

How to Implement and Maintain an Exceptional Evening Out Program
For Children with Disabilities and their Caregivers

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This project, submitted by Devon Gere, has been approved and accepted
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Abstract

Families of children with disabilities report a need for opportunities to attend to leisure interests and other responsibilities free from their children. Therefore the Exceptional Evening Out Program was developed and implemented at a local YMCA. The purpose of this program was to provide parents/caregivers with an evening out while simultaneously providing the children with disabilities an opportunity to practice and reinforce key developmental skills. The pilot Exceptional Evening Out Programs occurred monthly over 6 months and were staffed with volunteer occupational and physical therapy students as well as YMCA staff members. Activities were set up that focused on gross motor, fine motor, social, and sensory skill development. A manual was created to provide information on planning, implementing and sustaining the program in the current community as well as other communities that may desire to start such a program.

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Purpose Statement

The purpose of this project was to create and implement an evening leisure program at the Lakewood, WA YMCA for children with disabilities in order to enhance skill acquisition and social participation while providing a respite period for their caregivers.

Literature Review

Family and Caregiver Impact

In 2004, within Washington state alone, 1,700,265 children and youth were faced with at least one disability (Washington Department of Health, 2004). In addition, researchers have estimated that for every 250,000 people, approximately 25 of them will be children with disabilities (Mental Health Foundation, 1997, as cited in Wodehouse & McGill, 2009). Up to 9.3% of children under the age of 18 have a diagnosed neurodevelopmental disability (Center for Disease Control, 1991, as cited in Lach et al., 2009).

It doesn't matter how it is categorized, the number of children with disabilities in this country is profound. An illness or condition is not a solitary experience for a child and statistics do not take into account all of the people that each disability impacts. To glean a more complete understanding, the families and caregivers of the children must also be counted. Caregivers likely take the child to appointments, aide in daily care activities, interact with school personnel, provide heightened support for the child, and care for the child in a myriad of other ways. All of these activities can take a toll on the entire family and therefore respite and specialized care offers a much needed break (Strunk, 2010; Palisano et al., 2009). Respite provides the child an opportunity to interact with other support providers and, possibly, other children. In addition, caregivers can benefit from the brief amount of free time to attend to the multitude of other

responsibilities they have (Raina et al., 2005). The problem is that there are not very many options and those that are available tend to be offered during business hours on weekdays (Murphy, Christian, Caplin, & Young, 2006).

Parents and caregivers have indicated that respite and specialized care would be helpful. They often feel that they do not have enough time and attention to devote to the variety of tasks they must juggle: other family members, spouses/significant others, housework, jobs, and perhaps most importantly, themselves. Parents in a number of studies have reported reduced quality of life, physical, and emotional well-being as a result of full-time caregiving (Sawyer et al., 2010; Byrne, Hurley, Daly & Cunningham, (2010). In fact, research shows that caregivers of children with disabilities spend less time on their own health than parents of typically developing youth which results in an increase in poor health indicators (Raina et al., 2005).

A number of studies have looked specifically at the type of health burdens that most often emerge with being a primary care giver for children with disabilities. These studies have pinpointed both psychological health and physical health as two of the most impacted (Byrne et al., 2010; Lach et al., 2009; Raina et al., 2005; Sawyer et al., 2010). Some physical conditions that were commonly identified by caregivers include chronic health concerns such as asthma, back pain, migraine headaches, and arthritis (Lach et al., 2009).

Psychological well-being of caregivers is another area that studies have focused on. Research shows that the more time the caregiver must spend providing care, the lower the overall psychological health (Petrie & Poland, 1998; Byrne et al., 2010). That is to say, when not provided with adequate breaks from caregiving, the psychological health of primary caregivers decreases (Byrne et al., 2010). In addition, the mental health of caregivers of children with disabilities is poorer than that of caregivers of typically developing children. Lach et al. (2009)

collected statistically significant evidence that showed an increase in stress and depression in caregivers of children with behavioral and/or neurodevelopmental diagnoses as compared to those caring for children with neither diagnosis. In addition to the impact of the actual diagnosis, Lach et al. (2009) found that the perception of lack of social support also contributed to increased rates of depression among the caregivers of children with disabilities. This finding indicates that even perceived social support, such as respite or specialized care, may increase the psychological health of the parents.

Findings of these studies support the fact that there is a need and demand for a specialized evening care program (Doig, McLennan & Urichuk (2009); Murphy et. al., 2006; Palisano et al., 2009; Strunk, 2010). Caregivers can benefit, both emotionally and physically, from the ‘break’ that respite provides. Specialized care gives a time period for caregivers to address their own health and help ensure that they are in the best position to continue providing care (Kuhlthau, Kahn, Hill, Gnanasekaran & Ettner (2010). It allows for time with other family members when perhaps there usually is not enough and gives parents a chance to do something as simple as taking a shower or going out on a date night. It is clear that respite positively impacts the quality of life for families of children with disabilities.

Respite and Evening Care

When asked what form of care would be most beneficial, caregivers indicated ‘off-time respite care’ (Murphy, et al., 2006). This term specifies everything outside of regular business hours during the week. Specifically, caregivers were interested in evening and weekend options. Special needs-specific care was also listed as important. Parents wanted to be sure that those providing respite services were familiar with working with children with disabilities because, for many of the cases, a ‘normal baby sitter’ wasn’t able to provide the quality and type of care

needed (Damiani, Rosenbaum, Swinton & Russell (2004); Doig et al., 2009; Murphy et al., 2006).

Caregivers in a number of studies expressed frustration that access to respite care was difficult to obtain. Very few community clinics, websites, etc., had contact information or suggestions for local respite care options (Damiani et al., 2004; Doig et al., 2009; Murphy et al., 2006) and many parents indicated that they did not have any idea of where to begin looking for possible care options on their own (Doig et al., 2009; Murphy et al., 2006). Over 50% of the parents surveyed in one study expressed a need for knowledge on current and future options for their child, more personal time, and help finding community respite centers to alleviate some of the stress the families were feeling (Palisano et al., 2009). In many areas, the alternative to community care is to look through nanny or childcare websites searching for a provider with experience in working with children with disabilities. The care is designed to be in-home and family specific. Subsequently, it does not increase social interaction and relationship development between children as a community-based program would. Parents have indicated that fostering social skills is an important component of choosing respite care for their children (Doig et al., 2009).

In the South Puget Sound region, there are only a handful of daycares, nurseries, and childcare options that specialize in working with children with disabilities. When an online search was performed, it was challenging to find more than seven in the entire area. In addition, only one pediatric therapy location provided a monthly evening care program. These options likely do not meet the needs of the entire community.

Child Benefits

Caregivers are not the only ones who can benefit for specialized weekend care. Research has indicated that parents and guardians want their child with disabilities to feel a sense of self-efficacy, independence, and social competence. It has also been found that adaptive activities provide their participants with a sense of self-worth (Mazzoni, et. al. (2009). In addition, Blinde and Taub (1999) found that participation in a sports-oriented social group increased social integration, social competence, and goal attainment for participants. Studies also indicate that participation in after-school adaptive sports program facilitated competence and gross motor development and social interaction/connectedness (Groff & Kleiber, 2001). This social confidence booster and opportunity to increase a variety of skills plays an integral role in the desire to continue using the service which, ultimately, benefits both child and caregivers.

The focus over the last several years has been on inclusion in schools and community settings such as Boy Scouts and dance classes. The concept of inclusion, of placing children with disabilities with typically developing peers, can result in a child not having a place where they feel like they can be themselves, where they feel normal, where there are other kids with disabilities – just like them. Research shows that being involved with a group of like-peers with disabilities results in feelings of belonging, understanding, and camaraderie (Goodwin and Staples, 2005). The Exceptional Evening Out program provides a safe haven to build that camaraderie and comfort with other children with disabilities. It allows each child to share their story with others and to increase awareness of other disabilities and conditions within the world of disability. Not only is this helpful and beneficial between guests, providing information and getting to know the volunteers creates an opportunity for the children to practice social skills and for the volunteers to learn more about the child behind a diagnosis and how individual and

unique each person is. Social benefits of the program include child/child interaction along with volunteer/child interaction. It allows all participants to increase knowledge about each other and a chance to build a sense of belonging, camaraderie, and make friends.

Exceptional Evening Out

The Lakewood, WA YMCA provided an optimal space for the evening care program. With its adaptive programming in place, there was already an interest and need specified for events like the Exceptional Evening Out (EEO) program. On a monthly basis, the Lakewood 'Y' had an event called 'Kids' Night Out' where typically developing children and youth stayed overnight. Because of the well-established presence of this activity, the 'Y' already had key supplies on hand. In addition to supplies, the facility itself was conducive to this project. The therapy pool was a child favorite and a wonderful way to work on stretching, balance, and endurance. There was a large gymnastics gym complete with a foam pit, a long trampoline, and brightly colored, oddly shaped objects that allowed for play and exploration in a safe environment. Two gyms, four racquetball courts, multiple dance/yoga studios, a nursery, and a boardroom perfect for pizza parties and movies, added to what the location had to offer.

The Lakewood 'Y' already had a number of adaptive programs including swimming, open-gym, and Special Olympics for children and youth with disabilities that met on weekdays and Saturdays during the day. However, they did not have an evening program that would allow for caregivers to have a break for a few hours. Christine Daly, the Adaptive Activities director at the Lakewood, WA YMCA was interested in, and actively pursuing, increasing the options of the center's adaptive programming. She had the opportunity to ask parents and caregivers of children with disabilities what else they would like offered at the YMCA. The answer: a Saturday evening where they could share time with loved ones and/or attend to other roles while

knowing their child with a disability was supported and playing with like-peers. (C. Daly, personal communication, February 20th, 2011).

Talking with the parents and guardians of children already enrolled in the adaptive programs indicated clear that they shared the same feelings of frustration and fatigue as caregivers expressed in the studies previously discussed. When asked, all voiced interest in knowing more about the program and hope that it would begin soon. They spoke of the need for a program that would benefit both their children and their families and of the fact that they struggled to find respite options on their own. When combining the expressed need with the physical layout of the facility, the supplies that were already in place, and the research that showed the benefits of off-hours respite care, the Exceptional Night Out program was feasible as a sustainable and viable option for caregivers seeking off-hours care.

Implications for Occupational Therapy

A program such as the Exceptional Evening Out event is within the scope of practice of occupational therapy. It attended to the parents' rest and leisure areas of occupation as described in the Occupational Therapy Practice Framework, 2nd ed. (AOTA, 2008). It also encouraged development of the children's' play and social interaction skills. In addition, the use of adaptations and grading for activities helped meet each client's needs and abilities. Occupational therapists are trained to look at atypical behavior, movement, play, and social interactions, and then provide interventions to facilitate independence and functionality (AOTA, 2008). By providing customization of activities, a program that allows caregivers to attend to their rest and leisure areas of occupation, and an opportunity for children with disabilities to socialize and

engage in the occupation of playing with like peers, the Exceptional Night Out was well within occupational therapy's scope of practice.

The Exceptional Evening Out program provided a unique and beneficial experience with a focus on skill development to support occupational performance for the children who participated. The skill areas included play, feeding, dressing, social skill development, sensory modulation, fine motor, and gross motor skills. By utilizing a variety of different activities with different components, the program was able to attend multiple areas of occupation in a unique way for each child.

The parents and caregivers of the children who attended the event benefitted from an opportunity to engage in a slightly different area of occupation. For them, the goal was to do whatever they chose during a three hour respite period. Several areas of occupation and performance skills that were explored include: leisure, rest and sleep, social participation, ADL, IADL, rules, habits, and routines. As part of the 'evening off-duty', caregivers had the freedom to choose how to spend their time. Whether it was taking a shower, catching up on a favorite book, cleaning the kitchen, or going out to eat, the time was theirs to use as they pleased while their children had fun, explored, and interacted in a safe, supportive environment.

Occupational therapy students and other volunteers benefitted from volunteering at the Exceptional Evening Out event. They had a hands-on opportunity to interact with children with disabilities, gained an understanding of how various disabilities manifest in each person individually, and had fun. At a point when students are still discovering various aspects of occupational therapy, what it means to be client-centered, and what area of practice they would like to work in the future, this program provided a perfect match to the need of the families with children with disabilities.

The rationale and components of the Exceptional Evening Out program supported the Person-Environment-Occupation model (PEO model). This occupational therapy model was created by Cooper, Law, Letts, Rigby, Stewart, and Strong in the early 1990's, and sought to base therapy, assessments, and interventions on the complex interrelations of a person/s, the environment, and the occupations to be completed within that setting (as cited by Law & Dunbar, 2007). It is impractical to look at any of the three parts on their own as none function independently. The client is affected by his/her environment. The environment's characteristics impact the occupation. In essence, the three are completely interconnected and the PEO Model looks to provide intervention at the point where they all overlap, indicating increased participation in occupation (Law & Dunbar, 2007). When the fit among person, task, and environment is appropriate and all aspects are supported, there is increased likelihood that meaningful occupations will be able to occur (Law & Dunbar, 2007).

The PEO Model was used to guide the scaffolding of the environment and task for a child at the YMCA to ensure success in the meaningful occupation. The ability to view each component separately and adjust as needed made this model a good fit for this project (Law & Dunbar, 2007). It served as a perfect theoretical background for addressing various situations that came up during Exceptional Evening Out events.

The 'P' (persons) in the Exceptional Evening Out program were actually two 'persons' – both the child with disabilities who received the care, and their parents who got a much needed respite during a time that few other acceptable options existed. For the children who attended the event, play exploration and participation were incorporated along with social participation. For some of these children, interacting with other children with disabilities in a play environment was a rarity and a skill that they had not had the opportunity to attend to yet. By providing new

and novel forms of play in a safe and social environment, the program allowed for children to address at least two different important areas of occupation.

Another fundamental component of the PEO Model that influenced the EEO Program was the 'E' (environmental) impact. The different environmental setting included a quiet, private room for dinner, crafts, and movie watching to take place, a large gym for gross motor games, and a gymnastics gym that also addressed gross motor skills and endurance through different activities. The goal of using the variety of spaces was to support each child's ability to perform different tasks and skills in the most supportive environment as well as across environments. We based the length of time we spent in each room on how the children were responding and handling the activity and environment and attempted to modify each space to be more conducive to the success of the child. By managing the environment and how each child was able to interact with it, we were able to help ensure a 'just right' fit that encouraged skill growth and social skills.

The last part of the PEO Model, 'O' (occupation), was where the majority of adaptation and 'just right fit' occurred. Volunteers and staff members were able to customize and adapt activities to best benefit each child in their skill growth and social participation. Whether it was scaffolding an art project to provide additional support for cutting and gluing, or encouraging the children to work together during group games, every activity was designed and customized to fit the needs of each child. Because occupational therapy and the PEO Model focus so much on the 'just right fit', the impact of the night appeared to be beneficial for caregivers, children, and volunteers.

Procedures

Beginning this project required first connecting with a community organization that would share my plan and had the capability to host and facilitate it. Finding what I needed in the adaptive programming at the Lakewood Family YMCA, I began working with Christine Daly, the adaptive programs director. She was supportive and instrumental in helping to launch the program from the YMCA's side.

After developing a plan for the event, volunteers and participants were recruited. I asked University of Puget Sound occupational and physical therapy classmates to assist. They reported after the events that they had been a lot of fun and a good opportunity to see diagnoses that we've learned about in class. Recruiting children was also a fairly simple process thanks in large part to Christine's work. With adaptive programs already in place at the Lakewood YMCA, it was easy to promote the Exceptional Evening Out programs within these groups. In addition, fliers were placed at local occupational therapy clinics, including the student therapist clinic at the University of Puget Sound. These locations provided exposure but it is unclear if their placement resulted in someone signing up.

Spaces at the YMCA that we wanted to use were reserved and the schedule for the evening was planned and established around the room availability. The first event was a success both in how it actually went and also in the amazing learning experience. Afterwards we were able to review how the evening had gone and acceptable revisions to make for the next event. We found that a minimum of a 1:1 ratio of staff to child was important in managing the event and that informing caregivers of the date of the next event was valuable information to give when they came to pick up their child at the end of the night. The same procedure of

implementation and reflection was followed for the subsequent EEO events. It appeared that the overall quality and flow of the evening got better with practice.

Finally, a sustainability plan was established. This was done in the form of a program manual that provides suggestions to maintain interest, introduce other adaptive programs, market the event, and implement caregiver feedback to better the event.

Planning and implementing the EEO program required an understanding of the resources available, components of marketing the program, and ways to incorporate the concepts of occupational therapy into the activities to support the participants' success and growth. In addition, the success of the program required taking inventory of the supplies, resources, and likely costs associated with implementing each event. A \$5 donation per family member was suggested to cover supplies for the craft for the following event and found that it was enough money to pay for supplies and to put towards further adaptive items such as looped scissors and dynamic seating options. As time passed, my understanding of the needs of the program, those individuals involved, and future goals increased. After the initial implementation phase was over, I felt that I had a better grasp of the components of the program and the required skills and resources to successfully complete each step.

Products

The implementation of Exceptional Evening Out events and the corresponding manual were the two 'products' of this program. The manual provides information regarding how to properly prepare to run a program, supplies and space needed, how to recruit both volunteers and children to participate, activity ideas, and sustainability plans. The manual also provides a list of simple and inexpensive adaptations that could be made to support each child. In addition, the

manual contains components of this thesis to serve as supporting evidence for writing a grant, explaining the need to organization leaders, and highlighting benefits to the parents and caregivers. Sample forms for various components of the program were included as well.

Outcome

The implementation of the Exceptional Evening Out program was successful and most of the original goals and objectives were met.

Goal 1: After reading the sustainability manual for the Exceptional Night Out program, employees and volunteers with the Lakewood YMCA will be able to run a Night Out event successfully.

Objective 1: After reading the activities section of the manual, staff will be able to lead 3 different activities during the evening of the event. (An activity is considered: a beading activity, basketball game, etc.)

Objective 2: After reading the activities and grading section of the manual, staff will describe at least 3 different difficulty levels at which to grade the activity so as to accommodate as many children as possible.

Objective 3: After reading the activities section of the manual, staff will be able to describe at least 2 common adaptations for an activity to help the children succeed at the task.

Progress: while the manual has not been given to the YMCA yet, the ability of volunteers and staff to participate in, lead, and adapt activities over the course of the EEO programs suggests that the goal is close to being met.

Goal 2: After reading the sustainability manual for the Exceptional Night Out, employees and volunteers with the Lakewood YMCA will have knowledge of how to maintain and sustain the program.

Objective 1: After reading the sustainability section, staff will demonstrate an understanding of the tasks that need to take place in order to implement the 1 year plan as outlined in the manual. Staff will begin by implementing steps 1-3.

Objective 2: After reading the section with suggestions from parents and caregivers, staff will identify and implement a minimum of 2 adaptations to the program in order to better serve clients' needs.

Progress: The accompanying manual that will be given to the YMCA contains a large section of information for the sustainability component of a program such as the EEO Program. Caregivers have already expressed a wish that the programs will be continued and I anticipate that the sustainability section of the manual will be of benefit.

Goal 3: By April, 2012, An Exceptional Night Out will be implemented and regularly occurring event at the Lakewood, WA YMCA.

Objective 1: To ensure successful implementation and sustainability, a minimum of 3 official Night Out events will have been held by April, 2012.

Objective 2: To ensure successful implementation and sustainability, each Exceptional Night Out will average a minimum of 8 guests and/or show a general growth trend by April, 2012.

Objective 3: To ensure program satisfaction, a survey for caregivers will have been given and three goals for implementing their feedback will be outlined by April, 2012.

Progress: A total of 6 events were held between October of 2011 and April of 2012. On average, each event had 8 participating children had more volunteers than children present which helped to ensure a well-managed evening. A survey was not given to caregivers but a blank sample is included in the manual for future feedback.

In addition to the impact the program can make for children with disabilities and their caregiver, it's important to consider the impact on volunteers who help make the program possible. Volunteers indicated that helping out with the program was not only a fun experience, but that it also provided a lot of valuable information applicable to both occupational and physical therapy. The volunteers were able to use their knowledge of adaptation and levels of assistance to appropriately adapt crafts and activities to the skill levels of each child. The craft component of the evening was a time that the ratio of volunteers to children was especially important and contributed to a successful evening.

The program had a number of children who came multiple times, suggesting that both caregivers and children enjoyed and benefited from the experience. Parents indicated that the EEO program was an especially valuable time for them and, when picking up their children at the end of the evening, often asked when the next event was going to be. In addition, the manual supported the EEO program by providing adaptations and grading options for a number of activities that staff members could continue to utilize – not just in the context of the evening program but also in other adaptive programs at the Lakewood YMCA.

In general, goals were successfully met. The component of the goals describing the ability of staff to lead activities was not addressed during the events. Because the manual was not completed until after the last event, it has yet to be utilized by a volunteer of YMCA staff member to successfully run the event. Goals focused on knowledge of sustainability were

addressed in the accompanying manual that provides information regarding how to continue the program, what is needed, ways to continue to recruit guests and volunteers, and templates of documents and information to help with the maintenance of the event.

Limitations

Every program and project has limitations and areas for improvement. For the Exceptional Evening Out event, limitations included ensuring that we had enough people – both volunteers and children. Despite promoting the event at the University of Puget Sound on-site pediatric occupational therapy clinic for over a month, there was not a corresponding increase in attendance for the EEO program and other adaptive programs that the Lakewood YMCA offers. It is however, important to note that a lot of publicity and promotion is necessary to initially compel people to come to an event. After that first experience though, it's much easier to get buy-in and have individuals return. That principle was seen with the EEO program in the fact that after a family participated for the first time, they generally returned for a subsequent event.

Ensuring that there were enough volunteers was another difficult aspect of running the program. Because at least a 1:1 ratio of volunteer to child was required, it was tricky to find out how many children were supposed to be coming and then ask people to assist or to not bother coming at the last minute. In addition, one of the events was held on St. Patrick's Day which also marked the end of the University of Puget Sound's spring break. This made it especially challenging to obtain volunteers who were willing to help and in the area.

Overall, the only two big limitations or challenges were managing volunteers and children and making sure that the ratio was maintained to ensure that each child was well taken care of and received the care they required.

Recommendations

As the 2011-2012 school year comes to a close, a few simple steps need to be taken to help ensure the sustainability and continuation of the Exceptional Evening Out program at the Lakewood YMCA. It will be important that Christine Daly, director of aquatics and adaptive sports, have a copy of the EEO manual. In it, specific recommendations on sustainability procedures are detailed. Along with providing Christine with the manual, it is also important to continue promoting the Y's adaptive programs at the University of Puget Sound with students who will be in the area over the summer and/or plan to return to that school in the autumn semester. By increasing interest now, classmates can begin to consider if they'd like to assist or even take over planning and implementing the program. The only way it can be sustainable is if numerous people from the YMCA, University of Puget Sound, and local community members all work together for a common goal. While it may seem daunting at times, the project's benefits far outweigh the difficulties.

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Human Resources

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