

Inclusion

Reconceptualizing Research to Practice: The Role of Self-Advocates in Disrupting How We Think about Implementing of Research-Based Practices --Manuscript Draft--

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Abstract

Inclusive research advances the right of people with lived experience with intellectual and developmental disabilities to be involved in all phases of the research process. From an implementation science perspective, a critical component to inclusive research is addressing how research-based practices are adopted, implemented, and sustained in real-world contexts by real-world implementers – who in the context of this special issue are people with lived experience of disability. The purpose of this article is to advance inclusive approaches in the implementation of research-based practices in disability services and supports by highlighting strategies used by an innovative organization that supports self-advocates to implement research-based practices in disability supports and services.

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There is a movement toward inclusive research, as described throughout this Special Issue, that advances the right of people with lived experience with intellectual and developmental disabilities to be involved in all phases of the research process. This Special Issue has featured perspectives of people with lived experience with intellectual and developmental disabilities on acting as co-researchers and research team members, as well as highlighted strategies to integrate inclusive research practices into the planning, implementing, and disseminating of research as well as into policy development. The impacts inclusive research has on (a) people with intellectual and developmental disabilities, (b) researchers without intellectual and developmental disabilities, (c) the quality and impact of research, and (d) disrupting systemic barriers to the inclusive research process have been highlighted. This concluding article elaborates on another, often overlooked, aspect of inclusive research, advancing inclusive approaches in the implementation of research-based practices in disability services and supports.

The growing field of implementation science recognizes that just because practices have research support does not mean they will be or can be adopted, implemented, and sustained in real-world contexts by real-world implementers (Odom et al., 2020). The challenges to implementing research-based practices in real-world contexts are not always considered in research studies (Brookman-Frazee et al., 2020), much like inclusive research practices have not always been considered in the design of research studies in intellectual disability (Walmsley et al., 2018). However, implementation science is pushing a recognition of the importance of contextual fit in planning for the adoption and sustained use of research-based practices (McCreight et al., 2019). People with lived experience with intellectual and developmental

disabilities, including people with intellectual and developmental disabilities who identify as self-advocates, have critical experiences and insights that can advance contextual fit, however, their role in the adoption of research-based practices in real-world contexts has not been widely considered in disability services and supports. Including people with lived experience with intellectual and developmental disability as implementers of research-based practices can advance how we think about contextual fit and create opportunities for inclusive implementation of research-based practices in disability related supports and services.

This article highlights the power and possibilities of engaging people with lived experience in the implementation of research-based practices. We provide examples from an innovative organization and its leaders, showing how they have disrupted the status quo in implementation of research-based practices in real world settings providing a model for others on how to merge work on inclusive research, implementation science, and disability justice and advocacy. People with intellectual and developmental disabilities must not only have opportunities to be included in the research process but also in the implementation of that research in their communities, enhancing outcomes and systems change in disability supports and services.

Imagine Enterprises: Disrupting Existing Implementation Practices

Imagine Enterprises is a not-for-profit based in Texas that focuses on supporting all people with disabilities to be respected and to have supports they need. The Board and staff are committed to finding new and innovative approaches to assist people with disabilities and their families to successfully negotiate the service system and to use their public and personal resources to acquire a meaningful and productive life in the community — just like everyone else. Norine, the second author, is the Executive Director of Imagine Enterprises. Ricky, the first

author, is a Peer Support Leader who has lived experience with intellectual and developmental disabilities and identifies as a self-advocate. Ricky has worked with Imagine since 2007.

Norine shares her belief that you have to “Talk the Talk – Walk the Walk.” Throughout Texas (and beyond), people identify Ricky as the face of Imagine Enterprises. Norine shares that Ricky holds up what Imagine believes life can look like for people with disabilities both in his personal life (i.e., living in the community, managing his own budget for supports) as well as in his career as a teacher, trainer, and a mentor. It is important to emphasize that Ricky has more than a job at Imagine. He has a career that has given him the opportunity to grow, explore, and change directions over time. He is highly valued as a member of the Imagine team – and this is something that all the Imagine staff identify as important about who they are and what they do. As Norine says, “if Ricky wasn’t there to do his job and to represent Imagine through his work, there would be a significant deficit in how others see us and how we operate.”

When talking about how research fits into what Imagine Enterprises does in practice, Ricky shares that research-based practices give him the tools to go after his goals and to support others to go after their goals. For instance, Ricky shares how he has approached his career. When first starting at Imagine, his goal was wanting a job that paid enough money so that he could live in his own apartment with support. Prior to this, Ricky had lived in large, congregate facilities. He shared, the question he asked himself was:

Do I use Supported Employment or a Sheltered Workshop to help me meet my goal?

Both types of services serve people with intellectual developmental disabilities and hire staff to work with individuals who need help with work. BUT, Supported Employment is the evidenced-based practice that matches meeting my goal – to work and earn money.

Ricky highlights how his lived experiences make him better at his work now, supporting young people with intellectual and developmental disabilities to set goals and build self-determined lives by delivering self-determination instruction in schools. He builds relationships with the students with disabilities he teaches because of their shared experiences. He says,

Because I experienced living in several large facilities, I think it gives me a different look on what happens to people. Research is asking a question about a problem or idea, and figuring out what works to correct it. Without the support that I have now, I would still be in a large facility or a 6-person group home. I lived it, and now I'm here to show people with disabilities we can live like everyone else – as long as we have the support. To me, the most important piece is to say who comes in my home and who touches my body. Because when I lived in all those different facilities and all those different places; I've seen a lot of things that happen.

The difference is who makes the decision. Previously, Ricky had little or no control over financial, personal and daily care decisions that were made on his behalf by agency staff working for a provider. Now, he makes decisions every day, that includes his personal care, long-term services plan, career, volunteer work and the shape of his role in Imagine.

Ricky says that he thinks research is all about finding a problem and figuring out how to help the situation. He emphasizes the importance of inclusive research “they should have a person with an intellectual or developmental disability from the beginning all the way through the process.” But Ricky, Norine, and the team of self-advocates and staff at Imagine Enterprises are thinking beyond just doing inclusive research. They have long been thinking about how to get the research in the hands of people with intellectual disability and use research to change systems and challenge expectations. In fact, they have been working for almost 15 years to find

ways to elevate Ricky's knowledge and lived experiences as well as the knowledge and experiences of others with intellectual and developmental disabilities at Imagine to deliver research-based interventions in schools and communities and change expectations and systems. A large focus of Ricky's work is going into schools and delivering research-based self-determination practices during transition planning for students with intellectual and developmental disabilities. He is merging his lived experience into the delivery of research-based practices in self-determination and self-advocacy instruction.

So, what does it mean for people with lived experience with intellectual and developmental disabilities to lead the implementation of research-based practices in disability services and supports? Ricky has expertise in self-determination, self-advocacy and transitioning to the community. He also has strengths in connecting with other people with lived experience with intellectual and developmental disabilities and building relationships around shared experiences. This has led to the creation of Ricky's current role as Imagine's Peer Support Leader. He uses practices that are research-based (e.g., teaching self-advocacy skills, setting goals), and integrates his experiences to make the examples, activities, and strategies to engage youth with intellectual and developmental disabilities more relevant. Ricky is currently paid to implement self-determination instruction in schools through a contract Imagine Enterprises has to deliver pre-employment transition services (pre-ETS) through vocational rehabilitation. In delivering pre-ETS services Ricky shares how he connects with students as a person that shares lived experiences with the students.

I've been in their shoes and I have to remember that when I'm putting presentations together. I want to make sure they understand it. I try my best not to use big words. If another self-advocate sees me doing the training, I hope that will encourage them to

remember they have a voice and can use their voice to say ‘please help me with this’. I believe that self-advocacy is listening. If they have questions, I hope they are willing to ask me questions. I try my best to make sure I’m listening. You have to make sure you are open-minded when you are doing a training. I want to take all the information that I have and ask how can I make sure that the person(s) understand the information? I want to appreciate the way the information is broken down for me and then I need to make sure I break it down so they can understand it.”

Ricky uses not only his lived experiences but also training opportunities he has taken advantage of in the community, like Toastmasters, to connect with students and build relationships as well as lead and educate in this work.

People at Imagine support Ricky with formatting presentations and thinking about the key topics and objectives when he is facilitating a session. People also help with planning (and advocating) for accessibility, making sure he has enough room to move around in the place he’s presenting, has a microphone, and has the presentation on the flash drive. But, he says it’s all about “Practice – Practice – Practice.”

Ricky says that Imagine has always given him a chance to show up, to show he is dependable and do a good job and to build his career. Not everyone does this, and he wishes more disability service systems and potential employers did. Part of this has been figuring out the finances, which Imagine has had to think creatively about. Norine shares,

We have always looked for grants and funding opportunities that support both Ricky and the people who support him. Ricky is fortunate to have the Consumer Directed Services Medicaid waiver, so many of his personal care needs are taken care of by his staff. We helped to create his plan for transportation that keeps him on the road.”

Ricky earns a living wage that has moved him beyond the traditional funding limitations for long-term Medicaid services, requiring use of Texas' Medicaid Buy-in (MBI). MBI allows Ricky to retain his Medicaid waiver for long-term services. Ricky sends monthly earnings information and other reports to Imagine Benefits Planning staff to ensure he retains his eligibility with the Social Security System and Texas' Health and Human Services.

Securing a funding source for Ricky's salary was a long-term financial goal, says Norine. The first step was to establish Ricky's capacity and reputation as an informative and instructive speaker and mentor for youth and adults with intellectual disability as well as family members and professionals. Attending and presenting at conferences on the principles of self-determination, risk-taking, decision-making and authority over money are essential themes in Ricky's life history that he regularly speaks about. Serving on a wide variety of state and local boards and providing testimony at board and legislative meetings built stamina, knowledge, and relationships. Creating a circle of support and keeping them engaged to encourage long-term friendship and commitment has been essential; Ricky says, "That's much more difficult than it seems. Too many people only have a circle of support that are their parents and perhaps a direct support staff. There's so much more to life."

Next, it was critical to connect with agency decision-makers who could waive the systems' educational and work history requirements to perform services as an instructor/trainer/teacher so that Ricky could deliver pre-ETS services. This was necessary to be able to bill for the services that Ricky delivers in schools and create funding for a long-term, stable job with a livable income. The system does not always use an approach to peer mentorship with qualifications related to a person's demonstrated capacity, shared experience, and related expertise in self-determination/self-advocacy. Initially when Ricky would speak at a

conference, it was assumed that he would not charge for his presentation because it would endanger his benefits. But Ricky challenged that and more.

And the impact of Ricky and Imagine's efforts is huge. As a teacher in classes where Ricky was delivering pre-ETS said,

Students see Ricky roll in and are surprised when he is their instructor. They ask for him.

If he isn't there one day, they want to know why. Several students have said they want a job like his; then they start talking about other things they can do that could lead to a job.

Ricky talking about his job and the supports he needs to get things done make the possibilities realistic for students.

Plus, Ricky models how it's okay to use supports and the ongoing need for a circle of supports.

For example, sometimes students that might read better than Ricky support him with reading the implementation materials. They all learn together about how to build their circle of support.

Ricky says that self-determination and self-advocacy are the most important thing and what he teaches the students, and he can use his lived experiences to make this real for the students. He says, "People have to plan stuff out, then they need to say how will it help them to get what they want, and then ask who can help them get and keep what they want?" He says that he also focuses on, when delivering interventions that have existing PowerPoints or other materials, "Needing to make sure that I'm ME. Being comfortable in my own skin. Being respectful. Remember when it's right to give the other person respectful language." Ricky knows how to connect with young people with intellectual and developmental disabilities and build relationships and that's essential to the impact he is having. His lived experiences enable him to do this effectively, maybe even more so than people that do not have those lived experiences.

By implementing these interventions Ricky models what it means for people with intellectual and developmental disabilities to lead. And he is also challenging who has the “expertise” to deliver research-based practices. Most people have never seen a person with lived experience with intellectual and developmental disabilities facilitate the delivery of research-based self-determination interventions, but Ricky shows students, teachers, and other people that they can. He says too often other places that are supposed to support people with disabilities never think about having people with lived experience support other people with intellectual and developmental disabilities. Systems need to change to make this happen.

They are making decisions about our lives – but we are the ones that have to live it. If things go the way they should, we can have a normal life like everyone else and be a part of our community. BUT you need to make sure that things are set up the way the individual needs so they have their needs met. If it’s not set up the correct way, it’s not going to happen.

Ricky emphasizes that in life and especially in work, he and other self-advocates have to build a circle and advocate for change. His circle helps him reach his goals. As he says to students, “Have the team around you to make sure you have a good life. If you don’t, then it is very difficult for a person with a disability to experience quality.” But it’s also bigger than each person’s circle or even Imagine. It’s the system. At Imagine, Ricky and Norine have been able to figure out how to make the system work for them – not that it couldn’t be better – but Ricky’s self-directed funding has been a bit part of him being able to live on his own and have more options around how his staff support him to work. And, they have been able to advocate for advocate for Ricky’s lived experience to be recognized as expertise, creating career pathways for him, and hopefully others that follow.

Norine says, “Imagine has come a long way, but we still have a lot of people that we can help. There need to be more opportunities for the career pathways Ricky has had and Ricky is already mentoring the next generation.” Ricky says, “I love Imagine. It has given me the opportunity to be a real person and to grow. And I still have a lot of growing to do.” And that push to continue growing is what leads Ricky to strive, as we all do, to make his work as a peer educator have more impact on kids and to go beyond just Imagine and the current projects. He has also gotten involved in inclusive research as a paid implementer. He’s supporting a research project, serving as a self-advocate facilitator of the Self-Determined Career Design Model (Dean et al., 2017; Shogren et al., 2020), a research-based self-determination intervention. The goal is to show through research that people with lived experience with intellectual and developmental disabilities can serve as implementers of research-based interventions and implement them with the same fidelity as anyone else and with greater contextual fit. Plus, he’s traveling and continuing to speak at conferences in Texas and across the country, like the AAIDD conference, to share how self-advocates can implement research-based practices, building careers and impacting outcomes. He wants this to be an option for more people with intellectual and developmental disabilities, and maybe even some day the expectation.

He says, for self-advocates that want to be teachers and implementers of research-based interventions, “don’t let nobody tell you ‘You can’t.’ Because you can, if you believe in yourself, provide good services, and get people in your circle that help you reach your dreams and goals.”

Ricky shares:

I hope that the students are getting something out of what I’m teaching them. Hoping to let them know that you have a voice and you can tell people what you need help with and

how they can help you. Self-determination is very important for all of us. We have to do it every day. If there is something out there that you see and you think that you can try to make a difference – please do it because you have to speak up for yourself. And, not just for yourself, for other people too. It's not always going to be easy. So take baby steps.

Conclusion

Ricky's advice to people with intellectual and developmental disabilities who want to have careers helping and supporting other people with disabilities to use their voice and to take baby steps is powerful. But, as a field, it is time for us to take giant leaps in inclusive research, policy, and practice. Table 1 summarizes recommendations to advance inclusive practice that were highlighted throughout this article. The leaders with intellectual and developmental disabilities featured in this Special Issue and working through the world are a new and emerging group of professionals and experts who are providing a path forward. We just have to, as a field, embrace this pathway and disrupt systems to redefine expertise and to dismantle systemic barriers to inclusive disability research, policy, and practice.

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Table 1***Recommendations to Advance Inclusive Practice***

1. Disrupt the status quo. Assume people with intellectual disability can implement evidence-based practices and build career pathways as disability professionals benefiting other people with intellectual and developmental disabilities.
2. Celebrate the value of lived experiences and configure supports to enable people with intellectual and developmental disabilities to share their experiences to support others with intellectual and developmental disabilities.
3. Recognize that people with intellectual and developmental disabilities can take on multiple roles and identities, including as self-advocates and as professionals in the disability field.
4. Fight to redefine expertise. Create jobs and job descriptions that enable people with lived experience to act as disability professionals when this is part of their chosen career pathway.
5. Seek out equal pay structures for people with intellectual and developmental disabilities who are pursuing careers as disability professionals. Utilize the resources provided by Social Security Administration and state Medicaid agencies for people with intellectual disabilities to earn a living wage.
6. Recognize that the ways that people with lived experience present and deliver interventions may look different or require different supports, but this can still lead to powerful outcomes.
7. Engage people with lived experience in developing and delivering interventions in a proactive, purposeful, and planful way.
8. Build circles of support that have high expectations for career options for people with intellectual and developmental disabilities. Ensure long-term, sustainable supports in the workplace to drive success.
9. Advocate for changes with agencies that set the requirements for who can deliver research-based practices and interventions in schools, communities, and disability systems.
10. Challenge researchers, policy makers and practice leaders to adopt practices that advance inclusive research, policy, and practice.

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Ricky Broussard¹, Norine Gill¹, Evan Dean², Karrie A. Shogren²

¹ Imagine Enterprises

² Kansas University Center on Developmental Disabilities

Note: Karrie Shogren wrote the introduction and conclusion to this paper, all other co-authors edited and reviewed. Ricky Broussard and Norine Gill shared information by responding to questions in writing, over email, and through conversations, which Karrie Shogren shaped into the narrative text about Imagine Enterprises and reviewed with Ricky and Norine. Evan supported developing some of the interview questions for Ricky and Norine and edited drafts of the narrative.

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This article highlights the power and possibilities of engaging self-advocates in the implementation of research-based practices. We provide examples from an innovative organization and its leaders, suggesting ways that we could disrupt the status quo of implementation of research-based practices in real world settings, merging work on inclusive research, implementation science, and disability justice and advocacy. People with intellectual and developmental disabilities must not only have opportunities to be included in the research process but also in the implementation of that research in their communities, enhancing outcomes and systems change in disability supports and services.

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presenting, has a microphone, and has the presentation on the flash drive. But, he says it's all about "Practice – Practice – Practice."

Ricky says that Imagine has always given him a chance to show up, to show he is dependable and do a good job and to build his career. Not everyone does this, and he wishes more disability service systems and potential employers did. Part of this has been figuring out the finances, which Imagine has had to think creatively about. Norine shares, "we have always looked for grants and funding opportunities that support both Ricky and the people who support him. Ricky is fortunate to have the Consumer Directed Services Medicaid waiver, so many of his personal care needs are taken care of by his staff. We helped to create his plan for transportation that keeps him on the road. Imagine compensates Ricky at a level that he uses the Medicaid Buy-in to maintain his long-term services. Imagine staff support him to ensure that he remains eligible for his benefits to implement his personal goals.

Securing a funding source for Ricky's salary was a long-term financial goal, says Norine. The first step was to establish Ricky's capacity and reputation as an informative and instructive speaker and mentor for youth and adults with intellectual disability as well as family members and professionals. Attending and presenting at conferences on the principles of self-determination, risk-taking, decision-making and authority over money are essential themes in Ricky's life history that he regularly speaks about. Serving on a wide variety of state and local boards and providing testimony at board and legislative meetings built stamina, knowledge, and relationships. Creating a circle of support and keeping them engaged to encourage long-term friendship and commitment has been essential; Ricky says, "That's much more difficult than it seems. Too many people only have a circle of support that are their parents and perhaps a direct support staff. There's so much more to life."

Next, it was critical to connect with agency decision-makers who could waive the systems' educational requirements to perform services as an instructor/trainer/teacher so that Ricky could deliver pre-ETS services. This was necessary to be able to bill for the services that Ricky delivers in schools and create funding for a long-term, stable job. The system does not always use an approach to peer mentorship with qualifications related to a person's demonstrated capacity, shared experience, and related expertise in self-determination/self-advocacy. But Ricky challenged that.

And the impact of Ricky and Imagine's efforts is huge. As a teacher in classes where Ricky was delivering pre-ETS said, "Students see Ricky roll in and are surprised when he is their instructor. They ask for him. If he isn't there one day, they want to know why. Several students have said they want a job like his; then they start talking about other things they can do that could lead to a job. Ricky talking about his job and the supports he needs to get things done make the possibilities realistic for students." Plus, Ricky models how it's okay to use supports and the role of a circle of supports. For example, sometimes students that might read better than Ricky support him with reading the implementation materials. They all learn together about how to build their circle of support.

Ricky says that self-determination and self-advocacy are the most important thing and what he teaches the students, and he can use his lived experiences to make this real for the students. He says, "People have to plan stuff out, then they need to say how will it help them to get what they want, and then ask who can help them get and keep what they want?" He says that he also focuses on, when delivering interventions that have existing PowerPoints or other materials, "Needing to make sure that I'm ME. Being comfortable in my own skin. Being respectful. Remember when it's right to give the other person respectful language." Ricky

knows how to connect with young people with intellectual and developmental disabilities and build relationships and that's essential to the impact he is having.

By implementing these interventions Ricky models what it means for self-advocates to lead. And he is also challenging who has the "expertise" to deliver research-based practices. Most people have never seen a self-advocate facilitate the delivery of research-based self-determination interventions, but Ricky shows students, teachers, and other people that they can. He says too often other places that are supposed to support people with disabilities never think about having self-advocates support people and make interventions better by delivering them. Systems need to change to make this happen. They are "making decisions about our lives – but we are the ones that have to live it. If things go the way they should, we can have a normal life like everyone else and be a part of our community. BUT you need to make sure that things are set up the way the individual needs so they have their needs met. If it's not set up the correct way, it's not going to happen."

Ricky emphasizes that in life and especially in work, he and other self-advocates have to build a circle and advocate for change. His circle helps him reach his goals. As he says to students, "Have the team around you to make sure you have a good life. If you don't, then it is very difficult for a person with a disability to experience quality." But it's also bigger than each person's circle or even Imagine. It's the system. At Imagine, Ricky and Norine have been able to figure out how to make the system work for them – not that it couldn't be better – but Ricky's self-directed funding has been a bit part of him being able to live on his own and have more options around how his staff support him to work. And, they have been able to advocate for advocate for Ricky's lived experience to be recognized as expertise, creating career pathways for him, and hopefully others that follow.

Norine says, “Imagine has come a long way, but we still have a lot of people that we can help. There need to be more opportunities for the career pathways Ricky has had and Ricky is already mentoring the next generation.” Ricky says, “I love Imagine. It has given me the opportunity to be a real person and to grow. And I still have a lot of growing to do.” And that push to continue growing is what leads Ricky to strive, as we all do, to make his work as a peer educator have more impact on kids and to go beyond just Imagine and the current projects. He has also gotten involved in inclusive research as a paid implementer. He’s supporting a research project, serving as a self-advocate facilitator of the Self-Determined Career Design Model (Dean et al., 2017; Shogren et al., 2020), with the goal of showing that self-advocates can serve as implementers and implement interventions with the same fidelity as anyone else and with greater contextual fit. Plus, he’s traveling and continuing to speak at conferences in Texas and across the country, like the AAIDD conference, to share how self-advocates can implement research-based practices, building careers and impacting outcomes. He wants this to be an option for more people with intellectual and developmental disabilities, and maybe even some day the expectation.

He says, for self-advocates that want to be teachers and implementers of research-based interventions, “don’t let nobody tell you ‘You can’t.’ Because you can, if you believe in yourself, provide good services, and get people in your circle that help you reach your dreams and goals.”

Ricky says, “I hope that the students are getting something out of what I’m teaching them. Hoping to let them know that you have a voice and you can tell people what you need help with and how they can help you. Self-determination is very important for all of us. We have to do it every day. If there is something out there that you see and you think that you can try to

make a difference – please do it because you have to speak up for yourself. And, not just for yourself, for other people too. It's not always going to be easy. So take baby steps.”

Conclusion

Ricky's advice to self-advocates who want to have careers helping and supporting other people with disabilities to use their voice and to take baby steps is powerful. But, as a field, it is time for us to take giant leaps in inclusive research, policy, and practice. The leaders with intellectual and developmental disabilities featured in this Special Issue and working through the world are a new and emerging group of professionals and experts who are providing a path forward. We just have to, as a field, embrace this pathway and disrupt systems to redefine expertise and to dismantle systemic barriers to inclusive disability research, policy, and practice.

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