

EFFECTS OF INCREASED MOBILITY SKILLS ON MEANINGFUL LIFE PARTICIPATION FOR AN ADULT WITH SEVERE MULTIPLE DISABILITIES

STACIE B. WHINNERY AND KEITH W. WHINNERY

University of West Florida

Author Note

Stacie B. Whinnery and Keith W. Whinnery, School of Education,
University of West Florida.

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Correspondence concerning this article should be addressed to
Stacie B. Whinnery, School of Education, Building 85, Room 169,
University of West Florida, 11000 University Parkway, Pensacola,
FL 32514. E-mail: swhinnery@uwf.edu

ABSTRACT

This article presents a case study of an adult with severe, multiple disabilities and discusses issues affecting meaningful life participation. Emphasis is placed on the role of functional mobility skills to increase active engagement in age-appropriate activities and opportunities to make informed choices. MOVE for Adults (Mobility Opportunities Via Experience) is presented as a program designed to improve functional mobility in order to increase active participation and choice making in meaningful life activities. The impact of the MOVE for Adults program is presented.

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Francie (pseudonym) is a 49 year old woman who spent the majority of her life in a state institution for individuals with developmental disabilities. For the past 14 years, she has lived in a group home and attended a day habilitation program for adults with developmental disabilities. Francie is diagnosed with spastic quadriplegia, profound intellectual disability, obesity with high blood pressure, chronic constipation, and oppositional defiance disorder. Francie's preferred daily activities are rocking back and forth while in her wheelchair, playing with a shoestring tied to the chair, and looking out the window. Staff reports indicate that Francie becomes upset with changes to her typical daily routine and frequently becomes physically aggressive and yells. This is particularly true during transfers to the changing table for hygiene care. Staff use mechanical lifts and four-person lifts, but both approaches are problematic. Staff report difficulty working with Francie due to her inappropriate behaviors and large size. Consequently, some staff sustained on-the-job injuries and have been placed on permanent disability. As a result, there is frequent staff turnover and inconsistent programming for Francie.

This snapshot of Francie's life two years ago is representative of many adults with severe, multiple disabilities who live passive lives. Throughout history, programming for adults with developmental disabilities has focused more on caretaking than habilitation (Mary, 1998). In the mid twentieth century, adult programming was based on a Medical Model in which individuals with disabilities were viewed as having an illness needing direct, intensive intervention so that when "cured", the individual could return to society. However, since many individuals with disabilities were not seen as curable, most individuals did not return to society. By the 1970's with the advent of the Developmental Model, there was a shift in thinking from "patients & cures" to "clients & treatment". With the Developmental Model, treatment addresses the identification and remediation of skill deficits. This hierarchical approach emphasizes mastery of prerequisite skills typically resulting in isolated instruction on *age-inappropriate* skills (Barnes & Whinnery, 2002; Horn, 1991; Valvano, 2004). Consequently, programming lacks relevance and individuals make few gains, often working on the same goals year after year. Learners seldom reach the level of "readiness" (i.e., achievement of hierarchical developmental skills) deemed necessary to address functional life skills.

The influence of this model continues today. Many adults with developmental disabilities continue to spend too much time in passive, nonfunctional activities (Parsons, Rollyson & Reid, 2004; Reid, Parsons, & Green, 2001).

Also, adult programming typically provides limited access to age-appropriate activities (Singh et al., 2004), limited opportunities to make choices, and infrequent community integration (Certo et al., 2003; Clement & Bigby, 2009; Metzel, Boeltzig, Butterworth, Sulewski & Gilmore, 2007). Leisure activities tend to be passive with many days spent watching TV and videos, sitting in front of books/magazines, and manipulating objects without meaningful engagement in tasks or social interactions.

This situation can be even more bleak for individuals like Francie with severe, multiple disabilities, including mobility impairments. Limited mobility and compounding secondary disabilities and health issues typically result in more emphasis on caretaking than on habilitation. These individuals must rely upon others to help them move around their environments and engage in life activities. An emphasis on caretaking over habilitation typically leads to long hours of passive positioning with little interaction with others and few opportunities to make choices.

This was true in the case of Francie. In her earlier years, Francie had the ability to maneuver her own wheelchair and independently transfer in and out of her chair and onto the toilet. She was using the toilet regularly and was continent. However, over a seven-year period, Francie had several short-term medical issues, gained a great deal of weight, and lost many of her previous skills. She lost the ability to transfer, stopped using the regular toilet, and was put into adult diapers. Little effort was made to rehabilitate lost skills as these were viewed as a result of her disability and the aging process. Over time she continued to gain weight, developed secondary health issues (i.e., hypertension and chronic constipation), and became withdrawn, dependent, and aggressive toward others. At the time of this case study, Francie's days were typically passive with little to no interaction with others and infrequent opportunities to actively participate in meaningful life activities.

In an attempt to improve programming for adults with developmental disabilities, emphasis has been placed on supporting individuals to be active participants in life activities based on personal preferences (Barnes, 1999; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Wilson, Reid, & Green, 2006). Research addressing programming needs of adults focuses on two important components. First, to be effective, adult programming must include opportunities for *active participation in relevant, age-appropriate activities*. Age-appropriate activities that are meaningful create opportunities to learn and practice functional skills. This is in contrast to passive, nonfunctional, and/or age-inappropriate activities which tend to be void of learning opportunities (Dyer, Schwartz, & Luce, 1984; Kleinert & Kearns, 1999). This passive lifestyle is typical for individuals with severe, physical impairments who are very reliant upon others for all aspects of their day. Within everyday

30 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

activities, adult learners should be assisted to move beyond passive observation and to engage in meaningful ways (McDonnell, Thorson, McQuivery, & Kiefer-O'Donnell, 1997; Wilson et al.). Meaningful engagement implies that the person is participating to the fullest extent possible and is being challenged to contribute to the completion of the activity. Active participation has become a "best practices" indicator for adult programs (Billingsley & Kelley, 1994; Felce & Emerson, 2000; Kleinert & Kearns).

A second element of effective programming for adults with severe disabilities is related to *opportunities to make choices*. Choice-making opportunities have been shown to reduce challenging behaviors (Dyer, Dunlap, & Wintering, 1990), increase motivation (Foster-Johnson, Ferro, & Dunlap, 1994), improve work productivity (Mithaug & Mar, 1980), and increase task engagement (Dyer et al., 1990). Unfortunately, individuals with severe disabilities typically have few choice-making opportunities (Antaki, Finlay, Walton, & Pate, 2008; Reid, Green, & Parsons, 2003). Frequently it is easier and more efficient for others to make choices for them. When staff attempt to determine preferences they often rely upon facial expressions and vocalizations (Green & Reid, 1996; Green & Reid, 1999). Unfortunately, these can be easily misinterpreted (Finlay, Walton, & Antaki, 2008; Grove, Bunning, Porter, & Olson, 1999). Finlay et al. found that in some cases choice-making opportunities for adults in residential facilities tended to be disempowering with limited choice options and a lack of sensitivity to non-verbal methods of communicating.

While limited opportunities for choice-making is a common concern for all individuals with severe, multiple disabilities, this is a significant barrier for individuals with mobility impairments. Individuals with mobility impairments who are unable to explore their environment have decreased opportunities for choice making and active participation. These individuals spend the majority of their days in passive positions with little interaction beyond caretaking, thus limiting choice options and opportunities. When preferences are expressed, they are typically subtle, non-verbal communications that are difficult to interpret and easily overlooked. In other cases, what appear to be choices are actually responses to the closest or most recognizable object (Finlay et al., 2008). For these individuals, programming should emphasize the development of mobility skills to improve active engagement and choice-making opportunities.

Mobility, or being in an upright position and moving oneself, provides greater access to life activities and better opportunities for active participation. The physical activities of standing and walking have been shown to prevent chronic disease, increase independence, improve overall health, and improve quality of life for adults with disabilities (Cress et al., 2006). Walking or

standing increases the amount of verbal interaction from care providers (Duker et al., 1989) and being ambulatory increases active participation (Cress et al.). However, the development of mobility skills requires skill training and direct support.

While adults with severe physical disabilities require more support from staff to engage in activities, research on caregiver support has shown that more able users typically receive more assistance than less able users (Bradshaw et al., 2004; Seys, Duker, Salemink, & Franken-Wijnhoven, 1998). Specifically, Seys and associates found that staff provided less support to individuals with limited motor skills and ambulation. Given the strong influence of ambulation, they concluded that “teaching residents to walk or, if neurological and muscular constraints prohibit this, having them spend time in an upright position during large parts of their day may contribute to their well being” (p. 271). Cress and associates (2006) caution that knowledge of these benefits is not enough to increase active support. A systematic way is needed to plan support that is designed to overcome mobility barriers, thus facilitating more active participation in life.

MOVE FOR ADULTS

MOVE for Adults (Mobility Opportunities Via Experience) is a systematic program designed to provide adults with developmental disabilities opportunities, support, and skills to participate fully in a life of their own choosing (Whinnery & Whinnery, 2009). It accomplishes this through the use of meaningful activities to encourage upright postures and the development of basic mobility skills needed for exploring environments, participating in activities, and making informed choices based on personal goals and desires.

MOVE for Adults[®] was adapted from the MOVE Curriculum[®] (Mobility Opportunities Via Education) (Kern County Superintendent of Schools, 1999) which was developed to address the needs of students with severe, multiple disabilities in school settings. The MOVE Curriculum was created in response to the shortcomings of traditional developmental approaches and has been shown to be effective for increasing functional mobility skills for children with severe disabilities (Barnes & Whinnery, 2002; van der Putten, Reynders, Vlaskamp, & Nakken, 2004; Whinnery & Barnes, 2002). It uses top-down, activity-based programming to teach functional mobility skills to improve participation in school, home, and community settings (for additional information on the MOVE Curriculum see Bidabe, Barnes, & Whinnery, 2001; Whinnery & Whinnery, 2007).

32 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

Based on the success of the MOVE Curriculum in school settings, the program grew into an international mobility-training curriculum that is used across age levels and environments. Testimony from professionals and families indicates that informal use of the MOVE principles and techniques has been effective in helping adults with severe physical disabilities become more mobile and engaged in life. These early successes led to the need to develop a MOVE for Adults program that more specifically addresses the unique needs of an adult population. As a result, a three-year research study was conducted to develop the MOVE for Adults program and determine its effectiveness (Whinnery & Whinnery, 2011). The core principles of the MOVE for Adults program are aligned with current best practices for adult programming which call for increased engagement in age-appropriate activities, greater community integration, and more opportunities to make informed choices. The MOVE for Adults program provides this structure through a 6-step process: a) MOVE Assessment, b) Setting Goals, c) Planning Activities, d) Measuring Prompts, e) Prompt Review, and f) Teaching Skills (Whinnery & Whinnery, 2009).

In Step 1: MOVE Assessment, information is gathered about current life activities, use of functional mobility skills within those activities, and any physical supports needed to increase participation. In Step 2: Setting Goals, a person-centered interview process is used to identify personal priorities and barriers to participation, and to select target activities in which to integrate mobility skill instruction and practice. In Step 3: Planning Activities, target skills are selected and activities are planned to ensure active participation. Once MOVE activities are identified and planned, the support team determines the type and amount of physical support required in Step 4: Measuring Prompts. In Step 5: Prompt Review, a plan is developed to promote systematic review of prompts to guide reduction of support as skills are gained. In Step 6: Teaching Skills, practice schedules are developed and skill practice is promoted within meaningful activities throughout the day.

FRANCIE'S MOVE PROGRAM

The MOVE program was implemented with Francie over a three-year period. Her program addressed three priorities that were identified in the person-centered interview during Step 2: a) improve health, b) reduce challenging behaviors, and c) increase opportunities for meaningful participation in life activities. Although Francie could say a few words, she did not consistently use words to express herself. So based on observation, Francie's MOVE team identified three meaningful life activities in which to embed mobility skill practice to address the barriers that were affecting her quality of life. The first target activity identified by the team was *announcing the arrival of the transportation vans*. Observational data showed that Francie enjoyed looking

out the window so it was thought this might provide a motivational activity in which she could practice the sitting and standing skills needed for transfers. Francie was able to see out the window while sitting, but would need to stand up to push a switch with voice output to announce each time a van arrived. The staff hoped that as she learned to transition herself, she would have greater opportunities to be out of her wheelchair, use mobility equipment, transfer to a regular toilet, and better participate in preferred life activities. Additionally, it was hoped that as she gained mobility skills, the potential for injuries to staff and Francie would be reduced.

The activity of announcing the vans was motivational at first, but eventually Francie lost interest. Because an important component of MOVE for Adults is providing opportunities for individuals to experience a variety of activities, it was now easy to identify a more motivating activity for practicing transition skills. As a result of activity exploration, it became apparent that standing at the bathroom mirror to have her make-up applied and hair styled was a highly preferred activity for Francie. This became one of Francie's favorite activities, and she would readily practice sit-to-stand transitions to look in the mirror with periodic sitting to rest. This activity provided a very natural and reinforcing context for repeated practice of these critical motor skills.

The second MOVE activity focused on walking and choice making to address the need to increase opportunities for meaningful participation in life activities. Francie used a front-leaning walker, the Rifton Pacer (Rifton Equipment, 2004), to provide partial weight support allowing her to practice reciprocal stepping. With this support, Francie was able to independently take steps to *go to a leisure activity of choice*. Initially, her walking abilities were limited so she also used the Rifton Dynamic Stander (Rifton Equipment), a mobile stander that allowed her to easily propel herself over greater distances to explore other leisure activities. As Francie was exposed to new leisure activity options, she began to develop new interests. Also, Francie was beginning to develop strength and endurance and relied less on the Pacer for weight support, using it mainly for balance. Eventually, newly gained walking skills allowed her to easily walk in the Pacer to and from activities based on her own interests. She had opportunities to make "informed choices" and was using mobility to express her preferences.

A third activity, *participating in cooking class*, was selected because Francie enjoyed eating. This activity provided a motivating context for practicing walking, standing, and sitting skills. Although Francie often enjoyed cooking class, she began to show a preference for walking into the kitchen to get coffee. Based on this preference, Francie's daily schedule was adjusted to include walking to make a cup of coffee each morning. Not only did she practice walking and standing, but she developed upper body strength by reaching up into

a top cabinet to get supplies needed for her coffee and reaching to use an adaptive switch.

SCHEDULING PRACTICE

In accordance with current motor learning theory, MOVE for Adults uses distributed practice of critical mobility skills (short practice sessions distributed throughout the day) to increase acquisition, retention, and generalization of skills (Thomson, 2005). Motivation is addressed by embedding repeated practice into meaningful daily activities. To maximize repeated, meaningful practice, the ROMP (Repeated Opportunities for Meaningful Practice) (Whinnery & Whinnery, 2003) scheduling tool is used in Step 6: Teaching Skills (see Figure 1). The top portion of the ROMP plan lists the priority activities (left column) and the critical skills to be embedded into activities (across top). Priority activities serve as data collection activities to measure learner progress over time. The bottom half of the form lists other meaningful activities in which additional skill practice can occur. Activities should be updated according to adult learner preferences.

At the beginning of Francie's MOVE for Adults program, the MOVE team focused on the three priority activities described above. Eventually, as Francie developed strength and endurance, especially with sit-stand and stand-sit transitions, *using a regular toilet* was added as the fourth priority MOVE activity. Additional practice activities (noted at the bottom of the ROMP form) were used according to Francie's developing preferences.

CONCLUSIONS

After the implementation of the MOVE program, Francie's mobility skills improved significantly (Whinnery & Whinnery, 2011). Prior to MOVE, Francie had demonstrated a limited ability to bear her weight in standing while holding onto a stationary object (2-3 seconds), but typically refused and dropped to the floor. Transfers into and out of her wheelchair required fully supported lifts making them difficult and dangerous, thus resulting in very few opportunities to be out of her wheelchair. After using MOVE, Francie was able to independently stand up and sit down while holding onto a stationary object. She was able to fully support her own weight in standing while holding a stationary object for balance for about 3 minutes. Although she had not taken any steps prior to MOVE, she was now able to repeatedly walk to and from desired activities using the Pacer walker.

Figure 1. ROMP plan for Francie.

REPEATED OPPORTUNITIES FOR MEANINGFUL PRACTICE (ROMP)												
Adult Learner: Francie		Date:										
	Embedded Skills (motor, communication, other)											
	Sit-to-stand	Stand-to-sit	Stand for 3 minutes	Walk forward in walker	Sit in regular chair	Sit on regular toilet	Express choices	Use adaptive switches	Request help when needed			
Priority Activities												
Go to leisure activities	X	X	X	X	X		X	X	X			
Make coffee	X	X	X	X	X							
Standing for grooming	X	X	X		X				X			
Use regular toilet	X	X	X			X			X			
Other Practice Activities												
Walk to visit friends				X					X			
Eat at table with others	X	X			X				X			
Use computer	X	X			X			X	X			
Take dishes to kitchen			X	X					X			
Collect paper for shredding				X					X			
Use beauty salon services (hair, manicure, pedicure)	X	X		X	X			X	X			

36 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

These increased mobility skills led to improved life participation for Francie. Her ability to transfer independently allowed her to access many different postures and activities throughout her day. Francie was sitting in regular chairs, standing independently holding counters or grab bars for balance, and walking independently in the Pacer walker to activities of her choice. She was only using her wheelchair for long distances (e.g., shopping in a large shopping mall). As Francie gained mobility skills, she began to express preferences by walking to areas/activities of interest. Although a schedule of activities was provided for structure, Francie's improved mobility empowered her to change activities based on personal preference rather than a predetermined schedule.

As mobility skills improved and active engagement increased, Francie experienced other quality of life improvements. A significant change for Francie was the elimination of her challenging and aggressive behaviors with no additional behavioral intervention. Staff reported that Francie was choosing to walk in order to: interact with other adults, meaningfully engage in activities, and more readily communicate preferences. One preference she commonly expressed was the desire to use the regular toilet instead of a changing table. Prior to MOVE, Francie was being lifted onto a changing table. With her improved mobility, she would walk to the regular toilet when needed, stand independently, and request assistance from a staff member to adjust clothing. Eventually, Francie was able to transition out of adult diapers and into regular adult underwear and her chronic constipation improved.

Towards the end of the study, however, it was reported that Francie was once again displaying challenging behaviors in her group home. Interviews and observation revealed that Francie had a new direct support provider in the group home who was insisting on using a changing table instead of allowing Francie to use a regular toilet. Once this situation was corrected, the challenging behaviors once again ceased.

Francie also experienced health improvements throughout the study. Prior to the study, Francie was diagnosed as obese with high blood pressure. Previous attempts at controlling her diet had not resulted in weight loss. She continued to gain weight and became more sedentary. However, at the conclusion of the study, Francie was up and moving throughout her day and had lost 30 pounds without additional dietary changes.

Now, instead of sitting in her wheelchair playing with a string and/or looking out the window, Francie has continuous opportunities to actively engage in age-appropriate, meaningful activities. Francie's days are filled with preferred activities like going to the salon to have her hair and nails done, eating meals at the table with friends, preparing coffee and snacks in the kitchen, and participating in daily leisure activities and community outings.

Additionally, Francie's choice-making opportunities increased giving her greater control over her life. Not only does she make choices, but she has the opportunity to experience many different activities and situations in order to make more informed choices.

Francie's story highlights the challenges adults with severe, multiple disabilities often face and the resulting impact on quality of life. Mobility impairments can increase the chances of leading a passive life and can negatively impact the level of support given by care providers. The MOVE for Adults program appears to provide a systematic approach to guide care providers to actively support individuals with significant physical challenges to increase their participation and choice making within meaningful life activities. Future research could address: (a) systematic replication to provide additional support for the use of the MOVE for Adults program, (b) MOVE's impact on health, active participation, and choice making, and (c) an investigation of the criticality of specific components of the MOVE for Adults program.

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