Intellectual and Developmental Disabilities

Reflections on How What We Say, Do, and Acknowledge as Researchers Matters

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Abstract:	This article highlights reflections by the author on the importance of considering what we say, do and acknowledge in intellectual and developmental disability research. The goal is to advance thinking that can lead to personal and collective change in our approaches to truly share power and elevate the expertise of people with lived experience with intellectual and developmental disabilities in the movement for equity, inclusion, and disability justice. Implications for inclusive research, policy, and practice are discussed as is the need to engage in personal reflection and build new partnership for collective change.

Abstract

This article highlights reflections by the author on the importance of considering what we say, do

and acknowledge in intellectual and developmental disability research. The goal is to advance

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reflection and build new partnerships for collective change.

Reflections on How What We Say, Do, and Acknowledge as Intellectual and Developmental

Disability Researchers Matters

I recently was invited to deliver a public lecture at my university, summarizing my work in self-determination and disability as I was being appointed as a Distinguished Professor. At my university, this honorific is meant to recognize the highest levels of excellence in research, teaching, and service by University faculty. Preparing and delivering this lecture made me reflect on many things. First and foremost, it made me think about how I communicate and contextualize what I do and my values and goals for my work. It also made me reflect on how my personal and professional connections to disability have shaped my research, but how I have struggled, at times, to acknowledge and contextualize my positionality. It also made me reflect on how singular recognitions can fail to recognize the communities that advance the work being done and how this may inadvertently (or advertently, in some instances) further marginalize communities with lived expertise with intellectual and developmental disabilities in research.

Overall, preparing for this lecture has pushed my ongoing reflection about how what we say, do, and acknowledge as intellectual and developmental disability researchers matters and how we need to more explicitly consider this, discuss it, and identify new and different pathways forward as a research community if we want to continue to grow and challenge ableism in all forms and act as allies through our research (McDonald et al., 2023). This prompted me to write these musings in this perspectives piece to organize my thinking and to, hopefully, begin conversations with others who are thinking about personal and collective change in our approaches to truly share power and elevate the expertise of people with lived experience with intellectual and developmental disabilities in the movement for equity, inclusion, and disability justice.

What We Say

Theories, Terms, and Constructs

Academics, including myself, often pride themselves on developing new theories, new terms, and new constructs. And this can be critically important to advancing work in disability, generally, or in a specific subfield. Such work can advance thinking, policy, and practice in the field. A prime example is ongoing changes in terminology in intellectual disability and the underlying construct of disability (Schalock et al., 2007; Wehmeyer et al., 2008), as well as the introduction of the supports paradigm (Thompson et al., 2009). It is also reflected in the movement to more clearly address and name the intersectionality experienced by people with intellectual and developmental disaiblities, including the growing focus on DisCrit (Annamma et al., 2022) and black disability justice (Schalk, 2022). This is also true in more specific lines of work, like the evolution of my own work on self-determination (Shogren & Raley, 2022).

Academics typically acknowledge how new theories, terms, and constructs build on previous ideas; that is, we summarize how these new ideas reflect, build on, challenge, or change what has been learned from prior, accumulated knowledge about what works and what does not work. However, academics are often siloed – as so many of our systems are. Academic terms may not reflect what is being discussed or experienced in the real lives of people in the disability community and academic publishing does not typically reflect the voices of those with lived expertise with intellectual and developmental disabilities (Riches et al., 2020; Strnadová & Walmsley, 2018). Further, because many academics (including myself) are expected to be developing new ideas and new theories as part of our work, we have an incentive to introduce new terms, theories, and ideas. However, this can lead to multiple terms being used to refer to related constructs (e.g., self-advocacy, self-regulation, college and career readiness, self-

determination) and general confusion about where terms have evolved from and how they are

different from each other. It can also lead to a lack of focus on what matters to the disability

community when theories and research lines are developed (Pellicano & den Houting, 2022) as

well as the co-opting of terms and concepts that emerge from the disability community when

they are taken into academic theorizing, without acknowledgement of their roots in the disability

community. All of these factors likely contribute to the frequent confusion about whether a

term, like self-determination, refers to an outcome, a program, an intervention, a value, a right, or

a movement. And I increasingly wonder how this confusion contributes to the lack of adoption

of research in policy and practice and the lack of integration and elevation of what is learned

from policy and practice and the disability community into research and theory, particularly

when this learning comes from communities that are multiply marginalized by systems of

oppression.

Operationalization

The emergence of academic theories and resultant academic jargon can lead to

operationalizing of concepts and programatizing of ideas. And, at times, this has value. But,

without true engagement with the disability community, this can create a separation from the

values of communities that drove the ideas in the first place. This may contribute to solutions

and innovations that are not aligned with the needs and values of the community and all of its

members (Adams, in press; Beckwith et al., 2016; Bottoms et al., 2016; Scott et al., 2021).

While operationalizing and developing interventions and programs and policies can be positive,

it can turn dangerous if the original right or values-based orientation is lost. It can lead to people

claiming that they are, for example, "doing self-determination" in their practice or in service

delivery, while failing to consider systems of oppression linked to institutional ableism and

racism that do not create meaningful opportunities for true change aligned with disability justice-oriented views of self-determination (Smith & Routel, 2010). Further, failing to acknowledge the emergence, history, and community advocacy that led to the evolution and adoption of terms, like self-determination, in the disability community has implications for who has power in naming and claiming knowledge and choosing terms, theories, interventions, and programs. People with intellectual and developmental disabilities have individually and collectively advocated for self-determination and identified what they value and need (Finn et al., 2000), but how often do we acknowledge this?   To navigate through these barriers, I am struck by the need to continue to move toward centering the expertise of people with intellectual and developmental disabilities in academic research and ask:

- Do we fully acknowledge this expertise and elevate and center it in our work particularly as theory and frameworks and interventions and programs are being developed in academic sectors?

- How do we ensure that people with intellectual and developmental disabilities' contributions – even if not in scholarly texts or journals because those spaces have not been open to these contributions (Riches et al., 2020; Strnadová & Walmsley, 2018) – are recognized as driving change in the field, as much as academic theorizing?

- How can lived experience become the metric for whether theories are meaningful and impactful?

Advocacy

I am also striving to recognize the individual and collective advocacy by people with intellectual and developmental disabilities through history. Disabled people have communicated - in a range of ways publicly and privately - the desire to be supported, not fixed or cured or

managed by systems (Finn et al., 2000), and to have the right to choose terminology that

describes them and how it is used (Andrews et al., 2019; Spread the word, n.d.). But this has

typically been slow to be reflected in diagnostic and classification systems related to intellectual

and developmental disabilities, like those forwarded by the American Association on Intellectual

and Developmental Disabilities and the American Psychological Association. Even the use of

acronyms to describe people remains common, including in this journal, despite advocacy from

the community about preferences regarding using acronyms to describe people, and a growing

focus on bias-free language (American Psychological Association, 2023).

As an example, the 12th edition of the AAIDD Terminology and Classification Manual

was the first manual, that I am aware of, that actively acknowledged getting the input of people

with intellectual and developmental disabilities on terminology and implementation (Schalock et

al., 2021; Shogren, 2021). While this is a positive step, this is clearly not the first time that the

efforts of people with intellectual and developmental disabilities have led to change in

terminology and supports (e.g., "Rosa's Law," 2010).

- So, how is this the first time that academics have publicly acknowledged seeking this
  input, thereby communicating the importance?

- How often are people with disabilities involved in decisions about priorities for
  terminology and research, including how words are used, how grant funding is
  allocated, how information is disseminated, and what changes are needed in theory
  and terminology?

Recent examples, such as the designation of people with disabilities as a health disparity

population and push for changes in the mission statement of NIH, further highlight how the

disability community has had to advocate for their voice to be acknowledged in academic and

research funding spaces (Iezzoni & Swenor, 2023; Kennedy & Swenor, 2023). This shows how expertise of people with lived experience with disability is often not viewed as equal to expertise supposedly held by those without disabilities, without significant advocacy.

Inclusive Research, Policy, and Practice

All this occurs despite an increased focus on inclusive research and community-engaged scholarship, and powerful work across the world over an extended period of time in this area (Bigby et al., 2014; de Haas et al., 2022; Frankena et al., 2019; García Iriarte et al., 2021; Hughes & Schwartz, in press; Kramer et al., in press; McDonald & Stack, 2016; Nicolaidis et al., 2019; Nind et al., 2016; O'Brien et al., 2022; Schwartz et al., 2020; St John et al., 2018; Stack & McDonald, 2014; Vega☐Córdova et al., 2020; Walmsley et al., 2018)[1]. This raises the question of how we change who has the power to shape research, policy, and practice.

- How can people with intellectual and developmental disabilities voices be recognized as holding the same value as others that are part of the research process?

- How can these voices be the default sources of expertise, rather than the voices that always have to advocate for change in what "academics" have established?

- How can we begin to change how we define what an "academic" is – can't lived experience be just as meaningful to being an "academic" as having PhD or similar degree?

I am constantly reflecting on this in my own work. I remember my first (and only) solo-authored book about self-determination and wanting to use "we" throughout to acknowledge the

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[1] It should be noted this is not a comprehensive review or list of all inclusive research efforts across the world; many have been missed and for this I apologize. There are multiple leaders working inside and outside academic spaces that are leading change and advancing inclusive research, policy, and practice.

many others that contributed to the work and its implementation. The publisher required a note at the beginning of the text about my use of we, to clarify that I was using "we" to refer to myself, my colleagues, and the readers, given that we were all working together to understand self-determination and teach students about it. The need for a note has always stuck with me, as I have tried, throughout my career, to model the use of "we" as I am certainly not doing my work alone. But when I used "we" then I'm not sure I had deeply interrogated what "we" I was referring to. In this book, I defined "we" by referring to other researchers and professionals that were advancing the work– which at that time was not very inclusive of people with intellectual and developmental disabilities, despite people with intellectual and developmental disabilities being key sources of information not only for my work but also contributors to all the examples and solutions described in the book. While I was seeking to engage in inclusive research and adopting some principles in my day-to-day work at this time, it was not the norm in the spaces I was working in, and I did not have the language or experience to fully interrogate this issue. So, I am now asking continuously asking myself:

- What "we" did I actually mean then and now?

- How can I be a part of changing systems that struggle (or actively fight) the "we" including people with intellectual and developmental disabilities as equals, as experts, as just as much of a professional or a researcher as I am, particularly, as I am now in a position of power, afforded by tenure, grant funding, and my identities?

Elevating Lived Experience and Expertise

In my current work, I try to articulate and embody that I believe "we" refers to the collective lived experience of the disability community that has directed the focus on living self-determined lives, particularly members of the disability community who are multiply

marginalized by systems of oppression because of their communication, language, race, ethnicity, gender identities, and other marginalized lived experiences (Annamma et al., 2022; Goode et al., 2017; Hughes, 2022; Johnson, 2023; Johnson et al., 2021; Kover & Abbeduto, 2023; Schalk, 2022). Although I will admit I have much more learning and listening to do to fully center issues of intersectionality in my work and in my partnership with the disability community, I want to strive toward elevating lived experiences to drive the future of intellectual and developmental disability research.

It is also critical for me to acknowledge that academics were not the first people to identify what self-determination is and its power and meaning to marginalized communities (Ward, 1988, 1996, 2005).   The millions of people with intellectual and developmental and other disabilities who fight and fought every day to self-determine their lives are the ones that know what self-determination means (Williams, 1989). The collectives that elevate our recognition of intersectionality and the lack of focus on people of color with intellectual and developmental disabilities, know what self-determination means (Kafai, 2021; Sins Invalid, 2019). This is where knowledge exists and where it grows, but when we take terms, ideas and values identified in these spaces and then build theories, programs, and disseminate in academic spaces, do we adequately acknowledge these contributions and elevate and center these leaders and this expertise? Or, do we co-opt this knowledge and fail to recognize and celebrate its origins and partner with communities in its advancement, ultimately limiting impact?   The question I want to keep asking myself is:

- How I can give up my power and center lived experience in academic work?

- How can I elevate the "we" and give up my power to direct the process and change?

    I think about something Walmsley et al. (2018), wrote about inclusive research and how

we can shift the paradigm through inclusive research to academic researchers becoming a

"means to an end, no longer allies, but expert consultants who carry out the wishes of people

with a disability" (p. 753). I also think about what Bob Williams, a disabled leader, who as the

Commissioner of the Administration on Developmental Disabilities, said in 1989 when pushing

forward a greater focus on self-determination.

> we [people with disabilities] don't have to be told what self-determination means. We
>
> know it is just another word for a life filled with rising expectations, dignity, respect and
>
> opportunities (Williams, 1989)

This paralleled work in the U.S. Department of Education, Office of Special Education and

Rehabilitative Services (OSERS) when disabled staff in the office led a self-determination

initiative (Ward, 1996). The goal was to support youth to develop "the attitudes and abilities

which lead individuals to define goals for themselves and to take the initiative in achieving those

goals" (Ward, 1988, p. 2). This led to the Secondary Education and Transitional Services for

Youth with Disabilities Program within OSERS supporting 26 model demonstration projects to

identify and teach skills necessary for self-determination (Ward & Kohler, 1996). However, as I

reflect on my work in self-determination, I ask myself:

- To what degree did people with disabilities remain leaders and full partners in this work,

  when it transitioned into academic spaces?

- To what degree did the emphasis on creating opportunities remain a focus after these

  ideas transitioned from the visions of the disability community to programs of research in

  universities?

- Who were the leaders of these grants after they moved out of the policy context? How much of the history of disability leadership and the integration of lived experience into this work was maintained?

- How much have the contributions of disabled leaders (Ward, 1996; Ward & Meyer, 1999) has been lost, particularly to new and emerging scholars?

- How have the voices of BIPOC and LGBTQIA+ leaders with disabilities been integrated into this policy, research, and practice-related work (Forber-Pratt, in press; Hughes, 2022; Schalk, 2022; Sins Invalid, 2019)?

- And, how much has this lack of centering of lived expertise contributed to the programatizing of values like self-determination (including in my own work)?

- Have we, as we have sought to develop research or evidence-based practices, perhaps at times lost sight of the ultimate outcome that the disability community is advocating for, that is for change in society and the right to have opportunities to have voice and to live self-determined lives?

Leaders like Williams and Ward created a context where non-disabled teachers, families, researchers, and communities could begin to understand what self-determination means, but:

- Have we fully acknowledged these contributions and elevated them and other disability and intersectional identities as the work continues?

- Have we sought to build disabled voices in academic spaces and advance equitable opportunities to be a part of research?

- Or have academics (including myself) taken and exerted control, knowing that academic spaces are typically not inclusive of all the voices and experiences that initiated the focus

on these values and outcomes and historically have necessitated masking of those

identities if not outright exclusion?

These reflections are pushing me to ask myself and infuse in my work a greater focus on

sharing power in naming, defining, classifying, and researching the values disabled leaders are

communicating outside of academic silos throughout history and in the present. I want to learn

from, celebrate, and elevate these contributions, and make them part of our typical academic

activities and challenge our academic systems to more fully embrace partnerships, sharing of and

giving up of power, and inclusive research models and practices. Ultimately sharing power and

knowledge has the potential to advance outcomes, so how do we break down the barriers and

fundamentally change our approaches? This requires rethinking not only what we say but also

what we do. It requires us to directly name issues of intersectionality, ableism, and the barriers

that academic spaces create to centering disability voices and give up power (McDonald et al.,

2023; Shogren, 2022).

- How do we embody "all means all" in the entirety of the research process?

What We Do

Clearly, the questions I raised in the previous section provide an impetus to take action to

make change. Action steps for change must be embraced not just by disability researchers but

also by the systems that support them (e.g., academic departments, research administrators,

university administrators, grant funders), with direction and leadership from the disability

community (Adams, in press; Allan et al., 2019; Bosma, in press; Bottoms et al., 2016;

Broussard et al., in press; Camacho et al., in press; Forber-Pratt, in press; Linnenkamp, in press;

Milne, in press; Myers, in press). A concrete focus on bringing together lived experience with

research, policy, and practice is needed, but the resources and the systemic changes to do so are also needed.

- How do we do this?
- How do we counter the systemic ableism (Lewis, 2022) that pervades academic systems and shapes our individual and collective behaviors?

Ongoing Learning

I don't have all the answers, but I'm trying to learn and be open about my need to learn and grow– especially by trying to engage in inclusive research and hiring as well as by more fully engaging with writing, activities, and other learning opportunities driven by the disability community and by disability justice scholars. I'm also trying to bring my full self to my work and stop hiding my disability identity to support safer spaces for current and future disabled academic leaders, as my identities have fundamentally shaped my work. As I shared in my AAIDD Presidential address (Shogren, 2022), my shift to studying self-determination during my graduate training was highly personal, shaped by my sudden and jarring loss of personal self-determination when my disability emerged as an undergraduate student. During this time, I experienced, for myself, what the loss of a sense of personal agency felt like and how systems of oppression created barriers. My disability has become less visible to others (due to advances in health care), but no less central to my daily life or identity. I am continuing to explore how the stigmatization I experienced in academic spaces when my disability was visible shaped masking my disability identity when I had the privilege of being able to do so. I acknowledge that not everyone has that privilege and that the "disability hierarchy" creates significant barriers for people with intellectual and developmental disabilities, but I want to use the privilege that I do hold to seek to build safer spaces for current and future disabled colleagues.

I also want to consider terminology that creates divisions and centers power in one group or in one space. For example, I believe terminology that defines a "researcher" must be further considered. Can't a self-advocate be a researcher as well? We frequently use the co-researcher title to communicate that the researchers with lived experience with intellectual and developmental disabilities are fully participating members of a team, but how long will this be needed? Such demarcations remain essential at this point in time to communicate the added value of inclusive research (Walmsley et al., 2018) and to hold others accountable to centering the contributions of people with intellectual and developmental disabilities (Schwartz et al., 2019); but:

- Can we strive to accept the "we" in this work as equal?

- Can we work towards describing "who did what" in inclusive research (Garcia-Iriarte et al., 2009)?

- Can we work towards recognizing all contributions to research as critical to having an impact?

I hope we can, as a field, continue to strive to challenge the bias and systemic barriers that are created in academic spaces to sharing power (Dolmage, 2017) and recognize the specific impacts for people with intellectual and developmental disabilities (e.g., difficulties with funding personal supports, challenging assumptions about contributions that can be made by people with intellectual and developmental disabilities) to make real, systemic change.

The shifts we are experiencing as a field and society create opportunities to build spaces where each person can safely be themselves and can make meaningful contributions; however, it will take significant and substantial work to make this a reality in academic spaces as well as in other spaces in society. Change must be fostered and supported in academic spaces by people,

like me, that currently have power because of tenure and academic career status. We have to be

being willing to support leadership by disabled leaders. We have to be willing to use our power

not to protect existing systems but to advocate for and enact systemic change. Embracing the

fact that none of us fits into one label or category and many of us have shared and masked

identities can create space where steps can be taken to confront the ableism that has, for too long,

led to too many disabled people not being involved in shaping and creating academic and other

"professional" spaces. It can help us more directly contribute to building anti-ableist and anti-

racist spaces inside and outside of academic systems (Annamma et al., 2013; Johnson, 2023;

Johnson et al., 2021; Scott & Shogren, in press).

Inclusive Research and Dissemination

Breaking down these barriers has the potential to deeply impact our work and how we

think not only about research but also about dissemination of research and the partnerships

between community members, researchers, practitioners, policy makers, and all members of

society. Engaging in inclusive research and building an inclusive research team has pushed me

to think more concretely about how we use language in research and dissemination. In my own

work, I've always been very focused on terminology and theory, and continue to believe that

what we say matters. But I have started to recognize that in my professional work I have been

trained and socialized to be highly theoretical and to use academic jargon. I have theorized self-

determination, and while this may be valuable and make contributions, I was not taking the

critical, next step to figure out how to make this theory meaningful in day-to-day life. I was not

partnering with people that would use the knowledge in their day-to-day life and striving for

plain language communication. For example, Figure 1 shows the theoretical framework for self-

determination that we introduced in the early development of Causal Agency Theory. However,

Figure 2 shows how we increasingly talk about and seek to disseminate information on self-determination and advancing it in the lives of people with disabilities; shaped by the people with disabilities, teachers, family members and others that have collaborated in this work and made very clear Figure 1 does not support them to access and use what we am trying to communicate in their day-to-day lives. I've appreciated the push by members of my inclusive research team to simplify the jargon and seek to jointly figure out the meaning we are trying to communicate and to recognize that this does not have to be an "or" but instead can be an "and" so long as we take the steps to create a true "and" and equal valuing of all perspectives and needs in dissemination.

Key to elevating all voices, and rightfully acknowledging the role of people with intellectual and developmental disabilities in academic work means making clear what we are saying and staying attuned to the words, issues, and needs the disability community is articulating.

- Do we need more complex words, or do we need change in society?

- How can the two work together, rather than operating in silos?

- How can we be open to interrogating the possibility that there are times that solely focusing on academic jargon and terminology acts to maintain control over language and knowledge by academics and does not foster the democratizing of our work and the creation of spaces for collaboration to drive change?

- Could true, equitable, power-sharing lead to more impacts?

- Could questioning ourselves in these ways lead to actions that allow us to dismantle the systems of discrimination and marginalization that limit the voices and lived experiences of people with disabilities in academia and stop the distinctions drawn between academic and intellectual and developmental disability communities,

particularly when we center the contributions of those with the most complex

communication support needs and that experience other forms of intersectionality?

- If we seek to stop inadvertently (or advertently because of requirements of academic

  systems for publication and impacts) co-opting terms and movements to gain power

  over expertise and instead share power, what could the outcomes be?

Embracing the movement towards plain language in scientific communication and

recognizing that people with lived experience have the right and the expertise to inform, guide,

and lead research communication across all phases and types of research is essential (Broussard

et al., in press; Camacho et al., in press; Milne, in press; Nygren, 2022; Walmsley, 2004;

Weintraub, n.d.). Rather than being stuck in current systems that limit these opportunities, how

can we change these systems from the onset to enable leadership by people with intellectual and

developmental disabilities in research as well as in the dissemination and implementation of

research?

What We Acknowledge

Thinking critically about what we say and do also means we need to reflect on what we

acknowledge.   I have always been uncomfortable with singular recognition, as we are all

interdependent, even in current research structures. The irony that my reflections in this lecture

will be published and cited as a single-author publication, despite the fact that others that have

contributed to this work and my thinking is not lost on me. This makes me continue to wonder

how I (and the collective we) can elevate the range of contributions that propel research, policy,

and practice forward. Even in attempting to identify and cite multiple sources and exemplars of

inclusive research, policy, and practice is difficult and limited in this piece and, I would argue, in

current academic publishing structures. This, unfortunately, often leads to overlooking and a

lack of engagement with significant contributions or bodies of work because of our silos and the

lack of engagement of many academics in the growing range of information formats,

dissemination strategies, and spaces where people are coming together to learn and advance

disability justice.

Singular recognitions, and more frankly the pressures around authorship and the

development of new theories and ideas within university systems can contribute to failing to

recognize all contributors and leading to ideas being co-opted from communities, like the

disability community, something people from marginalized communities have long discussed.

Going back to my example from my early book and my use of "we," I think even then, I was

beginning to grapple with something I see in academia, that generating ideas leads to personal

gain, even if the intention is to try to move research and practice forward. We rarely talk about

how I (and the collective academic we) benefit personally from creating theories and

assessments and interventions that are derived from concepts, like self-determination, that come

from the disability community. However, not acknowledging this means that I maintain my

power, and am not striving to create spaces where power is shared, even if we are not there yet.

In preparing for my lecture, which was required to be singular, I made a deliberate

decision to use "we" to refer to the work, but realized I need to be very clear on what I meant as

a first step to recognize the harms of the singular recognitions. In defining the "we," I said:

> I feel it important to acknowledge that everything I do builds on words, terms, and ideas
> that the disability community itself has identified, elevated, and challenged me and our
> research community to focus on. I only hope that through my past and ongoing work I
> can elevate that knowledge and help challenge systems in our society that struggle to hear
> and accept… So, I will be using the collective "we" throughout my talk today to actively
> recognize, acknowledge, and honor the fact that all of my work is rooted in what the
> disability community has fought for, advocated for, and deserves as members of our
> society.

My inclusive research team also created two videos that elevated the voices of people with disabilities on why self-determination and why inclusive research matters, attempting to highlight to a largely academic audience that while I am talking about the work, it is people with lived experience that are driving the work, shaping it, and pushing the field to do better through our inclusive research approach. One of those videos focused on our efforts to embody inclusive research and hiring in all of our projects, taking steps to share resources and empower the disability community to be equal partners in research, even if there are still systemic barriers related to compensation and hiring that we must challenge and that I seek to challenge, using the power that I have inside systems.

I hope if we can all begin to engage in critical reflections, we can create safe spaces to further explore these issues and advance joint recognitions and equal acknowledgments across all sectors of our work. Acknowledging, however, is only a first, but necessary step to make systemic change. I hope that we can think more as a community about how to create equity in the recognition and honors bestowed on the work of the disability community. I also want to create more spaces for people to write their own stories, and have these stories be viewed as equitable contributions to generating and communicating research ideas and practices. With colleagues, we are seeking to take steps in these directions. For example, we have an inclusive team co-editing a text on research-based practices in intellectual disability and are including chapters written by people with lived experiences with the research-based practices as equivalent chapters to academic chapters reporting on the research-based practices in the text. We are also asking all research-based practices chapter authors to analyze the existing research through an equity lens, to recognize and acknowledge who has been centered in research throughout history. I believe, it behooves us as a field to take steps within existing systems *as well as* to seek to

make broader changes to create new systems that are inclusive from the outset. I hope

publishing by and with authors with lived experiences, especially when talking about complex

issues related to research, equity, and inclusion, can become a norm not an exception (Strnadová

& Walmsley, 2018).

Ultimately deep work is needed to disrupt systems. It is not singular work, nor it is the

work of traditional academic teams. Just as universal design articulates that retrofitting is never

the best solution, the same is true here.

- How can we change the fundamental ableist assumptions of research systems to

  challenge who is centered and who is recognized as driving knowledge forward?

- How can we expect inclusive research teams and focus on building the structures and the

  relationships to center them?

I don't have all the answers, and I alone cannot find them. But I hope "we" – and by we, I

include the disability community - can increasingly partner to make change inside and outside

the system and identify and take personal action steps and seek collection action. I look forward

to learning from others and doing more listening and more sharing of power, centering the lived

experiences of communities that have developed critical knowledge but have been excluded from

current academic systems because of ableism, racism, and other forms of systemic oppression. I

hope we can continue to come together as a field to identify the changes that we can personally

undertake and the changes that are needed in systems. Ultimately, I believe we must partner to

create a movement for collective spaces where we can come together to learn together and drive

real, intersectional change that creates real power sharing. I hope to continue to be part of this

process and to continue to reflect on and learn from others to advance equity and justice.

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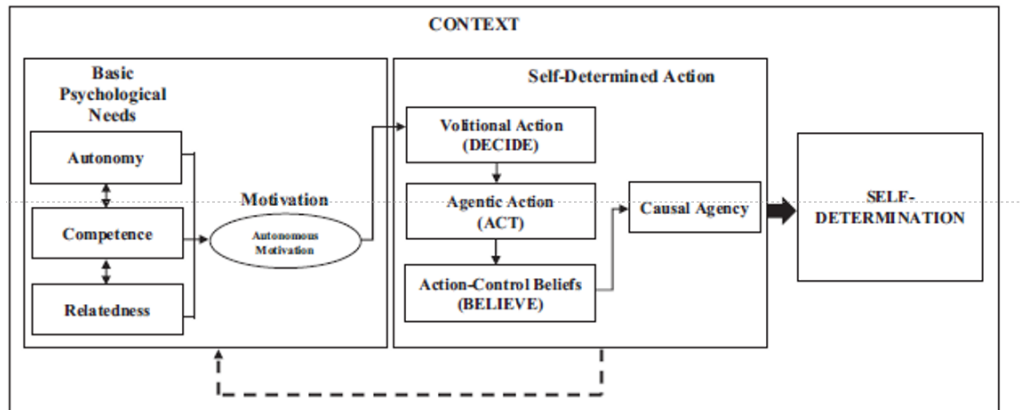
Figure 1

The development of self-determination. Copyright Kansas University Center on Developmental
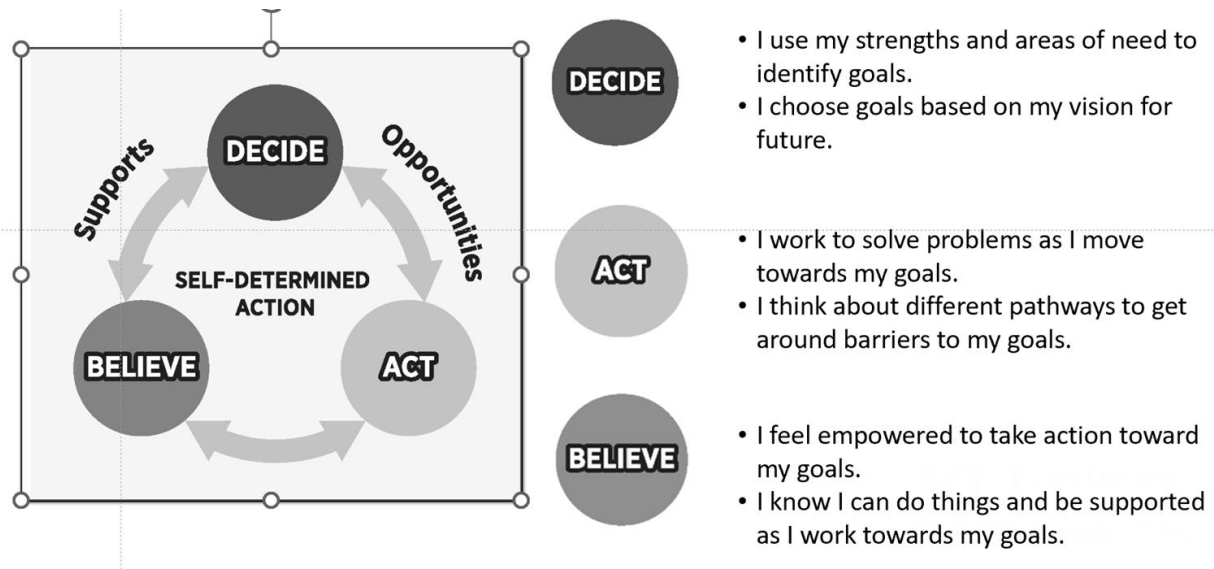
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Figure 2

Self-determined actions. Copyright Kansas University Center on Developmental Disabilities

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