CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association | Association canadienne d'études sur le handicap

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association
Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

From Loss to Gain? Identity Trajectories of People with Acquired Communication Disabilities

De la perte vers le gain? Trajectoire identitaire d’une personne acquérant un handicap communicationnel

Alexandra Tessier, Ph.D., M.P.O.
Postdoctoral Researcher
Département d’orthophonie, Université du Québec à Trois-Rivières
Centre interdisciplinaire de recherche en réadaptation et intégration sociale
alexandra.tessier@uqtr.ca

Abstract

This article examines the identity trajectories of people who acquired communication disabilities, arguing that their transition from a non-disabled identity to a disabled one is deeply shaped by societal ableism, dominant narratives of tragedy, and the limited scope of traditional speech-language therapy practices. Although social models of disability have entered clinical discourse, intervention remains often focused on correcting impairments and normative communication. Drawing from critical disability studies, including affirmative models of disability, crip futuralities, and concepts such as *crip doulaing* and *disability or deaf gain*, this article reflects on how people with acquired communication disabilities could navigate identity disruption, loss, and renegotiation. The paper argues that exposure to positive disabled experiences, communities, and narratives can serve as a transformative counterweight to dominant deficit-based understandings of acquired communication disability and an ableist society, offering newly disabled individuals alternative and desirable futures. The notion of *disabled gain*, inspired by deaf studies concept *deaf gain*, is proposed as a potentially valuable framework for reimagining communication disability beyond loss. Ultimately, this reflection calls for a deeper exploration of how people with acquired communication disabilities develop affirmative identities, particularly through connections with disability communities and artistic practices.

Résumé

Cet article examine les trajectoires identitaires de personnes ayant acquis un handicap communicationnel et argumente que leur passage d’une identité non handicapée vers une identité handicapée est profondément forgé par le capacitisme de la société, les récits dominants de la tragédie et la portée limitée des pratiques traditionnelles en orthophonie. Bien que des modèles sociaux du handicap aient fait leur entrée dans le discours clinique, l’intervention demeure souvent centrée sur la correction des incapacités et la

normalisation de la communication. S’appuyant sur les études critiques du handicap, notamment le modèle affirmatif, les futuralités crip, ainsi que des concepts comme le *crip doulaing* et le gain handicapé ou sourd, cet article propose une réflexion sur la manière dont les personnes avec un handicap communicationnel acquis peuvent naviguer la perturbation identitaire, la perte et la renégociation. Il avance que l’exposition à des expériences, des communautés et des récits positifs du handicap peut constituer un contrepoids transformateur aux compréhensions déficitaires dominantes du handicap communicationnel acquis et d’une société capacitiste, en offrant aux personnes nouvellement handicapées des futurs alternatifs et désirables. La notion de gain handicapé, inspirée du concept du gain sourd en études sourdes, est proposée comme un cadre potentiellement fécond pour réimaginer le handicap communicationnel au-delà de la perte. Cette réflexion appelle à approfondir l’exploration des manières dont les personnes ayant un handicap communicationnel acquis développent des identités affirmatives, particulièrement grâce à leurs liens avec des communautés handicapées et des pratiques artistiques.

Keywords
Communication disability, speech-language therapy, social participation, affirmative disability model, critical disability studies, disability gain, disability identity, acquired disability, crip futurities

Introduction

In Québec, speech-language therapy is a discipline that developed in close relation with medicine (Julien Prud’homme, 2003). In line with this medical conception of disability, the role of speech-language therapists has long been centered exclusively on the person and their impairments, with the objective of “helping” the person communicate as closely as possible with the norm. Despite the emergence of a more inclusive vision within speech-language therapy and the teaching of social models of disability, which highlight the role of the environment in shaping the experience of disability and social participation (Christopher Constantino et al., 2022), clinical practice often remains focused on improving the individual’s communication skills. Yet, beyond disabling situations and the role of environmental factors, a positive disability identity can be crucial for living a

fulfilling disabled life. This reflection examines the construction of disability identity among people who acquire an impairment that leads to experiencing communication disabilities[1]. Specifically, this article considers how positive disabled life experiences may inform the support offered to people who have become disabled as they transition from a non-disabled identity to a disabled one.

This reflection is grounded in my trajectory as a white, non-disabled woman trained as a speech-language therapist and now a postdoctoral researcher. My research is situated primarily within rehabilitation disciplines, particularly speech-language therapy. My work is rooted in a social and critical understanding of disability and aims to improve the inclusion of people with communication disabilities by developing transformative speech-language therapy practices that support their participation and emancipation. As a researcher working on issues that directly concern people living with communication disabilities, I strive to adopt participatory methodologies that recognize and value their experiential knowledge and that fully involve them in the research I conduct. This article is part of a formal effort to pursue further training in disability studies, and an earlier version of it was submitted as coursework within the graduate microprogram Handicap et sourditude: droits et citoyenneté[2] at the Université du Québec à Montréal. This article

[1] The distinction between impairment and disability is important. According to the Human Development Model – Disability Creation Process (Patrick Fougeyrollas et al., 2020), impairment refers to the embodied condition experienced by the individual, which can sometimes make life more difficult, messy, or painful. Disability, or disabling situations, occurs when a person is confronted with an environment, including other people, that does not allow them to carry out their life habits or to fully exercise their rights and citizenship. Given that the focus of this article is on disability identity, most of the time, I use the expression “people with acquired communication disabilities” to designate individuals who acquire an impairment later in life that can lead to communication disabilities.

[2] It could be translated in English by “Disability and Deafhood : Rights and Citizenship”

shares my reflections on the relevance of mobilizing theories and concepts from critical disability studies to develop emancipatory practices in speech-language therapy, particularly for people with acquired communication disabilities.

Becoming Disabled in an Ableist Society

Several conditions acquired later in life can affect a person’s communication. For example, brain injuries, such as strokes, traumatic brain injuries, or neuroevolutive diseases, can all have repercussions on a person’s communication, whether in their ability to use or understand words and sentences (language), their speech, their reading, their writing, or even how they use communication, for instance by following social conventions in interactions (pragmatics). People with acquired communication disabilities have most often grown up in an ableist society, referring to a system of oppression toward disabled people, including the stereotypes, prejudices, and discrimination they face (Kathleen R. Bogart and Dana S. Dunn, 2019). Their identity has therefore been constructed within this society as non-disabled. Rosemarie Garland-Thomson (2016) explains how many human beings will experience disability at one point or another in their lives, but that most are not born disabled and do not get acculturated to this identity in the way that most people do for other identities, such as race or gender.

Scientific writings on aphasia — a condition acquired later in life that affects a person’s ability to speak, understand, read, or write — are useful for understanding the identity trajectory of people who acquire an impairment that leads to communication

disabilities. It has been reported that the onset of aphasia disrupts a person’s biographical experience and confronts them with an identity change (Rianne Brinkman et al., 2025). Aphasia has even been described as a potential identity thief (Barbara Shadden, 2005): suddenly, the person becomes disabled and may experience this change as a tragedy, which aligns with representations of disability often circulated in our ableist society (John Swain & Sally French, 2000). Cathy McCormack and Bethan Collins (2012) explain that by internalizing this dominant view of disability, many people who become disabled adopt a negative self-image and assume orientations to disability that are either normalizing or resigned, and that, in both cases, perceive disability as undesirable.

Imagining Desirable Disabled Futures

Disability studies, and later critical disability studies, emerged in reaction to this personal and tragic view of disability and propose a politicization of disability (Normand Boucher, 2003). Alison Kafer, in her book Feminist, Queer, Crip (2013), argues that by enclosing disability within a monolithic block tied to the body and outside the political realm, it becomes impossible to imagine other disabled futures. She proposes thinking about the future of disability and the future of disabled people as political decisions. For example, she questions the assumption that the eradication of disability would necessarily be the best future for disabled people and instead suggests considering historical ableism and the oppression faced by disabled people to explain the supposed naturalness of this “good” future. Alison Kafer offers avenues for imagining more accessible futures, where

disability is understood differently, as a political state that is valid and integral. These narratives of desirable futures must also be part of the discourses heard by people acquiring communication disabilities, in order to better support them in negotiating their identity and to offer them a positive alternative to an unhappy future or becoming.

Rosemarie Garland-Thomson (2016) proposes that it is possible to prepare for and learn how to become disabled, and that this requires not simply living as a disabled person who tries not to be disabled. She shares her own experience of learning to become disabled and emphasizes that the changes are located in her consciousness rather than in her body. She summarizes that becoming disabled means moving from isolation to community, from ignorance to knowledge of who one is, from exclusion to access, and from shame to pride. Simi Linton refers to this process as claiming disability (1998). She offers as an example her personal story of a young woman with a spinal cord injury who learned, together with other people with the same condition or traumatic brain injuries, to become disabled during their several months stay in a rehabilitation hospital (Simi Linton, 2006). Stacey Park Milbern (2023) referred to this care work around disabled birth as crip doulaing. In her conversation with Leah Lakshmi Piepzna-Samarasinha (2023), she explains the importance of naming this invisible work, often carried out by disabled people of colour, and yet necessary for learning how to navigate an ableist society as a disabled person. Milbern and Piepzna-Samarasinha argue that using the term crip doulaing also makes it possible to reverse the perception of becoming disabled as death or tragedy into that of a birth, and of developing a sense of belonging to a disabled space where one can be welcomed by other disabled people. Alison Kafer (2013) also emphasizes the

importance of community in imagining a desirable disabled future. While people she met throughout her rehabilitation trajectory announced a dark and sad future, she reports that it was other disabled people who convinced her that she could imagine a future full of opportunities, that she could dream of a full life and belong to a community, again underscoring the importance of crip doulaing in adopting a vision of a desirable disabled future.

Yet in speech-language therapy, although the risks of life with an acquired impairment leading to communication disabilities are well documented, its benefits are very little known, if at all. The richness of life with an acquired communication disability is not a topic that is often foregrounded in speech-language therapy practice or investigated in research to date. On the contrary, a significant portion of research on speech-language therapy interventions aims to “correct” communication and bring it closer to the norm, which contributes to reinforcing the idea that disability is undesirable. However, integrating positive narratives of life with a communication disability and a view of disability consistent with the affirmative model of disability would allow speech-language therapists to better support newly disabled people in this renegotiation of identity and foster the emergence of a desirable future with disability. According to Cathy McCormack and Bethan Collins (2012), this accompaniment in one’s relationship to disability is a key element in occupational therapy practice, and I would argue that the same is true for speech-language therapy. Considering Paul Ricoeur’s (1988) theory of narrative identity, which proposes that identity is constructed from the stories people exchange with one another, the way a speech-language therapist perceives and explains different

communication disabilities could be a lever for constructing a positive identity with disability and for developing emancipatory practices. Given the role of community in imagining a desirable disabled future, it would be interesting to explore how spending time with other people with communication disabilities contributes to building a positive identity of life with an acquired communication disability.

Reframing Disability Identity through the Affirmative Model of Disability

The affirmative model of disability can be used as a lens to value disability identity. It rejects the view of disability as necessarily tragic and proposes that disability identity, both individual and collective, can be positive and satisfying (John Swain & Sally French, 2000). This model was inspired by disability arts movements and by the concept of disability pride, which creates positive images of disabled people and asserts the right to be who they are, as they are. The affirmative model of disability, as described by John Swain and Sally French (2000), challenges assumptions of tragedy, dependence, and abnormality. It foregrounds disabled people’s experiences and gives them the power to determine their own lifestyle, culture, and identity. The central point is the recognition that there is value in living with impairments and the rejection of the narrative according to which a life with impairments is necessarily tragic. This model can thus become a powerful tool for creating a different meaning and significance for the experience of living with disability in an ableist society (Colin Cameron, 2024).

The affirmative model of disability seems particularly relevant to mobilize in reflecting on the identity of a person who acquires an impairment that lead to experimenting communication disabilities, because it makes it possible to value and foreground the beauty of a disabled life, something that other social models of disability, more often used in the social practices of speech-language therapy, do not easily allow. For example, the Human Development Model–Disability Creation Process (Patrick Fougeyrollas et al., 2020) can be used by speech-language therapists in Québec who are interested in the role of the environment in the disabling situations experienced by the people they support. However, as John Swain and Sally French (2000) note, this type of social model of disability makes it possible to redefine “the problem” by focusing on the factors influencing disabling situations or participation, but it does not readily capture the possibility of a disability identity that can be celebrated, positive, rich, and valued. The affirmative model of disability thus makes it possible to immediately deconstruct the idea that being disabled is not a desirable situation, a process that seems promising to me for developing emancipatory practices in speech-language therapy.

Building Disability Identity through Disabled Gain

Consistent with the affirmative model of disability, exploring the experience of possible disabled gain among people who acquire communication disabilities is of interest to reveal desirable possibilities of life with acquired communication disabilities. The concept of gain in relation to disability or impairment was first proposed by British Deaf artist Aaron

Williamson through the term Deaf gain, which he used to subvert the socially constructed and imposed idea of tragedy linked to hearing loss (Aaron Williamson and Larry Lynch, 2023). The concept of Deaf gain was later formalized in Deaf studies by H-Dirksen L. Bauman and Joseph J. Murray, who propose reframing deafness (2009, 2014). Rather than perceiving it as a loss, they suggest describing it as something present in Deaf people, a way of living deafness as something whole in itself. To do so, the authors use a biodiversity framework. They propose viewing humanity as an ecosystem and attributing to human diversity the same significance as biodiversity within an ecosystem, namely that a rich human diversity (or biodiversity) helps reveal the full richness of a flourishing human life. The biodiversity framework has also been taken up by Rosemarie Garland-Thomson to conceptualize disability and defend why we should seek to conserve it, as a precious natural resource (2012).

Thus, the concept of Deaf gain emerged by reframing deafness as a form of sensory and cognitive diversity likely to contribute to the common good of humanity (H-Dirksen L. Bauman & Joseph J. Murray, 2014, 2009). The authors explain that three signs can be used to represent the concept, and that they are used depending on what best suits the context. Deaf increase foregrounds the idea that Deaf people possess something important; Deaf benefit expresses that deafness is not only a loss but also a benefit; and finally, Deaf contribution highlights all the ways Deaf people can participate in humanity. For Rosemarie Garland-Thomson (2012), disability, too, should be considered a resource for the world, particularly a narrative, epistemic, and ethical resource. As for Thomas Armstrong (2010), he writes a book devoted exclusively to the “extraordinary gifts” brought

by neurodiversity in different conditions, such as autism or dyslexia. The concept of gain thus does not seem meaningful only for Deaf people, but also for disabled people. Thus, like Deaf or disabled people, I wonder whether individuals who acquire a communication disability reframe their disability and come to perceive or experience some gains. Could it be a concept that resonates with them? The few individuals with an acquired communication disability with whom I have informally explored this question saw something promising in it for understanding their experience. Notably, one of these people mentioned the feeling of living a freer and more expansive life after acquiring a communication disability. In future research and in speech-language therapy practices, the concept of disabled gain[3], or deaf gain, could serve as a guide toward elements relevant for exploring the positive identity construction of a person with acquired communication disabilities. The idea would not be to use the concept to minimize the experience of loss or grief for a life as a non-disabled person, but rather to reconfigure the meanings often associated with becoming disabled.

Conclusion

[3] Or would it be impairment gain? Is it disability or impairment that really leads to the gain? On one hand, in the concepts of deaf gain and stuttering gain (Christopher Constantino, 2016), it is the condition (here, deafness or stuttering) that allows individuals to experience the world differently and to bring diversity and richness to it. We could therefore argue that it may be the experience of impairment itself that constitutes the real gain, hence, impairment gain. On the other hand, I argue that viewing disability more broadly through the lens of disability gain may also be fruitful for reframing disability in an ableist world and exploring a positive disability identity. In this paper, I do not aim to resolve this terminological/conceptual dilemma or to propose a fixed, immutable concept, but rather to reflect on the value of engaging with the concept of gain for the development of emancipatory practices.

This reflection invites speech-language therapists, researchers, and people with communication disabilities to deepen understanding of the identity trajectories of people who acquire communication disabilities in order to better grasp the benefits experienced, notably by mobilizing theories and concepts from disability studies, such as the affirmative model of disability or the concept of disabled gain. Such an approach could contribute to developing emancipatory practices in speech-language therapy in which communication disability is understood as a rich experience that can be celebrated. Given the role of disability arts, and later, political disability movements, in the construction of a positive disability identity (John Swain & Sally French, 2000), exploring this question within artistic communities of people with acquired communication disabilities could constitute a relevant starting point,

Acknowledgements

I would like to thank Sarah Heussaf for her careful reading of this text and her insightful suggestions for strengthening it. I am also grateful to Pierre Crête, Cong Nguyen and Annie Carrier for the stimulating conversations about how the concept of disability gain might resonate with their experiences as individuals with acquired communication disabilities.

References

Armstrong, T. (2010). *Neurodiversity : Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and Other Brain Differences*. Da Capo Press.

Bauman, H.-D. L., & Murray, J. J. (2014). *Deaf gain : Raising the stakes for human diversity*. University of Minnesota Press.

Bauman, H. D., & Murray, J. (2009). Reframing: From hearing loss to deaf gain. *Deaf studies digital journal*, *1*(1), 1-10.

Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of social issues*, *75*(3), 650-664. https://doi.org/10.1111/josi.12354

Boucher, N. (2003). Handicap, recherche et changement social. L’émergence du paradigme émancipatoire dans l’étude de l’exclusion sociale des personnes handicapées. *Lien social et Politiques*, (50), 147-164. https://doi.org/10.7202/008285ar

Brinkman, R., Neijenhuis, K., Cardol, M., & Leget, C. (2025). Who am I now? A scoping review on identity changes in post-stroke aphasia. *Disability and rehabilitation*, *47*(5), 1081-1099. https://doi.org/10.1080/09638288.2024.2367606

Cameron, C. (2024). Some things never seem to change: further towards an affirmation model. *Disability & society*, *39*(7), 1890-1895. https://doi.org/10.1080/09687599.2023.2295799

Constantino, C. (2016). Stuttering gain. International Stuttering Awareness Day. https://isad.live/isad-2016/papers-presented-by-2016/stories-and-experiences-with-stuttering-by-pws/stuttering-gain-christopher-constantino/

Constantino, C., Campbell, P., & Simpson, S. (2022). Stuttering and the social model. *Journal of communication disorders*, *96*, 106200. https://doi-org.biblioproxy.uqtr.ca/10.1016/j.jcomdis.2022.106200

Fougeyrollas, P., Cloutier, R., Bergeron, H., St-Michel, G., Côté, J., Côté, M., Boucher, N., Roy, K., Rémillard, M.-B., Barral, C., Robin, J.-P., Castelein, P., & Korpès, J.-L. (2020). Classification internationale. Modèle de développement humain- Processus de production du handicap (MDP-PPH) (2e édition). Quebec: RIPPH.

Garland-Thomson, R. (2012). The case for conserving disability. *Journal of bioethical inquiry*, *9*(3), 339-355. https://doi.org/10.1007/s11673-012-9380-0

Garland-Thomson, R. (2016, august 19). Opinion | Becoming Disabled. The New York Times. https://www.nytimes.com/2016/08/21/opinion/sunday/becoming-disabled.html

Kafer, A. (2013). *Feminist, Queer, Crip*. Indiana University Press.

McCormack, C., & Collins, B. (2012). The affirmative model of disability: a means to include disability orientation in occupational therapy?. *British Journal of Occupational Therapy*, *75*(3), 156-158. https://doi.org/10.4276/030802212X13311219571909

Linton, S. (1998). *Claiming Disability : Knowledge and Identity*. New York University Press.

Linton, S. (2006). *My Body Politic: A Memoir*. University of Michigan Press.

Milbern, Stacey Park, et Leah Lakshmi Piepzna-Samarasinha.(2023). Crip Lineages, Crip Futures: A Conversation by Stacey Park Milbern and Leah Lakshmi Piepzna-Samarasinha. In Chen, M. Y., Kafer, A., Kim, E., & Minich, J. A (ed), *Crip Genealogies*. Duke University Press.

Prud’homme, J. (2003). La formation universitaire et l’établissement d’une nouvelle profession: L’orthophonie-audiologie à l’Université de Montréal, 1956-1976 1. *Revue d'histoire de l'Amérique française*, *56*(3), 329-356. https://doi.org/10.7202/007617ar

Ricœur, P. (1988). L'identité narrative. *Esprit (1940-)*, 295-304.

Shadden, B. (2005). Aphasia as identity theft: Theory and practice. *Aphasiology*, *19*(3-5), 211-223. https://doi.org/10.1080/02687930444000697

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & society*, *15*(4), 569-582. https://doi.org/10.1080/09687590050058189

Williamson, A., & Lynch, L. (2023). Situating deaf-gain: performance and writing in the work of and Aaron Williamson. *Journal of Visual Art Practice*, *22*(2-3), 291-305. https://doi.org/10.1080/14702029.2023.2221910