for a group visit initiative.

Tip #7: ***Involve kids and families from the get-go.***

Last but definitely not least, it is essential that kids and families participate in every step of the planning process. Many families are familiar with key resources in the community. Also, a parent's ability to advocate should not be underestimated. It is extremely effective to include a parent or a child-athlete in meetings with funders, administrators and insurers. The opportunity for families to get to know each other in the group visit setting, and then continue to be a support and forge relationships that last beyond the group visit, is endless. For example, families who met via our group visit program have started a sled hockey team, an adapted dance program and a family swim night. They have also raised the bar for adapted physical education at several local schools. Working together, our families have brought about a positive change in our community. They have accomplished so much more than we could ever expect to do just within our medical setting. Family involvement is absolutely key to a group visit program!

Funding

We are able to run the Fit Families group visit program thanks to insurance reimbursement, annual grants, and service learning volunteers. In addition, because our spina bifida center is affiliated with an academic institution, we are fortunate to have space available to us at no additional charge. In this section we will discuss our three main funding sources.

Insurance Billing

At this time there are no nationally accepted standards for billing group visits. Cost analyses for group visit programs that are focused on chronic conditions such as diabetes suggest that the "break-even" point is 10-12 patients when standard billing codes are used.[1] The following billing codes are commonly used to bill for group visits:

99213 with 4 parts to the history, a brief exam, & decision making regarding a complex problem, with a stable patient and no therapy changes

99214 with 4 parts to the history, 2 past med parts, and 2 ROS parts, a brief exam, and a pt. requiring a change in therapy with documentation of a risk benefit discussion related to that therapy change

99078 describes physician educational services in a group

99499 this billing code (unlisted E/M) is the code that is recommended by the American Academy of Family Physicians.

It should be noted that some private payers will accept billing **(99201-99215)** based on the entire group visit. It may be helpful to contact local payers to ask for instructions (in writing) on how to bill a group visit program. At our program we use time-based billing for the time spent on the medical consultation portion of the group visit. Public insurance will reimburse time based billing as long as a nursing assessment with vital signs, height and weight are recorded in the chart and a note is dictated into the medical record that documents that at least **50%** of the visit was spent counseling. We dictate a visit note for every patient at every group visit. Although reimbursement rates are low, we bill for medical visits in order to be in compliance with our institution's provider policies. Also, having the group visit scheduled as a medical encounter permits families to request medical transportation to our group visit program. This is important because many of our patients are publicly insured.

If your group visits include the services of nutritionists or a behavioral health specialist, we suggest that you contact local payers to determine if that portion of the group visit can be directly billed by the non-physician provider. This typically would include codes for medical nutrition therapy **(97804)** or health and behavior intervention **(96153)**. Other codes that may be applicable are the codes for education and training for patient self-management involving a standardized curriculum **(98961-98962)**. Neither these codes nor medical nutrition or behavioral health therapy are billed by physicians. Physicians must use evaluation and management codes to report these services. As noted above, code **99078** describes physician educational services in a group. To recap, the following codes may be used to reimburse non-physician professionals for their time and expertise:

97804 non-physian medical nutrition therapy

96153 non-physician health and behavior intervention

98961-98962 self management education program with standardized curriculum

Grants

The Fit Families group visit program described in this manual requires medical staffing as well as the time and expertise of adapted physical education professionals. We also rely on student volunteers in order to provide a **1:2** ratio for supervised gym activities. Health insurance billing reimburses only a portion of these costs. Annual grants of approximately **$1500** are therefore needed to pay for costs of meals, transportation of extra wheelchairs, transportation of student volunteers, and to reimburse guest speakers for six sessions. We are fortunate that both SUNY Cortland and Syracuse University have extra wheelchairs and sports equipment that we can use, as in-kind support for our program. The start up costs for obtaining equipment would otherwise be at least **$2500** (see Equipment section). It is important to highlight in your funding requests that group visits offer an excellent service-learning opportunity for students in adapted physical education, physical therapy, and medicine. Group visits are also an excellent way to provide an interdisciplinary educational experience, and to foster understanding of community-based supports and services for children with disabilities. Funding or in-kind support from academic institutions may be granted if these aspects are highlighted as consistent with the institution's mission to educate future professionals. We have been successful with all of our internal funding requests. We believe that this is because the request amount has been modest and because the program is consistent with the mission of our institution. If institution funds are not available, other funding sources to consider are:

Your local SBA Chapter:
http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2643249/k.9254/SBA_Chapters.htm)

Your local Community Foundation:
http://www.communityfoundations.net/frameviewer9c1d.html?sitename=http://www.communityfoundationlocator.org&pageId=14122&location=botP

Service Learning

Our adapted physical education faculty have incorporated the group visit program into the curricula for their undergraduate and graduate classes in adapted physical education. This is an excellent way to absorb staffing costs of running a group visit program. Medical students and residents also volunteer. They consistently rate this experience highly. Medical student and resident participation in a group visit is consistent with the Accreditation Council for Graduate Medical Education (ACGME) requirement for core competency in systems-based practice.[2] It is an excellent way for medical students and residents to learn about the entire health care system, including community resources and school-based services for their patients with developmental disabilities. The interdisciplinary debriefing session at the conclusion of each group visit is a great way for students and residents to experience teamwork across systems of care. Some students receive course credit, others volunteer. Service learning is key to the success of our group visit program. Students give us the manpower we need to safely supervise gym and pool activities. Students are also very important because they develop friendships and are mentors to the kids. We would be unable to run our group visit program without student volunteers. We very much enjoy and appreciate their participation.

Nursing Assessment

Registration

Staffing

Staffing for group visits includes the core team at the spina bifida center of Central New York:

- scheduler
- nurse
- nutritionist
- social worker
- medical director
- faculty in adapted physical education
- faculty in physical therapy

Group visits are also staffed by

- adapted physical education students
- physical therapy students
- medical students and medical residents

At each group visit we bring in a

- guest speaker

And our patients have also brought along

- parents
- siblings
- grandparents
- neighbors
- friends
- local athletes
- adults with spina bifida (mentors)
- teachers
- therapists

> Altogether we typically have 50-65 participants

Before you know it, we have quite a crowd! Altogether we typically have 50-65 participants. The core team members for our group visit program, and their specific responsibilities, are listed on the following page.

Core Team Members

Scheduler

1. Send invitation/reminder letter 10 days before the group visit
2. Call to confirm participation 2 days prior to group visit
3. Pull charts for review 2 days prior to group visit
4. Prepare registration and billing forms for the group visit
5. Submit signed encounter sheets for insurance billing after the visit

Nurse

1. Take charts and supplies (stethoscopes, blood pressure cuff etc) and encounter tracking forms to group visit
2. Check room set-up for nursing assessments
3. Perform vitals, height and weight; review medications and allergies
4. Data entry into encounter tracking form, in collaboration with patient

MD

1. Participate in planning of the visit with the team, following suggestions of participants
2. Review charts, identify problems for review with individual patients
3. Facilitate discussion at information session
4. Address individual medical concerns. If needs are complex, schedule traditional medical appointment for after the visit
5. Document all visits in medical chart
6. Sign and submit billing sheets

Nutritionist

1. Plan and prepare healthy meals for group visit
2. Provide recipes and nutrition handouts
3. Follow up phone calls to families, as needed

Social worker

1. Write, publish and distribute newsletter on a quarterly basis
2. Invite & make arrangements for guest speakers, in collaboration with parents and team
3. Assist with transportation, as needed
4. Bring supplies for registration desk (name tags, pens, consent and billing forms)
5. Register patients and welcome families
6. Coordinate announcements by children
7. Facilitate discussion at information session

Faculty in Adapted Physical Education and Physical Therapy

1. Plan gym activities and provide necessary equipment
2. Recruit and supervise student volunteers
3. Serve as liason to school-based professionals

PT/OT

1. Participate in gym activities
2. Recruit and Supervise student volunteers

All core team members provide individual consultation to families and participate in de-briefing sessions with students.

Space

The Fit Families Group Visit program has access to a beautiful state-of-the-art gym and pool facility at the Institute for Human Performance at SUNY Upstate Medical University. Gym space is essential to the success of a group visit program. A high school gymnasium, the local YMCA, or a fitness center would be appropriate for a group visit program. Be aware that there may be restrictions regarding use of non-clinical space for medical visits. Clarify with your administrators whether you can bill for medical encounters in the space you are considering for use. It is also important to think ahead of time about parking fees and accessibility. Parking is free at our facility. We are fortunate also to have access to three separate spaces: a large classroom for meals with our entire group; a separate gym; and an alcove that is near the gym, where parents can participate in the information session in close proximity to their children. It is a luxury to have this much space. A gym and a meeting room are the basic space requirements.

Equipment

With the collaboration of SUNY Cortland Adapted Physical Education (APE)and Syracuse University Exercise Physiology faculty, the team discusses and plans the monthly events for parents and children. Once decided, the Cortland and Syracuse faculty and students bring a variety of equipment to encourage maximum participation and success. Much of the equipment is novel and not always available for use in physical education classes in their school settings. For example, extra sport wheelchairs of various sizes and types are available so that siblings and friends can join in on the games. Many of these chairs are simply used chairs that are stripped down to be as lightweight as possible. We suggest that you contact local wheelchair vendors to ask about purchase and/or donations. Balls of various sizes, texture, and color are used to encourage participation and success. Easy to grip pool noodles make great extensions for playing a warm up game of "Superman" tag, while yarn balls encourage easy grasp and release when throwing at bowling pin targets. Balance boards (www.spoonerboards.com), scooters, physioballs, Kin-balls, parachutes, and oversized goals make for high levels of success and encourage independent play. The participants' school based physical education and adapted physical educators are also encouraged to attend to learn about the equipment and observe how the student participates in this unique environment. Companies for finding adapted physical education equipment include Flaghouse (www.flaghouse.com)and PECentral (www.PECentral.com). Appendix D lists additional resourcesand ideas for equipment and gym activities.

Supplies

Nursing Assessment Area

- ❑ Patient Charts
- ❑ Encounter tracking forms
- ❑ Clipboards
- ❑ Pens
- ❑ BP cuffs
- ❑ Stethoscopes
- ❑ Wheelchair scale
- ❑ Stadiometer
- ❑ Calipers for skinfold thickness
- ❑ Clock

Registration Table

- ❑ Table and chairs
- ❑ Sign-in sheets
- ❑ Portable file box for storage
- ❑ Pens
- ❑ Nametags
- ❑ Billing, HIPAA, and Registration forms (standard)
- ❑ Note: If planning to take photos for newsletter etc., photo consent forms should also be signed
- ❑ Clock

Healthy Meal Area:

- ❑ Tables and chairs to seat 50-65 people
- ❑ Central buffet table
- ❑ Water bottles
- ❑ Napkins
- ❑ Plates
- ❑ Silverware
- ❑ Nutritional information and recipe handouts
- ❑ Several large trash cans, located by buffet and near doorways
- ❑ Clock

Timeline and Checklist

A. 6-12 months prior

1. **Identify team**
    a. Reach out to local adapted physical education professionals
    b. Recruit service-learning volunteers
2. **Set up monthly planning meetings**
3. **Obtain start up grant funding**
    a. **$1500** to pay for meals, transportation, guest speaker honoraria, printing costs.
    Note: This does not include cost of equipment or space rental.
4. **Contact insurers to clarify billing procedures**
5. **Reserve gym space and adjacent meeting area**
    a. Consider accessibility
    b. Clarify whether DOH regulations apply
6. **Order equipment if needed (consider where to store)**
7. **Order supplies**
8. **Identify initial speaker**
9. **Announce dates (post in clinic area)**

B. 6 weeks prior

1. **Send out invitation letter**
2. **Decide on pre/post evaluation measures**
3. **Consider hosting an information session for service-learning volunteers**
    a. watch our DVD and review this manual
    b. review and discuss rationale for evaluation measures

C. 2 weeks prior

1. **Call families who have not responded to RSVP request**
2. **Confirm headcount**
3. **Plan meal**
4. **Check equipment**
5. **Print encounter tracking forms**
6. **Print pre/post evaluation measures**
7. **Confirm guest speaker**
8. **Review agenda with team (see "Schedule at a Glance")**

Days prior to visit

1. **Pull and review charts**
2. **Set aside supplies**
3. **Prepare meal**

Day of visit

1. **Prepare meal**
2. **See "schedule at a glance" for detailed agenda**

Day after visit

1. **Document visit in medical chart**

One week after visit

1. **Review medical charts at spina bifida team meeting. Follow up with families as needed.**

Day of Visit

Group visits are 2-hour long evening sessions that are held in a gymnasium and reimbursed by insurance. Group visits are open to parents, siblings, friends, and school personnel. Each group visit includes an educational seminar for parents on topics that improve awareness, advocacy, and access to community services.

- Group visits combine medical care with information for parents, physical activities for kids, and informal social support and networking.
- Group visits are efficient~ we see 8-12 patients in 2½ hours.
- Group visits offer continuity of care. Having monthly meetings means that we can provide close follow-up for ongoing health concerns.
- Group visits also provide an excellent service learning opportunity to students of physical therapy, adapted physical education, and medicine.
- Group visits foster friendships (last but not least!)

At our Spina Bifida Center we offer a series of six monthly group visits during the academic year (October, November, December, February, March, April). We meet once per month on Wednesday evenings from **5:30-7:30**. This is a time that works well for most families.

"Schedule at a Glance" **A summary of the components of a typical group visit**

5:00-5:30	5:30-6:00	6:00-6:30	6:30-7:15	7:15-7:30	7:30-8:00
Set Up	Registration Nursing Assessment Brief Medical Encounter	Healthy Meal Announcements	*For Kids:* Physical Activities *For Parents:* Information Session with Guest Speaker	Individual Consultation with MD, RN, RD, SW, PT, OT and Adapted Physical Educators Informal Networking	Debriefing Session with Team and Students

Set Up

Who Adapted Physical Education Faculty and Students, Social Worker, Nutritionist, Nurse

What Adapted Physical Education faculty and graduate students arrive 30-60 minutes ahead of time to set up equipment in the gym. Our social worker sets up the registration area with name badges, registration, and consent forms. Our nurse sets up the weigh-in station with wheelchair scale and stadiometer, calipers for tricep skin fold thickness, and latex free blood pressure cuff and stethoscope. She also brings tracking forms that patients may help to fill out in order to monitor their vital signs over time. Goal setting forms are also brought to the nursing assessment station, for review and discussion regarding goal setting. Our nutritionist, social worker and nurse bring in the prepared meal (made off-site), silver ware, napkins, plates and water bottles. *Note: Families are asked to RSVP one week prior to the group visit, so that appropriate amount of food is prepared.*

Where Nursing station, Meeting Room, Hallway, Gym

Registration

Who Social Worker, Volunteers

What Because the group visit includes medical care, we start with patient registration, just as we would for a conventional medical appointment. Our scheduler sends families a letter 10 days prior to the group visit. A reminder phone call is placed 2 days prior to the visit. As with other appointments, a reminder call is often helpful. The caller should reinforce that this is an actual medical appointment, not a class or workshop, and people are expected to call and cancel if they cannot attend. Discuss the issues of co-pay and parking as necessary. Note that transportation to group visits is covered by insurance, just as it would be for a conventional medical appointment. Families know that they must RSVP in order to attend. Patients are checked in, which includes releases being signed, insurance information and demographics checked, and name tags donned.

Where Hallway outside meeting room

Nursing Assessment

Who RN

What Once registration is complete, we bring patients to a separate area for nursing assessment, vital signs, weigh-in and review of medications and allergies. An encounter tracking form is filled out together with the patient (if appropriate) to monitor longitudinal trends (see Appendix B). If medical concerns are identified, individual consultation is arranged with MD.

Where Nursing station ideally is a separate room or private area near the meeting room

Medical Encounter

Who MD

What The physician works with the nurse in the assessment area to identify specific concerns. If the concern is straight-forward, such as a prescription request or a discussion of side-effects, it is addressed individually on the spot by the physician. These one-to-one consultations do not replace the comprehensive care visits that we offer annually at our spina bifida center, but are ideal for ongoing concerns that require close follow up, such as bowel management, wound care, equipment needs, educational advocacy, and weight management. The physician may also decide to refer the patient to one of the other team members for individual consultation, if applicable. Physical activity goals and lifestyle recommendations are routinely and systematically discussed during all medical encounters at the group visit program.

Where Nursing station

Healthy Meal

Who Nutritionist

What Once registration and the nursing and medical assessments are completed, our entire group — kids, families, students, faculty and the medical staff — sits down together for a light meal. The students sit with the kids. This is always a great ice-breaker and a wonderful opportunity for mentoring. Group is geared to school age youth. This broad age range lends itself to role modeling for one another. Adults with spina bifida are also invited to attend and lend a hand.

They play a key role in inspiring our youths toward a future that may include service and meaning beyond themselves, as they see others give back. We also focus on mindful eating and make an effort to offer healthy foods. Julita Klopocka-Niemiec RD, Nutritionist for the Spina Bifida Center of Central New York notes: "Preventing obesity for individuals who have spina bifida is a family affair that must begin early in a child's life and continue indefinitely. Most eating behaviors and food likes and dislikes are learned in the context of home and family. Our families are encouraged to look at each meal as an opportunity to provide their children with nutrient dense, wholesome foods that support growth, development, and well-being. Also, we strongly recommend a feeding philosophy that excludes the use of food as a reward. High

fiber foods are particularly important because many of our patients have neurogenic bowel and chronic constipation. We provide water bottles at our group visits, and discourage sodas as well as high calorie foods. We encourage families to make our healthy meals at home as well. The recipes we use for the meals that we serve can be made for a family of six as well as a group of 50 (see Appendix C). These recipes were developed by kids and families as part of the "Let's Move" Recipe for Kids Initiative. For more information, please visit: http://www.recipesforkidschallenge.com/submissions."

Where Large room/dining area set up with tables and chairs for 65 people. Consider traffic flow when setting up tables. Be aware that many participants will be in wheelchairs. We recommend setting up a central buffet table.

Announcements

Who Social worker

What We usually wrap up our meal together by introducing new participants and with announcements about sports opportunities or events in the community. Kids are encouraged to speak up at this time, to share their accomplishments.

Where Large room/dining area

Physical Activities

Who Kids
Adapted Physical Education faculty
Physical Therapy faculty
Service-learning students

What After dinner, the kids head to the gym or to the pool for supervised sports and activities. SUNY Cortland Department of Adapted Physical Education and the Syracuse University Department of Exercise Science provide extra wheelchairs so that siblings and friends can join in.

Where The space that is needed for our activities is any area that is the size of a small gym or basketball court.

When creating adapted activities for kids who have mobility impairments, we use equipment that is easy to manipulate such as larger balls, softer textures, brighter colors, various shapes, and sizes and so on. The space that is needed for our activities is any area that is the size of a small gym or basketball court. Kids arrive excited and ready to play!

The goal of the evening is to promote independent physical activity and social interaction using peer mentors and fun activities. At our Fit Families Group Visit program we also do our best to reach out to traditionally underserved families. Because of the increased prevalence of spina bifida among the Hispanic population, it is particularly important to include these kids and families. A research study conducted by Luis Columna et. al.* found that Hispanic families with a child with a disability highly valued the benefits that arise from physical activity. These families faced constraints but expressed a preference for community programs, such as at a local park, and activities involving the entire family. According to Luis Columna:
"If physiological benefits are shared with Hispanic families of children with disabilities, while valuing their personal belief of perceived benefits of physical recreation, this cultural group may become more willing to be physically active."

> The goal of the evening is to promote independent physical activity and social interaction

Gym activities might include individual, small team games, or large group cooperative games. Some of these games are modifications of existing activities often found in physical education curricula such as soccer, ultimate Frisbee, volleyball, track and field and many more. College students majoring in physical education with an emphasis in adapted physical education help to create and modify the games to meet individual needs. The National Consortium on Physical Education and Recreation for Individuals with Disabilities maintains a directory of college and graduate programs in adapted physical education. We suggest that you search their database to identify a college program and potential service-learning volunteers in your area. http://www.ncperid.org/directory.htm

One example that the children seem to enjoy is a modified game of "Power Soccer." For this activity we use a large inflatable "kin ball" (www.omnikin.com) and oversized "multi-goals" (www.GenMoveUSA.com). It can also be played with any oversize ball. The game is played like traditional soccer. However children who are chair users can move the ball forward using their wheelchair, strike the ball with their arms/hands, and pass the ball using any part of their body. The Kin ball is very lightweight with a tough latex-free nylon cover and affords those with limited strength the ability to move the ball effectively while the oversized "multi-goals" promote scoring from

*Columna, L., Pyfer, J., & Senne, T.A. (2011). Physical recreation among immigrant Hispanic families with children with disabilities. Therapeutic Recreation Journal, 45(3), 214-233.

all directions. "Power soccer" promotes independent chair use, cooperation, and is great aerobic exercise. Siblings and peers without disabilities can also participate by using one of the many "extra" wheelchairs that are available. Dr. Timothy Davis has developed an activity guide (available at www.GenMoveUSA.com) that may be a good starting point when planning gym activities for your group visit program. For additional ideas with this type of equipment, see the textbook written by Todd Strong and Bernie DeKoven, entitled: *Great Activity Games for Big Activity Balls.* This book is published through Human Kinetics (ISBN #: **13:978-0-7360-7481-0**). It's a great source for ideas that can be easily modified for ALL children, and why not, adults and the entire family as well. Appendix D lists other ideas and resources for gym activities.

Individual activities are also available for children to enjoy. These include "exer-games" such as Wii and eye toy. These electronic games have been shown to promote high levels of physical activity in populations that have traditionally been sedentary.

Other sport-based activities include Paralympic sports such as curling, track and field, wheelchair rugby, wheelchair basketball, and swimming. Members from our local paralympic curling team join us for these sports and become mentors and friends with the children.

One of our most enjoyable activities is swimming. We are fortunate to have access to a heated pool, adjustable floor, built in ramp, and hydraulic pool lift. This is an ideal environment for our program. Parents are encouraged to join in the water activities as children learn to feel comfortable in a new environment. For many, the pool affords greater mobility and increased range of motion. Aquatics instruction is an essential component of physical education and an important safety and lifetime recreational skill for everyone. Swimming improves aerobic capacity and strength. It is an excellent way to stay fit across the lifespan.The student mentors provide a supportive atmosphere and a unique one on one situation for all participants. Students work closely with the parents, siblings, as well as the other disciplines creating an excellent learning situation for everyone. A variety of flotation devices can be tried in this supervised setting. Individual and group activities highlight the evening. Those children who are comfortable in the pool environment help provide peer support, promoting a "kids helping kids" synergy. The mood is up beat and energizing to all!

Information Session

Who

Parents
Guest speaker
MD
Social Worker
Any team member or student who isn't in the gym having fun with the kids!

What

After the meal, parents gather for an information session with a guest speaker, and for group discussion. The information session is moderated by our social worker, medical director, and other members of the spina bifida team. Each session begins with a quick review of family goals regarding physical activity. (***Please see Goal Setting form in appendix F***). Next, we invite experts to speak about topics that are decided upon by the parents. It is tempting to develop a "curriculum" or a themed series of talks, but studies have shown that group visits are much more effective if parents take the lead in identifying topics for discussion. We make every effort to bring in excellent speakers, including national experts via skype conferencing (this worked well!). We leave time during the first and last group visit sessions to generate topic ideas. Guest speakers have presented talks about:

- Educational advocacy
- Nutrition and weight loss
- Winter sports
- Financial planning
- Transition to adulthood
- Sibling issues
- Diet
- Executive dysfunction and non-verbal learning disability
- Ordering equipment
- Neuropsychological testing
- Panel discussion with adults with spina bifida
- Young adult/teen question and answer session (observed by parents, with kids leading discussion)
- Panel discussion with our surgeons

Over time, these information sessions require less and less moderation by the spina bifida team. The group eventually "runs itself"! The guest speaker typically discusses a topic for 20 minutes, followed by plenty of time for questions and discussion.

We have found it helpful to discuss "group visit norms" at the first group visit session. These norms include:

- Encourage everyone to participate
- State our opinions openly and honestly
- Ask questions if we don't understand
- Treat one another with respect and kindness
- Listen carefully to others
- Respect information shared in confidence
- Try to attend every meeting
- Be prompt, so meetings can start and end on time

Our social worker, Kim Garver, notes: *"As in any situation involving people, there are many personality types. The group discussion is ripe for positive issues of accountability and support but also ripe with challenges regarding conflict and inequality in group participation. The Stanford Patient Education Research Center has developed a moderator guide that provides descriptions of different types of people and potentially difficult situations. They are included in Appendix E to stimulate your thinking about how you might handle these situations effectively during a group session. Being prepared ahead of time may even help you prevent such problems. Each situation is different; therefore, use your best judgement to determine what suggestions might be effective in real situations. If a difficult situation persists, discuss it with your co-workers. Together, you will get the support you need and can decide how best to handle the problem."*

Where Meeting room with chairs set up in horseshoe arrangement.
The meeting room ideally is located near the gym.

Individual Consultation

Who All team members: MD, RN, PT, OT, SW, Faculty in Adapted Physical Education.

What After the information session the adults join their children in the gym for a closing circle at which time the kids share what they did that night. This is also an excellent time for individual consultation and informal networking. Examples of consultation topics include:

- Discussing school and community based activities where their children can participate safely and successfully
- Sharing equipment ideas and modifications so parents can inform their child's teachers of what is available to encourage child participation
- Talking with Adapted Physical Education faculty about what flotation devices to use for swim class
- Asking a nurse for a list of latex free products
- Talking with the medical director about 2 surgeon's perspectives regarding a clinical concern, such that the medical director follows up with the surgeons for further clarification.
- Asking our nutritionist for a healthy weight loss plan.
- Reviewing the Adapted Physical Education services available in the schools as well as sharing about their child's IEP goals and objectives
- Asking one of the physical therapy faculty for information about a new piece of equipment.

Where Dining area, hallway, meeting room, assessment station, gym

Informal Networking

Who Everyone

What At a traditional clinic visit, interactions among families are typically limited to brief waiting room encounters. One of the major goals of our group visit program is to prevent isolation. Built into the group visit model of care is the opportunity for families to interact, to share tips, to break bread together, and to talk about their struggles as parents and advocates. All this is accomplished during "down time" via informal networking. One of the parents at our group visit program started a Facebook page to stay in touch with other families between visits. Another outgrowth of the informal networking is increased awareness and participation in community based sports and recreation. For example, our group gets together for the March of Dimes walk. Families have also launched a sled hockey program and an adapted dance program. We run into each other also at community events such as Fun Runs. At our traditional spina bifida clinics, we have noticed that fathers rarely accompany their children to medical appointments. With few exceptions we have found that both parents attend the group visit program. This may be related to the time at which these are scheduled (evening) and/or our focus on physical activity. It could also be that we offer food and invite the entire family. Regardless of the reason, we have found that group visits are an excellent way for fathers to network and become involved.

Where Dining area, hallway, meeting room, gym

Debriefing

Who Service learning students

Faculty in Adapted Physical Education

Core team members of the Spina Bifida Center

What Last but not least, at the end of each group visit we set aside 10-15 minutes for the students to discuss their experience and to get feedback from our interdisciplinary faculty of doctors, nurses, therapists, and adapted physical education professionals. This is an excellent learning experience for us all. Appendix G includes a pre/post test that can be used to assess students' experience as service-learners at a group visit program.

Where We usually get together in the dining area, because families tend to linger in the gym. However, the debriefing session could really take place in any of the rooms.

Documentation and Follow-up

Who MD and RN

What As noted previously, the medical director dictates a medical note for each child at each visit. We use time based billing, but other coding options exist (see section on Funding). Many of the topics that are discussed during the medical portion of the group visit require close follow up. Our team reviews all patient notes one week after the group visit to make sure the plan for follow up is implemented. Accountability and follow-through is important to us. If parents ask for information that we are not able to provide at the time of the group visit, we make it a point to get this to them as soon as possible.

Where At clinic during routine team meetings for the Spina Bifida Center.

Program Evaluation

As with any initiative, it is essential to consider evaluation when launching a group visit program. Evaluation is an ongoing process that involves data collection and analysis with a goal of continuous improvement of your program's processes and outcomes. It is important to have this information for funders and insurers. Even more, it is important because we as clinicians want to understand how to be most helpful to our patients. The American Academy of Pediatrics has developed an excellent guide to program evaluation for community based initiatives such as the Fit Families Group Visit Program. This two part publication, entitled *"Evaluating your community based program: Part 1 and 2"*, is available on the Internet at http://www2.aap.org/commpeds/htpcp/resources.html. The AAP guide recommends use of the Logic Model for program evaluation. Components of the Logic Model are column headers for the table below. Note that we evaluate community participation as one of the key outcomes for our program. Please see Appendix F for evaluation measures that we have used for our program:

(a) Satisfaction survey

(b) Physical Activity Goal tracker

(c) Physical Activity Questionnaire

(d) Service learning pre/post test

	TARGET POPULATION	INPUTS	ACTIVITIES	OUTPUTS	OUTCOMES
Description: **Logic Model Components**	The characteristics of people or communities you work with and the needs they present	The resources required for this program to operate	Strategies you use or services you provide to try to achieve your goal	Basic data on program participation	Desired changes in the target population as a result of program activities
Example: **Fit Families Group Visit Program**	Families of children and youth with spina bifida who are seen at a regional spina bifida center	• Spina Bifida Team • Adapted Physical Education Faculty • Service-Learning Volunteers • Space • Supplies • Equipment	• Set up • Registration • Nursing Assessment • Medical Encounter • Healthy Meal • Announcements • Physical Activities • Information Session • Individual Consultation • Informal Networking • Debriefing Session • Documentation and Follow-up	• Recruitment • Retention • Safety • Privacy • Satisfaction	• Children/youth with spina bifida will achieve individual goals for physical activity • Families will increase their physical activity • Families will eat healthier meals • Children/youth with spina bifida will receive high quality adapted physical education at school • Children/youth with spina bifida will participate in physical activity programs in the community • Service-learning volunteers will gain knowledge about spina bifida and adapted physical education

Photo Gallery

Maeve D. skiing with grandpa and sisters

Tayisha B. family

Sarah C. Family

Elise H. Family (proud of her mom!)

Nienke P. Dosa MD, MPH
Developmental Pediatrician
Medical Director, Spina Bifida Center

Favorite Sports: Hiking and biking

"Group Visits are an excellent way to get kids to be more actively involved in their own health care. Last week Jaden (age 10) asked me for a script for a new set of AFOs! Some of us bring our own children. My daughters love to play power soccer."

Sherry Moore
Volunteer/Mentor, Spina Bifida Center

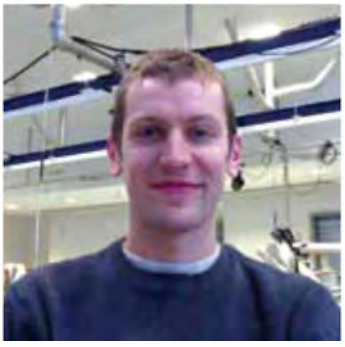
Favorite Sport: Basketball

"As I mentor, I was able to provide information to other individuals with Spina Bifida regarding their independence. My life experiences especially when it came to love, marriage, driving, and a career seemed to be very interesting to them because it showed them you can do it."

Jonathan Riddell MD
Urologist, Spina Bifida Center

Favorite Sport: Ice hockey

"Parents who met at the group visit program have started a sled hockey team. I think that's great!"



Samuel Mackenzie MS
MD/PhD Student in Neuroscience
Upstate Medical University

Favorite Sport: Track and field

"Socially, kids with spina bifida get the chance to play with other kids who are just like them. And through play, exercise, which is so important for all-around health but can sometimes feel like a chore, becomes an afterthought."

Zulma Tovar-Spinoza MD
Neurosurgeon, Spina Bifida Center

Favorite Sport: Zumba and walking

"I love to share with my patients in a non-medical setting. They teach me a lot"

Luis Columna, Ph.D., CAPE
Associate Professor Exercise Science
Syracuse University

Favorite Sports: Dancing (Latin music), Running & Skiing

"Group visits promote collaboration between professionals, parents, and students. Most importantly, it's a win-win situation for the patients and the entire family"

Julita Klopocka-Niemiec MA, RD
Nutritionist, Spina Bifida Center

Favorite Sport: Jogging

"Our families are encouraged to look at each meal as an opportunity to provide their children with nutrient dense, wholesome foods that support growth, development, and well-being."

Judy Hodge RN, BSN
Nurse, Spina Bifida Center

Favorite Sport(s): Zumba

"Group Visits foster independence. Children see that others are transferring themselves and not clinging to their parents. Before long, they develop independence with their own transfers and feel comfortable away from their parents."

Gregory Liptak MD, MPH
Developmental Pediatrician
Director, Center for Development, Behavior, and Genetics at SUNY Upstate Golisano Children's Hospital

Favorite Sport: bird-watching

"Group visits promote collaboration"

Leola Rodgers, MPH
Associate Administrator,
Upstate Golisano Children's Hospital

Favorite Sport: Gardening

"Group Visits deliver health care that is effective, efficient and value-added with information sessions for parents and gym activities for kids."

Danielle Katz MD
Orthopedic Surgeon, Spina Bifida Center

Favorite Sport: Soccer

"I enjoyed taking part in the panel discussion with other surgeons. The parents had great questions. I think that having us all there together helped parents to understand that we work as a team."

John T. Foley, Ph.D.
Associate Professor of Adapted Physical Education
SUNY Cortland

Favorite Sports: Running, Golf & Skiing

"It is so much fun having the kids engaged in the different physical activities. The hardest part of the group visit is getting the kids out of the building afterward, they just want to stay and play."

Tina DeRocha
Scheduling Secretary, Spina Bifida Center

Favorite Sport: Walking at the Nature Center

"I receive phone calls from families reserving their spots for group visits. Families often comment how much they look forward to getting together with the other families at group visit. Its nice to hear how much they enjoy the activities, especially swimming."

Timothy D. Davis, Ph.D., CAPE
Associate Professor, SUNY Cortland
Chair, Adapted Physical Education National Standards (APENS)

Favorite Sport(s): Kayaking, fishing, hiking

Favorite quote from a child, "I have been in my chair ALL DAY—I can't wait for PE so I can get out and play!"

Cindy Serviss, RN
Nurse, Spina Bifida Center

Favorite Sport: Golf

"Group visits are crucial for networking, social interaction and bringing valuable resources and knowledge to families."

Kimberlee Garver LCSW BCD
Social Worker

Favorite Activity: Cycling, inside and out

"I appreciate the opportunity to break bread together. It is very encouraging to me to step back and to let families and kids connect with each other. They learn so much from each other. I become a student too of their wealth of knowledge as experts in spina bifida as they parent, live and advocate day to day."

Cathy MacDonald, PhD
Assistant Professor
State University of New York, Cortland

Favorite Sport: Horseback Riding

"Group visits provide an opportunity for kids to be physically active and have fun. They're always asking... when do we get to come back?"

Kevin Heffernan, Ph.D.
Exercise Physiologist, Assistant Professor and Director of the Human Performance Laboratory
Department of Exercise Science, Syracuse University

Favorite Activity: Resistance/strength training

"Physical activity is the best medicine out there. Group visits are a great way to show the children (and parents) that being active can also be fun."

Appendix A: Sample Invite Letter

An Invitation to Participate in Group Visits!

You and your family are invited to join other families, doctors, nurses and therapists for a series of group visits for children and adolescents with spina bifida.

The use of group visits is growing around the country. Health care providers and families have found that these visits allow health care to be provided in ways that cannot be done during the usual office visit. Our group visits will focus on sports, physical activity, and wellness. This project represents a collaboration among adapted physical education specialists at SUNY Cortland, the Syracuse University Department of Exercise Physiology, and the medical staff at the Spina Bifida Center of Central New York.

Here's how it works

A developmental pediatrician, nurse and other professionals will meet with up to fifteen families of children/youth who have spina bifida. Visits last about two hours. There will be time to talk with other families. You will also get information about specific topics and concerns regarding your child's condition. In addition, our team will spend time talking with you and your child individually about health problems and concerns. We will offer a light meal, free of charge. Finally, students and staff from SUNY Cortland's Adaptive Physical Education Department and the Syracuse University Department of Exercise Physiology will provide a physical activity program specifically designed for children and youth with spina bifida. Siblings and friends are welcome to attend.

The group visits will be scheduled once per month in the coming year. Each session will focus on a particular topic decided upon by your group. This will give families the chance to learn from experts in the field, including other families, who are dealing with similar health issues, and to get their needs met and their questions answered. From time to time guest experts, such as para-athletes or health educators, may join us at the visits. The group visit program is a different way for families and children to meet with their health care providers and to learn how to deal with common issues. Please note that the group visits will not replace your child's regular medical care. We will continue to schedule your child's regular appointments at the Spina Bifida Center.

- Visits will be held at Upstate Medical University's Center for Human Performance on the SUNY Upstate Medical University campus in Syracuse.
- Visits will be scheduled once per month on Wednesdays from 5:30 to 7:30 PM.
- Parking will be free
- Food will be provided
- A professionally staffed physical activity program will be available for children at a state-of-the-art gym facility. Siblings are welcome to join in.
- Your insurance company will be billed for the medical portion of the Group Visit program.

If you are interested in attending, please let us know by calling Regina McConnell at (315) 464-7561, or by e-mailing her at McConneR@upstate.edu. We welcome your interest in this new opportunity for you to participate with us in your child's health care. Of course, if you decide not to participate, we will continue to see your child at the office as in the past. This project is being funded in part with a generous grant from the American Legion Auxiliary and from donations to our Spina Bifida Center fund. Below is our group visit schedule and enclosed is a map with directions. We hope that you will be able to join us!

Kindest regards,
Nienke Dosa MD and the staff of the Spina Bifida Center of Central New York

Date	Guest Speaker
October 15, 2007	Joann Armstrong, para-athlete and founder of the Rochester Rookies wheelchair sports team
November 12 2007	TBA
December 17, 2007	TBA
February 18, 2008	TBD
March 18, 2008	TBA
April 15, 2008	TBA

All Group Visits are on Wednesdays 5:30-7:30 at the Institute for Human Performance, SUNY Upstate Medical University

Appendix B: Encounter Tracking Form

Name:					
	HR	RR	BP	WT	Concerns
Visit 1					Consult: MD RN PT SW PE
Visit 2					Consult: MD RN PT SW PE
Visit 3					Consult: MD RN PT SW PE
Visit 4					Consult: MD RN PT SW PE
Visit 5					Consult: MD RN PT SW PE
Visit 6					Consult: MD RN PT SW PE

Appendix C: Healthy Meal Ideas

The following is a selection of recipes that were developed by kids and families as part of the "Let's Move initiative".

For more information and many more healthy kid friendly recipes please visit http://www.recipesforkidschallenge.com/

Porcupine Sliders

By Theresa G., Mary L., Wanda N. and Todd B. from South Education Center Alternative (S.E.C.A.), Richfield, MN 55423.
Served as an entrée this healthy mouth watering turkey burger is high in protein with just the right amount of spices and a kick of sweet cranberries. All served on whole wheat or whole grain buns. It is delicious and nutritious in an appetizing new way to get kids to eat healthy.

Nutrition Facts
Serving size: 2 oz, Calories 163, From Fat 30%, From Saturated Fat 4%, From Sugar 5 g%, Sodium 216mg

Ingredient	6 servings	50 servings
medium grain brown rice	1/2 cup	4 cups
vegetable oil	1 T	1/2 cup
yellow onions, minced	2 T	1 cup
garlic, minced	1 sm clove	1/4 cup
celery, washed and minced	1 small stalk	1 head
lean ground turkey	16 oz	8 lbs.
dried cranberries, rough chopped	2 T	1 cup
spinach leaf, well washed, drained, stems removed, chopped	3/4 cup	6 cups
eggs	2 large	16 large
salt	1/2 tsp	4 tsp
black pepper	1/2 tsp	4 tsp
Worschestershire Sauce	1 tsp	8 tsp
crushed red pepper	1 scant pinch	1 tsp

Preparation

For Sandwiches: 12/96 small multigrain or whole grain rolls Tomato, sliced Red Onion, thinly sliced (optional)
Condiments – your choice

Instructions:

1. Wash and sanitize hands, utensils and all equipment to be used.
2. To cook rice: follow package instructions for cooking brown rice. When cooked, transfer to a plate and cool completely in refrigerator. This can be done up to a full day ahead.
3. Preheat oven to 350 degrees.
4. In a skillet sauté onions, celery and garlic in oil until soft, about 5 minutes. Transfer to refrigerator and cool completely.
5. In a large mixing bowl combine all ingredients including cooked rice and cooked onion mixture and mix well.
6. Portion into 2.5 oz patties the diameter of buns onto a parchment lined baking pan. Bake at 350F for 12-18 minutes (time will vary depending on oven. Use a thermometer to check starting at 12 minutes) until turkey is at an internal temperature of 165 degrees F. Avoid overcooking – the lean turkey will dry out if cooked too long.
7. Serve on mini whole grain rolls with optional lettuce, tomato, red onion and condiments.

Tasty Tots

By Jeanne S., Lauren M., Jeanne G. and Rodney P. from Bellingham Public Schools, Bellingham, MA.

A healthy kid friendly alternative to traditional 'fried' tater tots. This item scored highest in all of our samplings. Best of all no one guessed the binder was 'chic peas'

Nutrition Facts

Serving size: 6, Calories 203, From Fat 23.05%, From Saturated Fat 3.77%, From Sugar 0%, Sodium 310mg

Ingredient	6 servings	50 servings
Yams, raw	1.5 lb	12 lb
garbanzo beans, canned, undraines	3/4 cup	1 #10 can
Oil, vegetable	2 tbs	1 cup
Salt	1/2 tsp	1 tbs
Pepper, white	1/4 tsp	2 tsp
Onion Powder	1/2 tsp	4 tsp
Cinnamon, ground	1/2 tsp	4 tsp

Instructions

1. Steam or boil yams until barely tender, approximately 15 minutes, let cool. Peel. Shred yams using course blade (1/4" to 11/32").
2. Puree Garbanzo Beans, including liquid until smooth
3. Combine shredded yams and pureed garbarbanzo bean with remaining ingredients.
4. Spray Sheet pans with Pan Spray
5. Using #40 scoop, scoop 1 inch apart on prepared sheet pans.
6. Bake at 400° for approximately 10-12 minutes, until starting to brown.

Mediterranean Quinoa Salad

By Jeanne S., Lauren M., Jeanne G. and Rodney P. from Bellingham Public Schools, Bellingham, MA.

This side salad that features a colorful variety of vegetables including red peppers, parsley, chopped cherry tomatoes & feta cheese in a light lemon based dressing.

Nutrition Facts

Serving size: 3/4 cup Calories 160, From Fat 34.9%, From Saturated Fat 6.33%, From Sugar 0%, Sodium 457mg

Ingredient	6 servings	50 servings
Quinoa	1 cup	2 qt
Chicken Broth, Low Salt	2 cup	1 gallon
Lemon Juice	2 tbs	1 cup
Vinegar, Red Wine	2 tbs	1/2 cup
Garlic, Fresh Chopped	1 tsp	2 tbs
Olive Oil	1 1/2 tbs	1/2 cup
Salt	1 tsp	1 tbs
Pepper, White Ground	1/4 tsp	1 tsp
Peppers, Sweet Red, Fresh, Chopped	1/2 cup	1 qt
Parsley, Raw, Chopped	2 tbs	1 cup
Green Onions, chopped, incl tops & bulbs	1/4 cup	1 cup
Red Onion, chopped	2 tbs	3/4 cup
Cherry Tomatoes, halved	1/2 cup	1 qt
Black Olives, sliced	2 tbs	1 cup
Feta Cheese, crumbled	1 tbs	1 cup

Preparation

1. Place quinoa in strainer and rinse under running water. Put quinoa and chicken broth in saucepan and bring to a boil. Cover and reduce to a simmer. Cook for 10-15 minutes or until all liquid is absorbed. Set aside to cool.
2. Combine lemon juice, vinegar, garlic, oil salt & pepper. Set aside.
3. Combine Veggies in a bowl. Stir in cooled quinoa, feta and dressing. Serve at room temperature or chilled.

Squish Squash Lasagna

By Jeff L. and Michelle L. from Liberty Elementary School-Worthington, Powell/Ohio.

The savory yet sightly sweet tomato sauce and layers of lasagna melt in your mouth. This is sure to please any crowd.

Nutrition Facts

Serving size: 1 piece, Calories 118, From Fat 24%, From Saturated Fat 10%, From Sugar 35%, Sodium 116mg

Ingredient	6 servings	50 servings
Yellow onion chopped	1/3 cup/3 oz	2.75 cup/25 oz
Garlic minced	2 tsp/19 g	5.5 Tbsp/158 g
Tomatoes diced in juice (no salt)	2.25 cup/12 oz	18.75 cup/100 oz
Oregano dried	1/8 tsp	1.5 tsp
Thyme dried	1/8 tsp	1.5 tsp
Basil dried	1/8 tsp	1.5 tsp
Butternut squash raw,sliced 1/4"	504 g	4198 g
Lasagna sheets (no boil)3.5"x7"	5 sheets/3 oz	42 sheets/25 oz
Spinach raw, sliced 1/8" thick	1 cup/42 g	8.33 c/350 g
Mozzarella Part Skim (Minerva Farms)	.75 cup/84 g	6.25 cup/700 g
Canola oil	1/4 tsp	2 tsp

Preparation

Tomato sauce

Heat oil in a sauce pot on medium heat then add onion and garlic and stir frequently once the onion and garlic are sweated about 2 to 3 minutes add the tomatoes and herbs and bring to a simmer for about 30 minutes stirring occassionally until most of the juice is cooked out of the pot reserve the sauce for building the lasagna

Lasagna

slice the squash length wise 1/4" thick on a mandoline or slicer, discard seeds and reserve squash to build the lasagna Chiffonade the spinach 1/8" thick and reserve For 6 servings use a 4" deep 1/4 hotel pan (when finished you will need to cut it once down the length of the pan and three even cuts across the width) and for 50 servings use two 4" deep full hotel pans and a 4"deep 1/4 hotel pan (when finished you will need to cut into three even sections down the length of the pan and across the width into eight even sections) To build lasagna start by spreading 4 oz of sauce across the bottom of a full hotel pan hotel pan or 1 oz across a 1/4 hotel pan Lay out one layer of lasagna sheets evenly, overlapping slightly For full pan ladel out 16 oz of sauce and spread evenly and 4 oz for 1/4 pan For full pan spread out 1 oz spinach evenly across and 1/4 oz for 1/4 pan Next lay out one layer of squash evenly and repeat steps 6 and 7 Repeat steps 5 through 8 two more times and then top with 1 pound of cheese for full pan and 4 oz of cheese for 1/4 pan Cover with foil tightly and bake in a pre heated 350 degree oven on low fan for 1 hour 45 minutes When done remove foil and slice according to step three and serve (it may be useful to use a heat resistant rubber spatula to serve)

Appendix D: Adapted Physical Education Resources

Eligibility Criteria for Adapted Physical Education Services
http://www.aahperd.org/naspe/standards/upload/Eligibility-Criteria-for-Adapted-PE.pdf

Adapted Physical Education National Standards
www.APENS.org

Colleges that offers a degree in adapted physical education:
http://www.ncperid.org/directory.htm

National Organizations for Professionals in Adapted Physical Education:

AAPHERD: Association of the American Alliance for Health, Physical Education, Recreation, and Dance
http://www.aahperd.org/

National Consortium for Physical Education, Recreation for Individuals with Disabilities www.NCPERID.org

NAPSE: National Organization for Sports and Physical Education
http://www.aahperd.org/naspe/

NCPAD: National Center on Physical Activity and Disability
http://www.ncpad.org/

NCPERID: National Consortium for Physical Education and Recreation for Individuals with Disabilities:
http://www.ncperid.org/

PALAESTRA: Adapted Physical Activity Council
http://www.palaestra.com/

Textbooks

Principles and Methods of Adapted Physical Education and Recreation by David Auxter, Jean Pyfer, Carol Huettig, 2001.

Adapted Physical Education and Sport (3d edition) by Joseph Winnick, 2000.

A Teacher's Guide to Including Students with Disabilities in General Physical Education (2nd edition) by Martin E. Block, 2000.

Journals

Palaestra Adapted Physical Activity Council	(800-687-5732)
JOPERD www.AAHPERD.com	(800-213-7193)
Adapted Physical Activity Quarterly	(800-747-4457)
Sports 'n Spokes	(602-224-0500)

Web Resources:

24 Acorns: Adapting Community Based Obesity Reducing National Strategies
http://www.24acorns.org/

PE Central: Website for health and education professionals
http://www.pecentral.org/adapted

PELinks4U
http://www.pelinks4u.org/

Appendix D: Adapted Physical Education Resources

Equipment:

Balance Boards
www.Spoonerboards.com

Colours Wheelchairs
http://www.colourswheelchair.com/

Flaghouse Physical Education Equipment
www.Flaghouse.com

GenMove USA Activity guides and equipment kits
www.GenMoveUSA.org

Human Kinetics
www.humankinetics.com

Multi-goals
www.GenMoveUSA.org

SPORTIME Physical Education Equipment
http://store.schoolspecialty.com/OA_HTML/ibeCCtpSctDspRte.jsp?minisite=10028

Sports Organizations:

Access Sport America
www.accessportamerica.org

Blaze Sports
www.blazesports.org

Boundless Playgrounds
www.boundlessplaygrounds.org

Challenger League
http://www.littleleague.org/learn/about/divisions/challenger.htm

Disabled Sports USA
http://www.dsusa.org/

Para-Olympic Committee
www.paralympic.org

Special Olympics
www.specialolympics.org

TOPSoccer
www.usyouthsoccer.org

Wheelchair and Ambulatory Sports
www.wsusa.org

Appendix E: Tips for Group Discussion

This information is provided courtesy of the Stanford Patient Education Research Center that maintains the copyright. It has been adapted for use by Fit Families Group Visits.

The Too-Talkative Person

This is a person who talks all the time and tends to monopolize the discussion.

- The following suggestions may help:
- Remind the person that we want to provide an opportunity for everyone to participate equally.
- Refocus the discussion by summarizing the relevant point, then move on.
- Spend time listening to the person outside the group.
- Assign a buddy. Give the person someone else to talk to.
- Use body language. Don't look toward the person when you ask a question. You may even consider having your back toward the person.
- Talk with the person privately and praise him/her for contributions, and ask for help in getting others more involved.
- Thank the person for the good comment, and tell him/her that you want everyone to have a turn at answering the question.
- Say that you won't call on someone twice until everyone has had a chance to speak once first.

The Silent Person

This is a person who does not speak in discussions or does not become involved in activities.

The following suggestions may help:

- Watch carefully for any signs (e.g., body language) that the person wants to participate, especially during group activities like brainstorming and problem solving. Call on this person first, but only if he/she volunteers by raising a hand, nodding, etc.
- Talk to them at the break and find out how they feel about the group session.
- Respect the wishes of the person who really doesn't want to talk; this doesn't mean that they are not getting something from the group.

The "Yes, but . . . " Person

This is the person who agrees with ideas in principle but goes on to point out, repeatedly, how it will not work for him/her.

The following suggestions may help:

- Acknowledge participants' concerns or situation.
- Open up to the group.
- After three "Yes, but's" from the person, state the need to move on and offer to talk to the person later.
- It may be that the person's problem is too complicated to deal with in the group, or the real problem has not been identified. Therefore, offer to talk to the person after the session and move on with the activity.
- If the person is interrupting the discussion or problem-solving with "Yes, but's," remind the person that right now we are only trying to generate ideas, not critique them. Ask him/her to please listen and later we can discuss the ideas if there is time. If there is no time, again offer to talk to the person during the break or after the session.

Appendix E: Tips for Group Discussion

The Non-participant

This is the person who does not participate in any way.
The following suggestions may help:

- Recognize that the people in the group are variable. Some may not be ready to do more than just listen. Others may already be doing a lot, or are overwhelmed. Some may be frightened to get "too involved." Still others may be learning from the sessions, but do not want to talk about it in the group. Whatever the reason, do not assume the person is not benefiting from the group in some way, especially if he/she is attending each session.
- Do not spend extra time trying to get this person to participate.
- Congratulate those participants who do participate.
- Realize that not everything will appeal to everyone in the same way or at the same time.
- Do not evaluate yourself as a leader based on one person who chooses not to participate in activities.

The Argumentative Person

This is the person who disagrees, is constantly negative and undermines the group. He/she may be normally good natured but upset about something. The following suggestions may help: Keep your own temper firmly in check. Do not let the group get excited.

- If in doubt, clarify your intent.
- Call on someone else to contribute.
- * Have a private conversation with the person; ask his/her opinion about how the group is going and whether or not he/she has any suggestions or comments.
- Ask for the source of information, or for the person to share a reference with the group.
- Tell the person that you'll discuss it further after the session if he/she is interested.

The Angry or Hostile Person

You will know one when you see one. The anger most likely has nothing to do with the leader, group or anyone in the group. However, the leader and groups members are usually adversely affected by this person, and can become the target for hostility.

The following suggestions may help:

- Do not get angry yourself. Fighting fire with fire will only escalate the situation.
- Get on the same physical level as the person, preferably sitting down.
- Use a low, quiet voice.
- Validate the participant's perceptions, interpretations, and/or emotions where you can.
- Encourage some ventilation to make sure you understand the person's position. Try to listen attentively and paraphrase the person's comments in these instances.
- If the angry person attacks another participant, stop the behavior immediately by saying something like, "There is no place for that kind of behavior in this group. We want to respect each other and provide mutual support in this group."
- When no solution seems acceptable ask, "At this time, what would you like us to do?" or "What would make you happy?" If this does not disarm the person, suggest that this group may not be appropriate for him/her.

Appendix E: Tips for Group Discussion

The Questioner

This is the person who asks a lot of questions, some of which may be irrelevant and designed to stump the leader. The following suggestions may help:

- Don't bluff if you don't know the answer. Say, "I don't know, but I'll find out."
- Redirect to the group: "That's an interesting question. Who in the group would like to respond?"
- Touch/move physically close and offer to discuss further later.
- When you have repeated questions, say, "You have lots of good questions that we don't have time to address during this session. Why don't you look up the answer and report back to us next week."
- Deflect back to topic.

The Know-It-All Person

This is the person who constantly interrupts to add an answer, comment, or opinion. Sometimes this person actually knows a lot about the topic, and has useful things to contribute. Others, however, like to share their pet theories, irrelevant personal experiences and alternative treatments, eating up group time.
The following suggestions may help:

- Restate the problem.
- Limit contributions by not calling on the person.
- Establish the guidelines at the start of the session and remind participants of the guidelines.
- Thank the person for positive comments.
- If the problem persists, invoke the rule of debate: Each member has a right to speak twice on an issue but cannot make the second comment as long as any other member of the group has not spoken and desires to speak.

The Chatterbox

This is a person who carries on side conversations, argues points with the person next to him/her or just talks all the time about personal topics. This type of person can be annoying and distracting.

The following suggestions may help:

- Stop all proceedings silently waiting for group to come to order.
- Stand beside the person while you go on with workshop activities.
- Arrange the seating so a leader is sitting on either side of the person.
- Restate the activity to bring the person back to the task at hand or say, "Let me repeat the question."
- Ask the person to please be quiet.

The Crying Person

Occasionally, a group discussion may stimulate someone in the group to express their feelings of depression, loss, sorrow or frustration by crying. People cry for many reasons. They may feel that someone finally understands what it's been like, which makes them feel safe to express emotions they have been suppressing for a while. Crying is usually a release that promotes emotional healing. To allow a person to cry is helpful; it may also help to bring the group closer together providing mutual support to one another. Your role is to convey that is okay to cry, so the person does not feel embarrassed in front of the group. The following suggestions may help:

- Always have a box of tissues handy and pass it to the person.
- Acknowledge that it is all right to cry — having a health problem is difficult, then continue on with the class.
- If the person is crying a lot, one leader may want to accompany the person out of the class to see if anything needs to be done. The other leader should continue on with the rest of the group.

- Generally, if no one tries to stop the crying, within a short period of time, it will play itself out. Tension will be released and the person will feel better and the participants will feel closer to the person.
- At the break or after the session, ask if the person is okay now and if he/she needs help with anything. Reinforce to the person that crying is a perfectly normal, healthy behavior, and that he/she is not the first to cry in this class. In fact, it has happened quite often and probably will in the future.

The Suicidal Person

Rarely, you may encounter someone who is very depressed and is threatening to take his/her own life or expresses severe hopelessness or despair.

- Talk to the person privately. One professional can accompany the person out of the room, and perform a further assessment of suicide risk. Refer to the Group Health "Strategies for Managing Suicidal Patients" and the "High Risk Patient Flow Chart" from the Depression Registry, which can be located on the intranet.
- Engage Behavioral Health Services.

The Abusive Person

This is someone who verbally attacks or judges another group member.

- The following suggestions may help:
- Remind the group that all are here to support one another.
- Establish a group rule and remind everyone that each person is entitled to an opinion. One may disagree with an idea someone has but under no circumstances will personal attack be appropriate. If the abuse continues ask the person to leave.

The Superior Observer

This is a person with a superior attitude who says he/she is present out of curiosity, and that he/she already knows everything about their health and is coping well.

- The following suggestions may help:
- If the person knows a lot and is doing well, you may want to have them provide examples of what they do at selected times for the group.
- A person may also act superior if he/she feels uncomfortable and not a part of the group. If so, include him/her in some way.
- If the person wants to be ignored, then ignore them. They will get bored and leave or start to participate.

The Person in Crisis

The person in "crisis" is the one with the problems, who wants help and/or just needs to talk about these problems. The following suggestions may help:

- Listen attentively, be empathetic, use open-ended questions, and use reflective listening.
- If after five minutes it is obvious that the person will need more time to "unload," talk to person during the break or afterwards, as you will have to go on with the group activities.
- Don't take up session time and energy with the very "needy" person because it takes time away from the other participants who can be helped. Refer them to appropriate services, such as social work or behavioral health.

Satisfaction Survey
Group Visits for Children and Adolescents with Spina Bifida

Please answer the following questions about your recent group visit.

Question	Yes	No	No Opinion
a. Did you learn any new information during the group visit?			
b. Was the information provided important?			
c. Will you change the way you help your child manage his or her condition?			
d. Were you worried about your privacy during the visit?			
e. Was the length of the visit OK?			
f. Was the time of day of the visit OK?			
g. Was the place where the visit was held acceptable?			

	Regular appointments			Group visits	
	are much better	are a little better	and group visits are the same	are a little better	are much better
1. Overall experience					
2. My issues and questions were addressed thoroughly					
3. I learned about my child's condition(s) and treatments					
4. I had enough time with my providers					
5. At the end of the visit, I feel that I have a good relationship with my providers					
6. I enjoyed my visit					

Appendix F: Evaluation Measures

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
7. I would attend another group visit in the future					
8. The group visit was well-run					
9. I was satisfied with the personal attention I received from my providers					
10. The medical expert speaker improved the care of patients in the group visit					
11. The recreation program was enjoyable					
12. The information I (we) received will be helpful in the future					

Physical Activity Goal Tracker

Name: Date:

PHYSICAL ACTIVITY

Our goal for the next month is:

The steps we will take to achieve our goal are:
(What, When, Where, How much, How often, etc.)

The things that could make it difficult to achieve our goal:

Our plan for overcoming these difficulties includes:

Support/resources we will need to achieve my goal include:

Today's Date:
Our confidence level today that we can achieve goal:
(Scale of 1-10, 10 being completely confident that you can achieve the entire plan.)

1 2 3 4 5 6 7 8 9 10
Not Confident Very Confident

Fill in at next visit :

Review Date:
How successful were we in achieving our goal? (scale of 1-10, 10 being entire plan was achieved)

1 2 3 4 5 6 7 8 9 10
Not Successful Very Successful

Comments:

Physical Activity Questionnaire - Older Children (PAQ-C)

Source: *The Physical Activity Questionnaire for Older Children (PAQ-C) and Adolescents (PAQ-A) Manual*
by Kent C Kowalski, PhD
http://www.mendeley.com/research/physical-activity-questionnaire-older-children-paqc-adolescents-paqa-manual-4/

We are trying to find out about your level of physical activity from the last 7 days (in the last week). This includes sports or dance that make you sweat or make your legs feel tired, or games that make you breathe hard, like tag, skipping, running, climbing, and others.

Remember:

- **There are no right and wrong answers — this is not a test.**
- **Please answer all the questions as honestly and accurately as you can — this is very important.**

1. Physical activity in your spare time: Have you done any of the following activities in the past 7 days (last week)? If yes, how many times? (Mark only one circle per row.)

	No	1-2	3-5	5-6	7 times or more
Skipping	❍	❍	❍	❍	❍
Rowing/canoeing	❍	❍	❍	❍	❍
In-line skating	❍	❍	❍	❍	❍
Tag	❍	❍	❍	❍	❍
Walking for exercise	❍	❍	❍	❍	❍
Bicycling	❍	❍	❍	❍	❍
Jogging or running	❍	❍	❍	❍	❍
Aerobics	❍	❍	❍	❍	❍
Swimming	❍	❍	❍	❍	❍
Baseball, softball	❍	❍	❍	❍	❍
Dance	❍	❍	❍	❍	❍
Football	❍	❍	❍	❍	❍
Badminton	❍	❍	❍	❍	❍
Skateboarding	❍	❍	❍	❍	❍
Soccer	❍	❍	❍	❍	❍
Street hockey	❍	❍	❍	❍	❍
Volleyball	❍	❍	❍	❍	❍
Floor hockey	❍	❍	❍	❍	❍
Basketball	❍	❍	❍	❍	❍
Ice skating	❍	❍	❍	❍	❍
Cross-country skiing	❍	❍	❍	❍	❍
Ice hockey/ringette	❍	❍	❍	❍	❍
Other: _____	❍	❍	❍	❍	❍
Other: _____	❍	❍	❍	❍	❍

2. In the last 7 days, during your physical education (PE) classes, how often were you very active (playing hard, running, jumping, throwing)? (Check one only.)

- I don't do PE ❍
- Hardly ever ❍
- Sometimes ❍
- Quite often ❍
- Always ❍

3. In the last 7 days, what did you do most of the time at recess? (Check one only.)

- Sat down (talking, reading, doing schoolwork) ❍
- Stood around or walked around ❍
- Ran or played a little bit ❍
- Ran around and played quite a bit ❍
- Ran and played hard most of the time ❍

4. In the last 7 days, what did you normally do at lunch (besides eating lunch)? (Check one only.)

- Sat down (talking, reading, doing schoolwork) ❍
- Stood around or walked around ❍
- Ran or played a little bit ❍
- Ran around and played quite a bit ❍
- Ran and played hard most of the time ❍

5. In the last 7 days, on how many days right after school, did you do sports, dance, or play games in which you were very active? (Check one only.)

- None ❍
- 1 time last week ❍
- 2 or 3 times last week ❍
- 4 times last week ❍
- 5 times last week ❍

6. In the last 7 days, on how many evenings did you do sports, dance, or play games in which you were very active? (Check one only.)

- None ❍
- 1 time last week ❍
- 2 or 3 times last week ❍
- 4 or 5 times last week ❍
- 6 or 7 times last week ❍

7. On the last weekend, how many times did you do sports, dance, or play games in which you were very active? (Check one only.)

- None ❍
- 1 time ❍
- 2 - 3 times last week ❍
- 4 - 5 times last week ❍
- 6 or more times ❍

8. Which one of the following describes you best for the last 7 days? Read all five statements before deciding on the one answer that describes you.

A. All or most of my free time was spent doing things that involve little physical effort .....❍

B. I sometimes (1 — 2 times last week) did physical things in my free time (e.g. played sports, went running, swimming, bike riding, did aerobics).....❍

C. I often (3 — 4 times last week) did physical things in my free time .....❍

D. I quite often (5 — 6 times last week) did physical things in my free time.....❍

E. I very often (7 or more times last week) did physical things in my free time .....❍

9. Mark how often you did physical activity (like playing sports, games, doing dance, or any other physical activity) for each day last week.

	None	Little bit	Medium	Often	Very Often
Monday	❍	❍	❍	❍	❍
Tuesday	❍	❍	❍	❍	❍
Wednesday	❍	❍	❍	❍	❍
Thursday	❍	❍	❍	❍	❍
Friday	❍	❍	❍	❍	❍
Saturday	❍	❍	❍	❍	❍
Sunday	❍	❍	❍	❍	❍

10. Were you sick last week, or did anything prevent you from doing your normal physical activities? (Check one.)

Yes .....❍

No .....❍

If Yes, what prevented you?

Service Learning Pre/Post Test

Dear Student:

We are conducting a survey to ***determine the impact of interacting with medical professionals in the "Fit Families Group Visit" program for children and adolescents with spina bifida.*** The survey was developed by Davis, Foley, Columna (2008). Participants will complete the survey prior to the initial visit and again after the visitations are completed. Data will consist of the participants' responses to the survey questions. No identifying information (i.e., names, e-mail, IP addresses, etc.) will be collected.

Drawing from your past experiences, we would like to invite you to provide comments on the survey. Here is what we want you to do:

1. Please take the survey that was distributed to you. Read carefully each survey item.
2. Make an "X" in the box that best describes your opinion about the relevance of each survey item to the purpose of the study.
3. Make any additional thoughts or comments about the survey item in the space provided.
4. Finally, return the survey before you participate in the group visitation activities.

Survey Item

1. What is your gender M F

2. What is your age ___ years

3. What is your student status? ___ Undergraduate ___ Graduate

4. Have you participated in a group visit program in the past? Y N

5. Does your state have an approved credential and/or endorsement validation in Adapted Physical Education? Y N

6. What degrees have you earned, and in what area of study (list below)

Appendix F: Evaluation Measures

Tell us what you would say about teaching a student with spina bifida who is a wheelchair user in your Physical Education class. In the questionnaire you are about to complete, we ask questions that make use of rating scales with seven places; you are to make a mark (X) in the place that best describes your thoughts. For example, if you were asked about "The weather in Southern California" on such a scale, the seven places would appear as follows:

The Weather in Southern California is good

Strongly Agree_____:_____:_____:_____:_____:_____:_____**Strongly Disagree**

If you strongly agree that the "Weather in Southern California is good" then you would place your mark as follows:

The Weather in Southern California is good

Strongly Agree X :_____:_____:_____:_____:_____:_____**Strongly Disagree**

1. Generally speaking, it would be difficult to find activities to include a student who was a chair user.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

2. Generally speaking, I feel that I have enough experience in working with students with spina bifida.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

3. Generally speaking, I would do what parents of students with spina bifida think I should do.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

4. Generally speaking, I would do what the medical doctors serving the student with spina bifida think I should do.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

5. Generally speaking, I would do what the principal of students with spina bifida think I should do.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

6. It is a good idea for me to take additional courses at a university or through an inservice program to learn more about how to teach a student with an spina bifida who is a chair user.
   Strongly Agree_____:_____:_____:_____:_____:_____:_____***Strongly Disagree***

11. Please complete the following definition:

Group Visitation Model Definition	
a.	The medical group visitations were developed to:

Comments:

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Fit Families Group Visits

Spina Bifida Center of CNY
SUNY UPSTATE Golisano Children's Hospital
Syracuse, NY 13210
315.464.6395