Advancing Participant-Oriented Research Models in Research-Intensive Universities: A Case Study of Community Collaboration for Students With Autism

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Abstract

The purpose of this article is to advance the importance and value of participant-oriented research (POR) at research universities. We highlight a case study of community collaboration as it relates to a strengths-based educational model for students with autism. This evidence-based program's success centers on the inclusion of students, parents, and community partners in design, delivery, and evaluation. Bench science and experimental designs may be complemented by the inclusion of POR to address complex social issues.

Keywords: autism, participant-oriented research, community involvement, strengths, campus community partnerships

The goal of this article is to highlight the strengths and applications of participant-oriented research (POR) and indicate how this community-engaged scholarship is relevant and important in research-intensive universities to solve complex community and social issues such as the underemployment and low rates of higher education entry for those on the autism spectrum. We propose that community-engaged scholarship represents a critical bridge of connection between university research activity and community-based needs and priorities (Furco, 2016).

POR facilitates interactions with community partners and stakeholders, family networks, and targeted populations for critical input on interventions, programs, and services that are designed with and for them in the immediate time horizon and for longer range policy outcomes. As others have argued, it is timely and relevant to acknowledge in faculty reward systems this viable research methodology, which transcends the standard "service" dimension of the academic mission and offers a pragmatic and progressive approach to creating a robust reciprocation through university and community connections (Saltmarsh, 2017).

We further examine the promise of the POR model by presenting our own scholarship as a case study in which community collaborators are involved in the research focus, design, curriculum development, implementation, and evaluation. Our scholarship engages those with autism, their families, and their priorities for addressing the high unemployment and low college enrollment rates in this underserved group.

One issue that any advocate of POR must confront is the reception in a research university setting in view of incentives for faculty to follow a pathway of traditional research that may discourage the intensive "ground work" and longer time frames necessary for POR (Foster, 2010; Wenger et al., 2012). In addition, many research universities present attitudes, traditions, and constraints that actively discourage involving community participants in research. In this regard, we agree with Crow and Dabars (2015), who have offered a proposal for a new American research university model in which they emphasize the need for a "maximization of societal impact" and a call for a reengagement of the university to serve the needs of people served by the knowledge enterprise. Although research universities represent a "gold standard" for successful

research endeavors, Crow and Dabars (2015) have expressed concerns about the viability of the traditional research-focused model into the near future when a trend of disinvestment from state or legislative funding sources presents challenges for many research-intensive institutions:

> To an alarming extent, the American research university is captive to a set of institutional constraints that no longer aligns with the changing needs of our society. Despite the critical niche that research universities occupy in the knowledge economy, their preponderant commitment to discovery and innovation, carried out largely in isolation from the socioeconomic challenges faced by most Americans, will render these institutions increasingly incapable of contributing decisively to the collective good. (p. 56)

One way to address this challenge and to respond to this changing landscape is to reconsider research approaches that capture a greater connection to community needs and social impact. The emergence of POR represents an approach to building important bridges with individuals, family networks, and community partners by developing programs that meet their needs, while also supporting the inclusion of the participants in program development and implementation of research activities.

This article has three distinct goals: (1) identify the unique contributions of POR that complement basic research models, (2) provide an example of our research that involves students with autism as well as family and community members as codesigners and participatory researchers, and (3) present insights for future research through considering more inclusiveness of members of the autism community in the research process.

Although research may reference "community-based" programs, this terminology often indicates research in the community without stakeholder participation in identifying research questions or performing the research process. Research can occur in the community (community-based), but this often does not entail the direct involvement of the community stakeholders being researched. In other words, this unidirectional process can be disconnected from the priorities and needs of the community (Stahmer et al., 2017). The bidirectional approach of participatory research can help to build effective programs that match the priorities of communities as well as meet the needs of faculty for knowledge production.

Participant-Oriented Research (POR)

Participant-oriented research methods involve commitment to an inclusive process with individuals whose real-life, meaningful experiences are critical to examining research and social problems (Robertson, 2010; Stanton, 2008). POR reflects an orientation to research that "focuses on relationships between academic and community partners, with principles of co-learning, mutual benefits, and long-term commitment, and incorporates community theories, participation, and practices into the research efforts" (Wallerstein & Duran, 2006, p. 312). Through it, power of knowledge is shared between the community and researchers (Spiel et al., 2017). The approach also promotes social change strategies developed with researchers and community participants to design practical, beneficial programs primarily for underserved groups such as individuals with autism.

One goal of POR is to give members of marginalized groups a voice in the research process. It incorporates participants' everyday experiential knowledge to build solutions to complex social problems. They bring their experiences, knowledge, and abilities into the research process and provide unique perspectives and insights (Simonsen & Robertson, 2013). The combined views of academic professionals and community research partners are critical assets to research. Investment in the knowledge and abilities of those on the "inside" and what we can learn from them is critically important. Without leadership and input from within the autism community, research efforts may misrepresent it. It is not possible to learn about the unique needs and desires of autistic people from nonautistic people. The process enables community coresearchers to take equal ownership of the research and to question traditional interpretations of educational approaches and curriculum strategies as well as design future research agendas (Jacquez et al., 2016).

Few researchers in the autism field are engaged in this type of participatory,

community-engaged research, although it is strongly promoted as an essential approach by multiple agencies, including the Interagency Autism Coordinating Committee (IACC, 2017). Despite a call to action going back a decade or more from those with autism and their families for inclusion in the research process, few published studies use this approach (Wright et al., 2014). One exception in relation to participatory research and autism is the organization Academic Autistic Spectrum Partnership in Research and Education (AASPIRE, https://aaspire.org). AASPIRE is an excellent example of a collective effort, an academic community partnership to bring "together people from the three communities: the academic community, the autistic community, and the community of people who provide support and services to autistics" (Nicolaidis et al., 2011). In general, there is the call to consider the rights of adults with disabilities in the research process (Coons & Watson, 2013). This approach highlights the respect for families, individuals with disabilities, and other interested stakeholders, and this inclusion of stakeholders in meaningful research is ethically important and can provide a positive impact on families and communities. Additionally, the neurodiversity movement, particularly for individuals with autism, focuses on the "difference" versus "deficit" label associated with much of the primary research in autism. New efforts are increasingly focused on strengths-based approaches rather than on impairments or deficits. Despite calls to action for POR approaches, barriers make these approaches challenging to implement. Below, we discuss some of the barriers to the POR approach.

Barriers to the POR Approach in Autism

One of the challenges to the inclusion of this research approach in the field of autism is that it involves a demanding and lengthy communication and relationship-building process. This can be particularly challenging in autism where communication difficulties are a part of the condition. However, our experience has been that using a variety of creative communication strategies (videos, storytelling, etc.) can elicit responses from our partners with autism reflecting that they are eager to contribute their ideas on research focus, program development, and evaluation. In our program, academics and participants meet, interact, and develop research program ideas together.

Although interventions associated with autism often remain grounded in the biomedical paradigm, many individuals with autism are challenging this view (Robertson, 2010; Robison, 2012). Some individuals with autism contend that research approaches focused on cures are dehumanizing and harmful and a greater focus on strengths-based approaches is needed. Some also argue that many traditional research agendas fail to create interventions that address their real-life concerns such as unemployment and access to higher education. Conventional research is driven by research questions that matter, but to whom? Understanding participants' experiences with the desirability and challenges of an intervention is as important as understanding whether the intervention group is statistically significantly different from the control group (Christ, 2014). We argue that both approaches have benefit and equal merit, despite the emphasis on experimental design and randomized controlled trials; they complement one another, and both are necessary to avoid methodological singularity (Christ, 2014). Although federal funding tends to prioritize the biomedical approach, we have successfully addressed the need for funding by using foundations, corporate partnerships, and local government agencies who see the benefit in supporting the populations with whom they engage on a daily basis.

Another challenge is the traditional separation of research, teaching, and service with emphasis placed solely on research, without an acknowledgment that these dimensions of academic life are often intertwined with a participatory, community-engaged approach. These issues present challenges but can be addressed, as exemplified in our approach, which is described in greater detail below.

Case Study Example: POR Autism Research

In comparison to our autism research, most interventions and programs for those with autism are deficit-oriented; this deficit perspective may inadvertently send the message that individuals with autism need to be "fixed," and they themselves are the problem, rather than the idea that the structures, services, and policies they encounter provide barriers to their full participation and success (Robertson, 2010; Robison, 2012). In contrast, our participant-oriented ap-

proach is strengths focused. In collaboration with our community partners, the mission of our scholarship is to develop an educational technology program for competency and skills in response to the high rates of unemployment in youth with autism. Another long-term goal of our scholarship is to address the underemployment and barriers to higher education for youth on the autism spectrum. To address these issues, we developed an educational technology program that teaches students with autism 3D modeling skills (Diener, Wright, Wright, & Anderson, 2015).The program focuses on the visual–spatial abilities of some on the autism spectrum to demonstrate skill and ability through 3D modeling (Wright et al., 2011). The specifics of our program are addressed elsewhere (Diener et al., 2015).

In this article, we highlight the strength of our community engagement in developing our scholarship. First, our research team is interdisciplinary across eight colleges at our university (Social & Behavioral Science, Nursing, Education, Health, Medicine, Business, Fine Arts, and Engineering), and we have begun working with other higher education institutions in our state. This broad, interdisciplinary perspective is necessary to address complex social challenges from multiple perspectives. Furthermore, our research team includes undergraduate students, faculty, and staff on the autism spectrum. These inclusive, diverse perspectives have guided and strengthened the evolution and development of our scholarship.

Most importantly, the participant-oriented inclusion of students with autism, along with their families and community partners, moves our research closer to a community-engaged endeavor and helps to build a stronger science that is translational and sustainable. In addition to students, families, and university personnel, our collaborators include schools (public, private, and charter schools), disability employment agencies, vocational rehabilitation services, and various business partners from 3D design fields (architecture, construction, navigation) and technology companies.

This time-intensive participatory research creates better interventions because it includes input from our students with autism, their families, and these community partners. The inclusion of stakeholders in our research helps to facilitate the effectiveness and sustainability of our intervention. Our program has been in existence for almost a decade due to the inclusion of stakeholders who are most invested in the outcomes and services provided. With this approach, participants play an essential role in the development of scholarship that is designed by and for those it impacts (see Figure 1).

Extended family members, including grandparents and siblings, have also played an important role in determining the focus, direction, and approach in our scholarship (Diener et al., 2015; Wright et al., 2012). Our research team has placed a priority on developing these relationships where those researched become coresearchers and contribute their ideas and input into the research questions, program development, and evaluation. This approach provided a more inclusive and comprehensive research process for engaging in socially relevant research that has impact on participants' lives. We have established a relationship of trust and respect with stakeholders that values their contributions.

Impact of Our POR Research

Traditionally, indicators of research impact involve peer-reviewed journal publications and books, letters from experts in the field, research grants from peer-reviewed funding agencies, and citation counts, which focus on the knowledge base among academics within a discipline. Traditional models are focused on impact on the field of study but not necessarily on the participants in the research. Furthermore, as others have argued, when addressing complex social problems in the real world, each situation and community is likely to have unique aspects that require an element of inquiry and discovery, leading to new knowledge (Lynton, 2016). The flow of knowledge is in both directions, from the university to the community and from the community to the university (Lynton, 2016). This type of new knowledge is less likely to be recognized in traditional faculty reward structures. The most significant impact and relevance of our research is focused on the direct impact on communities, including the families and students served by our program. Our inclusion of those with autism and their families is one of the most critical impact dimensions of our research.

The youth we work with are not intellectually challenged; they are challenged by social communication, making them a difficult population to assess with conventional pre–post evaluation measures. Instead, data
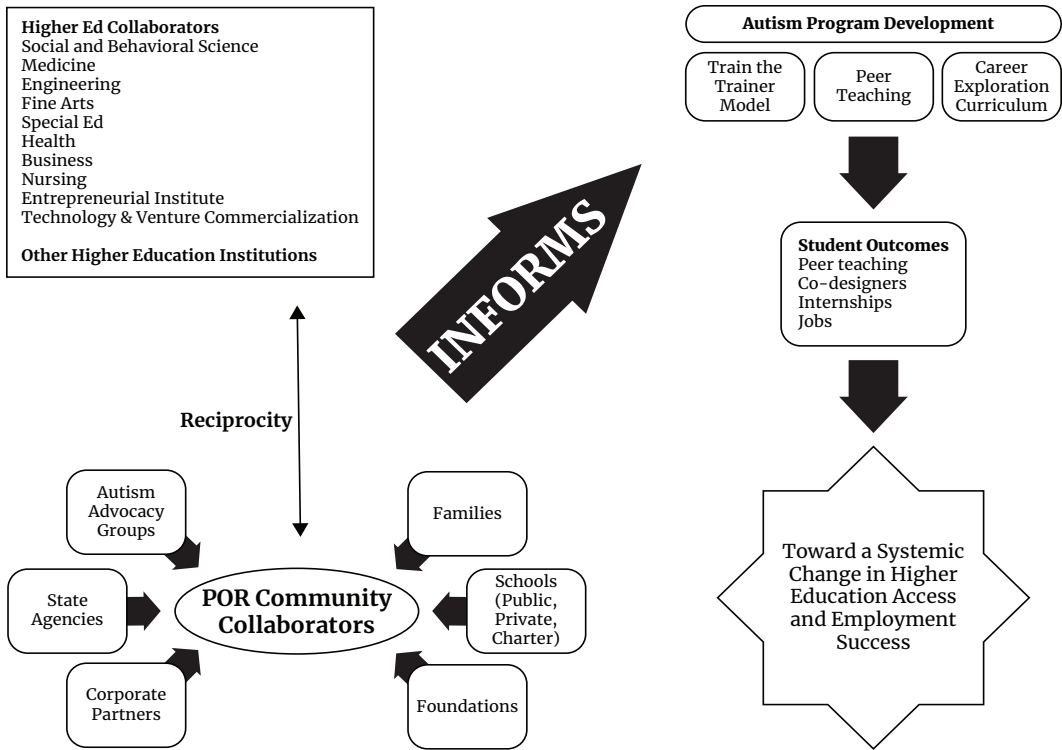
Figure 1: Case Study of Participant-Oriented Research Model

evaluating the program have come from multiple community sources, including focus groups, individual interviews, surveys, observations, and more innovative assessments, including student video evaluations and story narratives for our students with autism. Our research demonstrates that the students developed a sense of accomplishment based on their competence in their 3D modeling skills (Wright et al., 2011; Wright et al., 2012). Students gained confidence and reframed their abilities in this skill- and strengths-based program. Because the program involved family members who witnessed the development of competence, parents, grandparents, and siblings were also able to change their perceptions of the students (Diener et al., 2015; Wright et al., 2011; Wright et al., 2012). Thus, the program positively impacted both students in the program and the expectations of their family members. Although the initial focus of the program was vocational, parents emphasized the importance of the social engagement that occurred (Wright et al., 2011). The focus on social engagement came from the input of parents, who recognized the role that social engagement played; we might not have identified social engagement as an important outcome without the continuous collaboration with family members.

Our peer-to-peer teaching model is also an innovative component of our program (Wright et al., 2019). We have worked with 11 students in paid peer positions across multiple sites. This is an empowering experience for students and is unique in autism and peer-teaching research in that most peer teaching involves neurotypical students teaching students with autism. The peer-to-peer teaching model represents structural changes, in that it provides opportunities for students to gain work experience in the field. In addition, we have a mentoring/expert model where we involve local 3D modeling experts (e.g., architects, construction managers, gaming professionals) to work with our students, providing potential employer/employee education and exposure to autism issues in the workplace.

Our research is also unique in its inclusion of youth with autism as codesigners and evaluators in the development of our technology-based 3D modeling curriculum. These products, although often overlooked in faculty reward systems, are critical to the sustainability of the program, and reflect the role of community partners in demonstrating the impact of the program on real-world teaching practices. In addition to traditional scholarly products, we have hired our students with autism to codevelop

curriculum activities around career exploration themes based on their interests. The students have created the designs associated with our curriculum manuals. These curriculum manuals are constructed around the interests of our students with the input of industry partners' expertise. Our curriculum has been reviewed, evaluated, and revised based on feedback by our local community partners in architecture, gaming, theater, and landscape and interior design.

We have also developed a virtual reality game with our students with autism as codesigners and coevaluators in collaboration with an interdisciplinary team across fine arts, engineering, and social science. To our knowledge, it is the only VR game developed with and for those on the autism spectrum.

POR System-Level Impacts

In addition to the impact on the students, their extended families, and our community partners, POR research also has great promise for system changes. For example, our recently funded research grant, "Developing Tech Talent: Building Utah's Neurodiverse Workforce," focuses on system change for greater higher education access and success for employability in high-demand tech fields that usually require postsecondary degrees. In addition to our university collaborators, our partners include a charter high school for students with autism, a disability employment agency, vocational rehabilitation services, advocacy groups, technology councils, and other state universities (see Figure 1). We are also focused on developing educational materials for higher education (faculty, staff) and employers and coworkers for awareness and acceptance of people with neurodiverse abilities. This series of educational programs is similarly focused on educating the technology community about autism so they can reduce some of the barriers to employment in their workplaces. We educate them about how their employees might be involved in our program through mentoring, career coaching, internships, and potential job placement. This program has the potential to be replicated in other institutions of higher education and partnering companies that are interested in employing individuals on the autism spectrum (with a focus on their unique skills and abilities). This focus expands our most recent research on "insider views" of the challenges of employment

through interviews with individuals on the spectrum and supervisors who work with employees with autism (Diener et al., 2020).

POR Sustainability

POR research also has great promise for sustainability for interventions. We have developed a train the trainer model to teach local instructors how to implement our program with fidelity. This model will allow us to scale our program to serve more students and families in more communities. We have trained 10 professionals to implement our program with fidelity. The training starts with an on-site orientation meeting, online training, program implementation and replication (with on-site training), follow-up consultation, and program oversight for quality control.

Entrepreneurship: Creative Funding for POR

This project was selected as a research project for the development of a business plan at our university entrepreneur center. We work with an interdisciplinary group of graduate students (business administration, bioengineering, and finance) to develop and continue to revise a sustainability plan (that includes tuition, scholarships, and agency reimbursement for students with autism). This is an exciting academic venture that applies an entirely different perspective on research. It requires more attention than traditional research to functions such as marketing and business proposals. This plan resulted in the development of the social entrepreneurship startup NeuroVersity (https://neurov.com). NeuroVersity is a trademark registered with the United States Patent and Trademark Office (2015). In recognition of research overhead costs, a percentage of our income from product sales is set aside for the university, although we are still in the product development stage and not yet revenue generating. This social enterprise has provided graduate student funding and summer employment for our graduate and undergraduate students. We have also secured funding from foundations, advocacy groups, state economic development sources, and industry partners as well as reimbursement for skill training from state disability agencies.

Future Developments

Working with a broad range of stakeholders

can be frustrating because of the inherent delays, compromises, and unforeseen obstacles to progress. However, overcoming these challenges has led to the creation of an innovative educational program valued and sustained by students, families, and community partners. Actively engaging the people we hoped to develop educational programming for has resulted in scholarship that benefits those involved and best serves their strengths and abilities. As our students have transitioned into adulthood, another primary concern has surfaced in the low higher education enrollment rates of students with autism. Our most recent research addresses this important issue.

The POR approach can be a time-consuming and difficult process involving a continuous feedback loop with participants and community partners, and it presents many obstacles to overcome. These obstacles include coordination of meetings, inclusion of stakeholders, communication, time, and competing agendas, resources, and missions, as well as the university reward system that focuses on the impact on academics, rather than on the community.

Some researchers emphasize the ethical approach of involving those you are learning from in the research process (Coons & Watson, 2013). Students on the autism spectrum are the primary stakeholders and most invested in the outcomes. By not including them we marginalize their important role in the research process and may stigmatize them further. Individuals with disabilities are the experts on their own experiences, although these individuals have been largely omitted from research and program development (Coons & Watson, 2013).

A participant-oriented methodological approach has transformed our research perspective and our research agenda, which has as a priority the inclusion of students with autism, their families, and our community partners. In addition to employment issues, students, parents, and industry partners were also interested in access to higher education. Additionally, health care of individuals with autism has been identified as an important issue to our community researchers; thus, our future research will address the needs of youth with autism in the health care setting. This exemplifies how multiple stakeholders, rather than faculty acting unilaterally, determine research questions and goals so that the outcomes are personally meaningful to those involved and to the community.

Summary

The scholarship described here has developed over a period of nearly 10 years. The POR approach is a long, intensive process that involves inviting community partners, students, and families as coresearchers and codesigners. Their voices have enabled scholarship that complements traditional research on individuals with autism. The scholarship described here has empowered students on the autism spectrum and has directly addressed community needs. The voices of our community offer a rich and in-depth examination that can only be captured by intimate research approaches such as POR. POR approaches can also help build community–university relationships that are essential to the survival of higher education. Community partners see firsthand the role that the university plays in improving the quality of life for students with autism while also cocreating knowledge that complements basic research models.

Our research presents insights for future research in the consideration of more inclusiveness of members of the autism community in the research process. By serving as the facilitator of the collaboration, the university can help to drive system change that is sustainable, long term, and relevant to community partners. The knowledge created by this partnership takes both traditional and nontraditional forms that are meaningful to the academy and have direct application to individuals with autism, their families, and the community.

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