

A Project Access White Paper



Dance for Parkinson's: Access and Transformation Through Movement, Music, and Community



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Art Beyond Sight



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A Project Access New York White Paper by David Leventhal, Mark Morris Dance Group/Dance for PD®

Anecdotal evidence and preliminary research suggest that there are emotional, social, and physical benefits to engaging persons with Parkinson's (pwPD) in artistic and cultural programming. Nonetheless, two distinct challenges potentially restrict full access. First, persons with Parkinson's may experience a range of symptoms that exacerbate feelings of inertia, isolation, and poor self efficacy. It can be difficult for persons with Parkinson's to find the motivation to participate in group activities, especially those that may lack the definitive endorsement of a medical professional. Participants may have poor mobility, making it difficult to travel to venues where cultural programming takes place, and they may fear that symptoms will make the experience too arduous once they arrive. Finally, people with Parkinson's and their care partners may think of disease management in primarily medical terms, considering pharmaceutical, surgical, and therapeutic interventions rather than artistic ones. Meanwhile, on the cultural side, arts institutions have not traditionally viewed the Parkinson's community as a significant subset of the population that needs special attention, access, and dedicated programming. People with PD may

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be grouped in with other elders, or with Alzheimer's groups. Additionally, a lack of knowledge about Parkinson's disease may cause institutions inadvertently to overlook the benefits that a particular art form can provide for this community.

Over the past decade, however, a movement has developed that has successfully overcome these obstacles. As seen through one branded international program and a series of independent practitioners, dance has taken a central role in bridging the Parkinson's community with arts and cultural institutions around the world. Dance for Parkinson's or Dance for PD® provides persons with Parkinson's direct contact with dancers and dance companies, and allows them to access strategies and perspectives that are dramatically different from traditional therapeutic interventions. These dance programs also provide cultural institutions with a new service area, helping to expand their missions, partnership rosters, and potential funder lists. Around the world, people with Parkinson's have access to an art form that they never thought was appropriate for them, and they accumulate significant benefits by participating through dance in the cultural life of their communities. This white paper looks briefly at the symbiotic relationship between persons with Parkinson's and the dance institutions and professionals who work with them, and makes concrete suggestions of best practices that foster maximum engagement and access.

Managing a life with Parkinson's disease

Parkinson's disease (PD) is a neurodegenerative disorder that affects more than one million Americans, with 60,000 new diagnoses each year. Parkinson's takes many forms, but its cardinal symptoms are slowness of movement (bradykinesia), rigidity, tremor, and postural instability that can make persons with PD more prone to fall. This tendency combines with mobility issues related to freezing—an often unpredictable

inability to initiate movement—to make people less likely to go out and engage in cultural activities and isolates them from friends and networks. Additionally, many people with PD exhibit inertia, and may have trouble motivating themselves to go out and about. Social isolation and depression both result from and compound the physical symptoms, causing a negative spiral of waning self-efficacy and reduced engagement with the world. Parkinson’s takes its toll on family relationships as well. Care-partners are overwhelmed with the new demands on their time and energy, and struggle simply to maintain activities of daily living, often at the expense of external activities that could potentially have a positive effect on the family’s quality of life. In all of these cases, the issues of access are not so much pre-scribed by external forces or circumstances but rather determined by internally-perceived limits and tolerance thresholds. The doors may be open, but the individual or family can’t move.

A shift for dance organizations

Many cultural institutions offer a wide range of programming for a variety of ages, abilities, and objectives. But dance institutions have traditionally developed and programmed arts education initiatives that focus overwhelmingly on young persons whose access to the performing arts may be limited by socioeconomic factors, geography, in-school arts education funding cuts, or parental priorities. With a few notable exceptions (Liz Lerman, Stuart Pimsler), very few dance institutions have offered active programs for older adults or for those with disabilities. Additionally, while dozens of established arts and health programs exist in the fields of visual art and, to some extent music, there are very few dance institutions offering programming that could fall within this emerging field. Even as Gene Cohen’s ground-breaking 2006 report *The Impact of Professionally Conducted Cultural Programs on Older Adults* (aka *The Creativity and Aging Study*) outlined the measurable benefits of high-quality artistic programming for elders, few dance organizations have built programming around the undeniable connection between cultural engagement and wellness.

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There are clear reasons for such an absence. First, funding skews the field. Many funders traditionally are interested in arts education for children and young adults, and so dance companies focus their grant-writing on programs for people under 18. Second, the art form itself appears, on the surface, to be prohibitively difficult for older adults, who may not be readily inclined to take a dance class. Finally, dance institutions often have difficulty translating the burnished, rarified identity they establish through their professional performances into accessible, welcoming, down-to-earth community programming. There are many notable exceptions, including American Ballet Theatre’s *Make A Ballet* program, developed during Michael Kaiser’s tenure at the company, that gave children an opportunity to engage in all aspects of creating a professional ballet production—set design, stage management, costume design, lighting, and administration, in addition to dancing. Ballet suddenly became an appealing umbrella for all kinds of talents, interests, and personal passions beyond tutus. But by and large, dance—especially in America—has had a difficult time marketing itself as universally accessible by the general public.

Parkinson’s meets dance, dance meets Parkinson’s

In spite of these apparent barriers, persons with Parkinson’s over the past ten years have

enthusiastically embraced dance classes taught by professional dancers and teaching artists. A few pioneering practitioners like Janet Hamburg developed programs based on their own personal methodology. Then in 2001, Mark Morris Dance Group and Brooklyn Parkinson Group collaborated to develop a monthly, then weekly, Dance for PD® class in Brooklyn, NY. This program has since become a model for more than 100 such programs around the world, all of which share similar principles and approaches but differ somewhat in content and artistic pedigree. Additionally, there is a growing number of ballroom dancers who have been influenced both by Dance for PD® and by the work of researchers Gammon Earhart and Madeleine Hackney, who study how Argentine tango may improve balance and locomotion in persons with Parkinson's.

Dance in all of its forms seems to fit Parkinson's like a glove. Dance training, with its focus on balance, strength, and flexibility offers many of the same physical benefits that exercise does. But because dance is an art form, it adds significant benefits that other movement forms do not. It is a musical art form, and provides rhythmic and emotional stimulus that may help persons with PD initiate movement more easily; it engages the imagination and imagery in the service of movement; it encourages self-expression; and it is inherently social in how it is learned, practiced, and enjoyed. It is also, first and foremost, a cognitive activity. The act of learning unpredictable, new sequences of movement, or the challenges that come with improvisation, stimulate and challenge the mind in ways that other movement forms may not. Preliminary studies show that specially designed Parkinson's dance classes may positively affect patients' sense of confidence and social inclusion, as well as their motor skills. Learning and practicing the art of dance may allow persons with Parkinson's to regain some access to grace, control and confidence, and provides a social outlet that may help to counter the depression and social isolation that often affect a person with Parkinson's. Although dance classes are not a solution for Parkinson's symptoms, they can provide a welcome escape from PD while simultaneously offering concrete, stimulating approaches to developing and improving Parkinson's movement quality, and cognition.

Early but promising evidence

Preliminary research shows a variety of encouraging results in areas relating to motor skills and quality of life. A team from the Cortical Motor Control Laboratory at University Hospital of Freiburg, Germany found significant improvements in rigidity scores followed by significant improvements in hand movements, finger taps, and facial expression. The results of the questionnaires showed positive effects of the dance class on social life, health, body-feeling and mobility, and on everyday life competences of the PD patients. Meanwhile, English National Ballet and University of Roehampton announced the findings of a ground-breaking research project that reveals that dance benefits people with Parkinson's by relieving debilitating symptoms, aiding short-term mobility and significantly improving stability, as well as contributing to social inclusion and artistic expression. In Brooklyn and Manhattan classes, 91 percent of respondents to an evaluation reported that the class increased their sense of well-being, while 62 percent said the class made them feel motivated to be active in other areas of their lives. Although more research is needed, it is clear that access to a high-quality dance program plays an important role in transforming participants' lives.

Concepts and accessibility best practices

The success of Dance for Parkinson's programs based on the Brooklyn model is built on a set of best practices that, taken together, can provide a clear, replicable template for ensuring that persons with PD, and perhaps other chronic conditions, have unlimited access to cultural programming.

1. Explain the essence of the art form in clear language that addresses condition-related concerns but always speaks in the language of art.

Olie Westheimer, the executive director and founder of the Brooklyn Parkinson Group, and the visionary behind the Dance for PD® program, mined her knowledge of dance to develop ten reasons why dance works so well for PD:

1. Dance develops flexibility and instills confidence.
2. Dance is first and foremost a stimulating mental activity that connects mind to body.
3. Dance breaks isolation.
4. Dance invokes imagery in the service of graceful movement.
5. Dance focuses attention on eyes, ears and touch as tools to assist in movement and balance.
6. Dance increases awareness of where all parts of the body are in space.
7. Dance tells stories.
8. Dance sparks creativity.
9. The basis of dance is rhythm.
10. The essence of dance is joy.

These core concepts are simple and accessible, and are designed to explain the art of dance to those who may at first seem reluctant—persons with Parkinson's, care partners, or neurologists—or who may feel that the world of dance is inaccessible to them.

2. Use professional artists who are experienced and sensitive teachers.

Dancers are movement experts who spend their lives studying, analyzing, and initiating graceful, fluid musical movement naturally. Since it is that very movement that becomes more difficult for persons living with Parkinson's, it makes sense to create a safe environment where dance professionals can share their knowledge with people who may not be familiar with a dancer's thought process and training method. Professional artists bring in a wealth of knowledge and experience in translating images and concepts into concrete approaches to movement.

3. Focus on the art form—dancing for dancing's sake—not on symptoms or therapy.

The dancers and dance teachers involved in Parkinson's dance classes do not, by and large, presume to offer a therapeutic experience, nor do they see what they do as in any way related to changing or improving Parkinson's symptoms. Although they are specially trained to adapt what they already know to work with this special population and provide access to their field, the teaching artists are just that—artists

who view their students as artists and learners, not as patients who need to be remedied. As one regularly-attending participant noted, “The fact that our condition is acknowledged but [is] not the focus of the class allows us the dignity of managing that ourselves.”

4. No shortcuts--use live music if you can afford it.

Integrating experienced musical artists into the experience engages participants in unique and spontaneous ways that recorded music cannot. The addition of a musician adds another artistic collaborator to the mix, and creates an atmosphere of rigor and fun.

5. Context speaks volumes.

Holding classes in a dance studio tells participants that they are dancers, not patients. We believe that an initial reason for the program’s success was that participants had an opportunity to take class in a beautiful dance studio, and worked in a building in which they were surrounded by movement and music produced by people of all ages. There are also recognized benefits to bringing arts into healthcare environments, but for the general Parkinson’s population, which isn’t particularly hospital-bound, a non-clinical space is much more inviting.

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6. Maintain consistency

With the logistical difficulties many persons with Parkinson’s experience, it’s important to maintain a consistent time and location for the program so that people can rely on the program and not become anxious about changes. The Dance for PD® class in Brooklyn has been on Wednesday at 2pm for eleven years.

7. If at all possible, provide the class free of charge

There are enough internal barriers to access without adding financial burden. It is not always possible for a dance studio or institution to cover its expenses without passing them on to participants, and it is always better to have a class with participant fees than no class at all. But since Parkinson’s takes a substantial financial as well as physical toll, and potential participants could add cost to a long list of reasons why not to participate in a cultural activity, it is worth investigating what you would need to do to offer a class free of charge.

8. Foster community (Only Connect)

Teachers interact with students as friends and colleagues. They know students’ names, and check in with them. Participants come early and stay late to chat with other students. Special events and holiday parties deepen bonds. These aren’t extra things that happen to occur around the dance class; as any professional dancer will tell you, they are the glue that make the experience worthwhile, and that deepen the experience of dancing together. Additionally, class participants learn excerpts of actual choreography, not simply classroom sequences. In Brooklyn, for example, the class frequently includes excerpts from Mark Morris’ extensive repertory. In London, the English National Ballet carefully structures its Dance for Parkinson’s lesson plans to reflect the ballets that the professional company is working on so that there can

be a dynamic exchange. In both sites, people with Parkinson's are provided access to belong to an artistic community in which professional and recreational dancers share knowledge and relationships. They meet the dancers, learn the work, and come to see the company perform. In this way, dance organizations around the world like English National Ballet, Houston Ballet, Hubbard Street Dance Chicago, and Danshuis Station Zuid (Netherlands) have begun to nurture special, intimate and unexpected relationships with Parkinson's individuals and organizations in their communities. By collaborating with local Parkinson's support groups and organizations, dance institutions create a vital conversation between dancers—who dedicate their lives thinking about moving well—and persons with PD, who must learn new strategies to cope with difficult physical and emotional challenges. Everyone wins.

Implications

The Dance for PD® model has significant implications for how Parkinson's and other chronic diseases are managed. Because of its success in changing peoples' perception of themselves and their abilities, and in motivating people to be active and creative, Dance for PD® may inform how neurologists and allied health professionals advise their patients and manage their experience in the future. It is possible, though perhaps not desirable, that dance classes—because of the variety and specificity of the material—could be used to track the progression of the disease. It's also possible that dance—in its significance to the Parkinson's population—could be a valuable window through which neuroscientists could view issues of cognition, memory, and emotion.

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For the purposes of cultural institutions, the model also demonstrates how the artistic community can play a vital role in engaging new populations and addressing community or public health issues that may not have been previously considered. The convergence of ever-increasing healthcare costs and ever-decreasing dance institution budgets may create arts and health partnerships that fill important niches while staying true to organizational missions.

But more than anything, the model's best practices can be seen as essential points of consideration for any cultural institution interested in increasing program access for person's with Parkinson's. They are simple points, but they all speak toward three fundamental building blocks when considering issues of access for any population: sensitivity, compassion, and respect.

In conclusion

Dance for Parkinson's classes provide access to a high-quality arts experience to a population that can benefit regularly from such an engagement. Dance for PD® can be seen as part of an international trend in which arts institutions come out, meet you where you are without judging you, and invite you in, all without diminishing or diluting their artistic rigor or values. The program also transforms the traditional role of a performing arts company, and redefines the term 'outreach'. Rather than simply providing access to seats at performances, or providing lectures, the companies that offer Parkinson's dance programs share a diverse range of resources with populations who need them, and create programming that goes beyond a 75 minute weekly class. In Brooklyn, for example, members of the Dance for PD® class participated in

a public performance of five pieces, two adapted from Mark Morris' repertory, and three new pieces choreographed on them. In London, the Parkinson's students sat in and asked questions in an intimate studio rehearsal for Romeo & Juliet. In all of these instances, cultural organizations provide access, and access builds community. Wherever Dance for PD® or other similar classes develop, they seem to create new communities where none existed. This act of community building may not have fallen within the traditional parameters of a performing arts company, but programs like Dance for PD® bring this role of a cultural institution front and center, redefining the significant of the arts organization as creative town square—open, accessible, enriching, and vitally important.

Resources

Dance for PD: www.danceforpd.org

Tango research: <http://www.ncbi.nlm.nih.gov/pubmed/19479161>

Global Alliance for Arts and Health: www.thesah.org

Freiburg study: <http://danceforparkinsons.org/wp-content/uploads/2011/10/FrontiersAgingNeuroscience.pdf>

Creativity and Aging Study: <http://www.nea.gov/resources/accessibility/CnA-Rep4-30-06.pdf>

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