The History of Person-centered Planning in New York in Relation to People with Intellectual and Developmental Disabilities and the Employees Who Work with Them

Noah Wistman

Hunter College

Mellon Public Humanities

December 19, 2022

The history of care for people with intellectual and developmental disabilities (PWIDD) is rife with abuse, misunderstanding, and mistreatment. While there have been many examples of these problems at different times and places, most relevant to the state of modern disability care in New York were the conditions present in the Willowbrook State School. The institution was supposed to be dedicated to the care and education of people with mental disabilities. However, a combination of underfunding, understaffing, overpopulation, and poor management led to horrible conditions for the PWIDD and employees at the facility. Designated to support about four thousand people, the site would end up with over six thousand people at its peak (Reimann, 2017). This meant that staff were unable to provide the education and activities that the school was meant to provide. Instead, children and adults would sit in place with nothing to do for hours on end, moaning, crying, and sleeping on the floor with no clothes on. Conditions often got bad enough that staff failed to keep up with even basic cleaning, meal assistance, and bathroom assistance responsibilities. This led to unsanitary conditions throughout the facility, and severe disease outbreaks of measles and hepatitis. On top of this, poor management led to a lack of oversight and accountability, and it is now known that physical and sexual abuse occurred on many occasions (Weiser, 2020).

While the bad conditions at the facility had been known within certain circles for many years, it wouldn’t be until 1972, when an investigative report done by Geraldo Rivera aired on WABC, that the conditions at Willowbrook would be brought to the attention of the broader public (Weiser, 2020). The effects of this report were far reaching, generating momentum for public outcry, advocacy groups, and policy changes. The immediate aftermath of the Willowbrook scandal saw several key milestones in disability support, most importantly the founding of the Office for People With Developmental Disabilities (OPWDD) as a new cabinet of the New York state government in 1978, which was, and is, responsible for defining and protecting the legal rights of PWIDD (Office for People With Developmental Disabilities, 2022).

After the scandal at Willowbrook, the governmental, non-profit and advocacy movements supporting PWIDD would continue to develop over the course of the following decades. In the present day, a system of government and non-profit organizations has been established and expanded to improve the quality of life for PWIDD. Comparing the conditions present at Willowbrook and other similar institutions to the current situation reveals a dramatic improvement in the overall quality of life for PWIDD. While instances of neglect and abuse still occur, professionals in the field broadly agree that these cases are relatively rare when compared to conditions in the 1970s, and that the ability to hold transgressors accountable has also improved (Weiser, 2020). These improvements have come from a series of developments in the field of disability care, which have changed the approaches used by institutions which provide services to PWIDD. This includes a number of important developments, including a shift away from large, impersonal approaches to supporting PWIDD, and towards a "person-centered" approach to care.

The person-centered approach has influenced policy and procedure in a variety of fields under the umbrella of social work, including care for PWIDD. The exact way this approach is applied to practice and policy differs between different fields, however the overarching concept is consistent. The person-centered approach aims to shift the perspectives of people working in the field away from making decisions for the people they're working with, and towards allowing the person who is receiving care to make their own decisions about the type of support they're receiving. In the past, the general perspective about providing care for PWIDD was that employees would decide what kind of support the people they worked with would receive.

Employees would create a schedule, come up with activities, and get PWIDD to follow the program. This was most evident at the Willowbrook facility, where staff had nearly complete autonomy to make decisions for the people they were working with, even if those decisions constituted neglect and abuse. By contrast, the person-centered approach encourages PWIDD to discuss their goals, perspectives and preferences with employees, and work together with them to make decisions about the support they will receive. This approach is put into practice through policies written both in government policies and in the institutional policies of non-profit organizations.

The most direct application of this approach is seen in life plan meetings, a standard procedure present in disability care institutions. As described in OPWDD's website page *What is the Life Plan?*, these meetings involve the person with disabilities, one of their family members, their assigned care manager, a supervisor working for the institution which supports them, and one of the employees who works directly with them discussing and creating a plan for what type of support the person will receive. The goal of these meetings is to create plans which match the individual needs of the person with disabilities. Taking these different viewpoints and putting them together will ideally result in goals that represent the wishes of the person with disabilities, and that can be worked towards on a daily basis. Typically, the meetings result in two specific goals being agreed to, however more can be added in some cases. Because these goals are created on a person-to-person basis, they vary widely in terms of what they can include, however they will typically be something that builds a skill, such as doing reading exercises, or practicing moving independently. Employees are expected to work on these goals with the people they support every day, and create monthly reports about the person's progress towards those goals.

However, the person-centered approach has also influenced perceptions of best practice in other, less formal ways as well. This includes changes in perception about best practice concerning the language used when discussing PWIDD. People working in the field are generally encouraged to use language which places an emphasis on the personhood of the people they support, rather than their disability. This includes saying “person with disabilities,” rather than “disabled person,” and “person receiving supports,” rather than “client” or “patient” (Office for People With Developmental Disabilities, 2022). However, language isn’t the only element of best practice which the person-centered approach applies to. Even when not specifically working with people on their goals, employees are generally expected to take the perspectives and opinions of the people they’re working with into account when they make decisions about activities. This can play out in many different ways in practice. To give just one example, if a person was supposed to take part in a reading activity, but is now saying that they don’t want to do that activity, employees would be expected to find an alternative activity for them to do, rather than trying to force them to do the activity that was scheduled. This broad expectation highlights that the person-centered approach is really conceptualized as an overall approach, rather than being a limited set of specific rules to follow.

While the person-centered approach is currently the accepted standard in the field of disability care, this was not the case just a few decades ago. While the Willowbrook scandal created the onus to deliver quality support to PWIDD, what exactly constitutes the best way to provide this support was, and is, the subject of ongoing debate amongst professionals in the field. One of the initial changes that followed the Willowbrook scandal was an increase in the presence of medical professionals working in the field of disability care. The staff at facilities like Willowbrook facility were generally, at best, only responsible for a baseline level of care limited to helping PWIDD eat and stay clean. After Willowbrook was shut down, more professionals who were nurses, doctors, and psychologists began working in the field, shifting the focus of disability care towards assisting PWIDD with the health conditions associated with their disabilities (Racino, 1999). This change in the professional makeup of people working in disability care was associated with a change in perspective of the relationship between PWIDD and the people working with them. Broadly speaking, the tendency shifted towards seeing PWIDD as “patients,” and the support they were receiving as “treatments” for their “disease.” This was an improvement from the perceptions of PWIDD that were present in the Willowbrook facility, in which they were seen as people who could be mistreated without consequence. The idea that conditions for PWIDD could be, and deserved to be actively improved was a step forward in the field of disability support.

While this treatment-leaning approach led to improvements in clinical and medical procedures that support PWIDD, it also limited the types of support they could expect to receive, and left them with little agency to set their own priorities. This type of support for PWIDD often took the form of doctors and psychiatrists evaluating a person’s condition, and then assigning treatments based on their evaluation (Racino, 1999). As is often the case more broadly with medical diagnoses and treatments, PWIDD are usually expected to follow the prescriptions of professionals, without issuing their own feedback. While this is sensible for medical treatment, the focus on this specific type of support deemphasized other aspects of the lives of PWIDD. By contrast, the modern, person-centered framing of support for PWIDD, sees them as individuals with agency, who are receiving support to help them achieve their personal goals. This can involve prescribing medications and therapies to help them deal with the health issues associated with their disabilities, but also involves other goals. Like most people who don’t have intellectual and developmental disabilities, PWIDD often have goals beyond their physical and mental health, such as finding jobs, and living independently. But by perceiving PWIDD primarily as people with diseases that needed to be treated, professionals in the field prior to the adoption of the person-centered approach often failed to take these factors into account.

An example of this “treatment for disease” perspective, and the dangers associated with perceiving PWIDD through this lens can be found in the debate surrounding the practice of “aversive treatment procedures,” which was occurring primarily in the late 1980s. A 1988 paper by Thomas and McGuire covered this debate, describing the techniques, as well as common arguments for and against using them. “Aversive treatment procedures” was a general term used to refer to any technique which looked to change the behavior of a PWIDD by punishing the person when they displayed the behavior. In clinical settings, aversive treatments have been used in many types of therapy, often as a way of curtailing addictive behaviors such as smoking and gambling. However for PWIDD, aversive techniques were mainly associated with discouraging physically harmful or inappropriate behaviors. This could include self-injurious behaviors like scratching, biting or hitting oneself, removing clothing, or playing with fecal matter. The aversive techniques themselves could include many different punishments, including removing desired items, physical restraint, and in some cases administering shocks.

In their paper, Thomas and McGuire describe the then ongoing debate about whether or not the use of these aversive treatment procedures was ethical. Some professionals, including the authors of the paper, argued that aversive treatment procedures could be the appropriate intervention in cases where behaviors are particularly harmful, and the treatments are shown to be effective in reducing instances of the behavior. They argue that if a treatment is effective, it should be employed, even if it seems intrusive. On the other side of the debate, other professionals claimed that the use of aversive treatment procedures is unethical, and violated the individual rights of their clients, who couldn't consent to the uses of the techniques.

While a genuinely controversial debate in the past, compared to the standards of modern practice, the aversive treatment procedures which were used for many years seem blatantly unethical and abusive. Using techniques which punish people without their consent, and having no way for those people to end the treatment violates many ethical principles relating to clinical, and medical practice. In current times, nearly all of the practices that would have been classified as aversive are not only frowned upon, but are illegal altogether. This makes the many years in which psychologists used and debated the techniques seem strange in hindsight, however it makes sense as a consequence of seeing a person's disability first, and their personhood second. Through this perspective, if a procedure would help treat a person's condition, then other concerns become secondary, no matter what they are.

This bias against seeing PWIDD as full persons can be seen throughout the Thomas and McGuire paper, as they are often discussed as non-factors in decisions being made about their own treatment. To begin with, the use of the terms "clients," "treatments," and "interventions" throughout the paper show the "treating a disease" mentality discussed before. The discussion of the paper is entirely focused on debates among professionals, with the opinions of PWIDD, and their family members left unrepresented. In fact, the paper spends more time discussing the potential legal liabilities for clinicians who would use the techniques than it does any potential harm to the people the techniques would be used on. The authors of this paper argue that, to avoid legal issues, it should be the right of professional clinicians to assess whether or not aversive treatments are appropriate, which they propose as the "Psychotherapist Judgement Rule." The authors of the paper don't deny that the PWIDD subject to these treatments would be stressed by the procedures, or that they would likely choose to cease them if they could. They instead argue that it should be the right of professional clinicians to make decisions for the PWIDD, based on their own best judgment, regardless of how the person receiving the treatment is responding. This is a case of PWIDD being held to different standards than people without intellectual and developmental disabilities. A person with a smoking addiction would have to give consent to aversive treatments before they could be initiated. However, many PWIDD are not in a reasonable position to give informed consent, or to communicate that they want a procedure to stop. This may be especially true for those who display behaviors concerning enough to potentially warrant aversive intervention.

As shown by the aversive treatment debate, the guiding principles of disability care were still in flux at the end of the 1980s, and widely different opinions about appropriate practices could be found between different agencies and workers. This would begin to change in the 1990s, as a clear shift in professional consensus began to take place. Through the decades, the theory, terminology, and policy surrounding person-centered planning started developing and gaining prominence in the field of disability care. This transition can be seen in a 1999 paper by Racino, in which the state of care for PWIDD is described. In the paper, the principles of person-centered care can be seen influencing the changes to care, however the terminology is still being developed. The paper describes a traditional “clinical” style of treatment, now being replaced by a community-based, “user-directed” approach. “User-directed" in this case being a precursor to “person-centered,” describing many of the same principles of taking the person’s feedback into account, however still using the somewhat impersonal term of “user.” The article also describes how these changes are still in the process of being accepted and implemented by government bodies, and states a need for continued advocacy in this area. This shows a clear change in thinking from the 1980s, in which the field was predominantly led by the perspective of applying treatments to diseases. However, the paper still describes a scene that is changing, and still clearly distinguishable from current-day practice.

By the mid-to-late 2000s, the conversation had shifted away from whether or not the person-centered approach should be the way forward, and towards how best to implement this change (Shogren et al, 2009). This can be seen in a number of articles that were published around this time, which focused on refining and expanding the approach, rather than arguing for or against its merits. For example, a 2009 paper by Martin and Carey already displays a shift from discussing whether or not a person-centered approach should be implemented, to how best to implement a person-centered approach. The article describes what the process of creating a life plan should be, stressing that it should be the person with intellectual and developmental disabilities who is leading the creation of the plan. In this paper, a person-centered approach is assumed as the default way of structuring practice, and the terminology and procedures described by the paper matches the one used now fairly closely.

Other papers published around this time focus on how to expand and develop the person-centered approach beyond day-to-day practice. For example, a 2006 paper by Hartley and MacLean argues for the validity of using surveys and questionnaires to assess the opinions of PWIDD. The paper emphasizes the importance of getting broad access to the opinions and perspectives of PWIDD to improve care, very much in keeping with the person-centered approach. This approach of steadily expanding and refining the understanding of the person-centered approach has continued to be relevant to this day, as showcased by a 2021 paper by Márquez-Caraveo et al, which focuses on the need for person-centered approaches to be better implemented for children with intellectual and developmental disabilities, as much progress to this point has centered on adults. The study taking place in Mexico also shows the spread of the person-centered approach to locations outside of New York, now influencing international practice.

In current times, person-centered approaches have become standard practice in disability care, and person-centered policies have been written into governmental and institutional regulations. However, as is often the case in public policy, there can be a substantial difference between how policies are written and how they're put into practice. One of the major issues facing the implementation of person-centered policies is a disconnect between written policies and the people responsible for putting them into practice, due to the way that policies are written. The policy and theory surrounding person-centered planning tends to describe the systems that are to be implemented in broad, technical terms. By necessity, person-centered policy often leaves a lot of leeway for how guidelines are going to be interpreted and implemented. Any plan that involves taking the specific needs of individuals into account will have to leave space for changes to be made as particular situations arise. However, attempting to create policies which are at once comprehensive and open to interpretation can result in vague policies that require many elements of care to be determined situationally. This puts a lot of responsibility on institutions and employees to understand and interpret policies well, if quality care is to be delivered.

One example of these issues can be found in an excerpt from a 2021 paper by Schalock and Luckasson, who make recommendations for how best to enhance research practices for PWIDD by using a person-entered evaluation method. This is an excerpt from the paper, which displays some of these issues clearly:

> “person-centered outcome evaluation meets these criteria because it: (a) is a systematic endeavor that aligns the current understanding of IDD, individualized supports, valued outcomes, and meaningful impacts; (b) involves a collaborative partnership among the individual, a human service organization or system, and a team; and (c) incorporates the knowledge, skills, and resources of the partnership to measure and effectively use outcome information to enhance human functioning and personal well-being, and to increase transparency, accountability, and understanding”

This excerpt is one sentence of a six-part methodological description, with sub-sections, each of which reads similarly to this one. This single, run-on sentence displays fairly well the issue of trying to be comprehensive enough to account for all possible outcomes, and vague enough to allow for flexibility. However, this also results in the sentence not describing any specifics of how the broad ideas presented should translate into day-to-day practice. The article also demonstrates a clear problem with heavy use of jargon, which hampers its ability to be understood. At various points, the article will include the terms “psychoeducational,” “teratogens,” and “multifactor contextual variables.” This style of writing may be legible to technical experts in the field, but probably not to people without that expertise. Regardless of whether or not good points are being made about how to improve practice and evaluation, most ground-level employees would find it nearly impossible to read about and understand the possible changes. When policies are written in a way that’s too technical, employees, and PWIDD are unlikely to read and understand them fully. This disconnect between theory, policy and practice can result in discrepancies between a policy’s intended purpose, and how it plays out in the real world.

Research about the romantic and sexual lives of PWIDD showed how one of these disconnects between policy ideals and implementation can play out in practice. Of the many issues faced by PWIDD, handling desires for romance, sex and intimacy can be some of the most challenging. As the paper points out, stereotypes about PWIDD cause many people to be uncomfortable with sexual relationships in which they are involved. Many people have the perception of PWIDD as being grown-up children, and therefore not desiring or understanding intimate relationships. However these beliefs aren't supported by the statements made by PWIDD themselves. This was shown by a study done by Black and Kammes in 2019 in which they analyzed interviews done with PWIDD about the subject of intimate and sexual relationships. Because of the sensitive nature of the topic, most of the studies that have been done with PWIDD involved a small number of participants, who chose to keep their identities private. Therefore, Black and Kammes compared many smaller studies which covered this issue, and pulled out common themes that were present in each study. They found that across the studies that they looked at, PWIDD consistently showed an understanding of, and a desire to participate in romantic and sexual relationships.

Not only did PWIDD express desires for intimate relationships, they also felt that their opportunities to find such relationships were being restricted by staff. PWIDD reported that staff members would discourage and often prevent them from discussing and engaging in romantic and sexual relationships while on sites. As noted in the paper, this restrictiveness isn't in keeping with the principle of person-centered care. If PWIDD want to discuss and participate in romantic relationships, then a person-centered approach would involve the staff who work with them facilitating those activities, rather than restricting them. However, many employees choose to avoid or restrict these topics and relationships. In this case, staff may be aware of the ideals about person-centeredness laid out in policy descriptions, but they aren’t following them in practice.

The focus of the Black and Kammes paper is, rightly, on the perspectives of PWIDD, and how their lives could be improved. This is in keeping with the spirit of the person-centered approach, where the perspectives of PWIDD are considered to inform possible changes. However, the paper is dismissive of the objections raised by employees about facilitating these relationships. The paper tends to treat the perspectives of employees as shortcomings that should be improved, rather than as input to be valued. If employees had been asked about their rationales for the restrictions, or their ideas for possible solutions, those weren’t described in this paper. The authors assumed that the worker’s reasons were likely linked to general attitudes towards PWIDD. However, this wasn’t confirmed to be the case, and there are many other possible explanations as to why employees may discourage these activities. For example, a person who works with PWIDD may come from religious backgrounds which discourage talking about sexual relationships in general, not just as pertained to PWIDD. Other employees may have cultural and personal reasons for feeling uncomfortable with these topics. Telling an employee that they must put their strongly held cultural, religious, and personal beliefs aside to facilitate the people they work with may be in line with the person-centered approach, but it may be crossing a line when it comes to their rights as workers.

This tendency to expect employees to always prioritize facilitating the individual wishes of the people they support, even if they clash with other priorities can also be seen in the 2009 paper from Martin and Carey. The paper makes clear an expectation for employees to consistently find ways around barriers to accomplishing a person’s goals, even if doing so would present practical difficulties. The paper gives several theoretical examples in which staff working with “Mary,” a hypothetical thirty-four year old woman with down syndrome find ways to facilitate Mary’s wishes, even when this creates more work for them to do. The paper takes the stance that there will always be a way to get around conflicts between a person’s goals and practical concerns, and that it will always be the responsibility of staff to make these solutions happen, even if it would be difficult for them to do. While looking for ways to solve problems should be the standard of supporting PWIDD, it’s still important to understand how much is asked of the people who work with PWIDD before asking them to take on more work.

To understand the difficulties faced by people working with PWIDD, it’s important to understand who they are, and what kinds of challenges they face while working. The 2009 paper from Martin and Carey brings up the, at the time, ongoing debate about whether or not a person should have to be a trained health professional in order to work with PWIDD. Since that time, however, it’s become standard for the people working day-to-day with PWIDD to be minimum-wage workers, as those are the wages that government funding allows for. While specialized professionals are often brought in for the planning and evaluation process for people’s plans, the people working on a day-to-day basis with PWIDD often have no specialized training outside of their organization’s onboarding process. This can be seen in the job requirements for the common entry-level position of Direct Support Assistant (or Direct Support Professional), which comprises the bulk of people who work directly with PWIDD. In their website page *Become a Direct Support Professional*, OPWDD lists the job requirements for this position as possessing a high school diploma or GED, and passing basic medical, criminal, and abuse background checks. In line with these minimal standards is the pay received by employees in this position, which typically ranges from fifteen to eighteen dollars an hour, which is at, or just above New York’s minimum wage.

This range of starting salaries contrasts with the often physically and emotionally difficult work that employees are expected to do. Some common responsibilities include changing adult diapers, cleaning soiled clothing, and preventing self-injurious behaviors. It shouldn’t be a surprise then that many employees in this line of work report struggling with personal issues. While not only about people who work with PWIDD, a study done by Shulamith Lala et al in 2018 about social workers working in various fields found that mental health problems were very common amongst employees in the field. Among active social workers, 40.2 percent reported having struggled with mental health issues before becoming social workers, and 51.8 percent reported struggling with mental health issues after becoming social workers. Both of these figures are higher than the general population, and the increase in mental health issues after becoming social workers suggests that the stresses of the job may contribute to these issues. The most common mental health issues were anxiety and depression, with rates of both issues increasing after beginning work.

The prevalence of these mental health issues put the high expectations placed on people who work with PWIDD into context. As described in the paper by Schalock and Luckasson in 2021, the ideals of person-centered planning involve employees continually adjusting their work to meet the specific and changing needs of each individual they’re supporting, based on the stated desires of each of those people. This is a lot to ask of employees who are already struggling with mental health issues, while also doing tough work for little pay. It may be unreasonable to expect employees to live up to the ideals set out in policies when they are already working through tough conditions. It calls into question the standard of expecting employees to always prioritize the desires of PWIDD, regardless of the associated practical difficulties.

Along with these difficulties, while employees may be expected to consistently evaluate and adapt their support based on the changing individual needs of the people they work with, in practice this is often difficult to accomplish. This is true even in the case that employees are well-informed, and act with good intentions. Employees are often faced with unclear decisions, in which the best approach based on person-centered principles is difficult to determine even for someone deeply familiar with them.

A paper by Glicksman et al from 2017 discusses some real-world examples of these kinds of situations. For example, the paper brings up a specific case in which a PWIDD wanted to have a job to make money to support himself, but had difficulty maintaining one for an extended period of time. This was not due to his inability to perform the jobs he landed, instead he would consistently become dissatisfied with his bosses and coworkers, and therefore either quit, or stop showing up to work. The reasons he typically gave for disliking his bosses were often the types of issues that would be present in any job, such as being criticized for being late. Staff were faced with a difficult choice between trying to respect the person's short-term wishes and autonomy by supporting their decision to quit jobs they were unhappy with, or prioritizing their long-term goals of making their own money by encouraging them to work through their discomfort. It's unclear which decision is truly in keeping with the person-centered approach, the one which prioritizes the person's immediate autonomy, or their stated long-term goals. This is just one example of the types of unclear and difficult decisions faced by employees when trying to interpret what a person-centered approach should look like in practice.

Taking these factors into consideration creates an overall picture of minimally trained, minimally paid employees who are struggling with mental health being expected to continually make difficult, complicated decisions which may continually increase their workload. This state of affairs creates conditions in which the temptation to take shortcuts is strong, and a regression back to the times of understaffed facilities and overworked employees seems closer than it has been in many years. However, while not perfect, the state of disability care and policy in New York has been one of consistent improvement. From the closing of the Willowbrook State School, to the cessation of the use of unethical and abusive aversive treatment procedures, to the widespread adoption of the person-centered approach, PWIDD have generally seen the quality of support they receive steadily increase over the past several decades. PWIDD have increasingly been able to give their perspectives, and exert agency over the decisions being made in their lives, and this is undoubtedly an improvement over previous standards.

However, the perspectives of people who are responsible for working directly with them are still underrepresented, and they are still expected to follow guidelines put in place by other people. Ultimately, the goal of disability policy is to provide the best possible support for PWIDD. However, to accomplish this goal in practice, the people responsible for providing that support must be put into position to succeed. To do this, the perspectives of ground-level employees must be incorporated into the field’s conceptions of good policy, best practices and necessary training. Employees who are confused about the policies they’re expected to implement, and who are struggling to keep up with a mentally demanding job will always struggle to implement the best possible support, even if they have every intention of doing so. A better understanding of the lives and perspectives of the ground-level employees who work directly with PWIDD will allow for better support to be given to these employees, and therefore for better support to be provided for PWIDD.

References

Black, R. S., & Kammes, R. R. (2019). Restrictions, Power, Companionship, and Intimacy: A Metasynthesis of People With Intellectual Disability Speaking About Sex and Relationships. *Intellectual & Developmental Disabilities*, *57*(3), 212–233. https://doi-org.proxy.wexler.hunter.cuny.edu/10.1352/1934-9556-57.3.212

Glicksman, S., Goldberg, C., Hamel, C., Shore, R., Wein, A., Wood, D., & Zummo, J. (2017). Rights-Based and Person-Centered Approaches to Supporting People With Intellectual Disability: A Dialectical Model. *Intellectual & Developmental Disabilities*, *55*(3), 181–191. https://doi-org.proxy.wexler.hunter.cuny.edu/10.1352/1934-9556-55.3.181

Hartley, S. L., & MacLean, W. E. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research, 50(11), 813–827.* doi:10.1111/j.1365-2788.2006.00844.x

Lala, S., Straussner, A., Senreich, E., Steen, J. (2018). Wounded Healers: A Multistate Study of Licensed Social Workers' Behavioral Health Problems, *Social Work*, *63*(2), 125–133, https://doi.org/10.1093/sw/swy012

Márquez-Caraveo, M. E., Rodríguez-Valentín, R., Pérez-Barrón, V., Vázquez-Salas, R. A., Sánchez-Ferrer, J. C., De Castro, F., Allen-Leigh, B., & Lazcano-Ponce, E. (2021). Children and adolescents with neurodevelopmental disorders show cognitive heterogeneity and require a person-centered approach. *Scientific Reports*, *11*(1), 1–14. https://doi-org.proxy.wexler.hunter.cuny.edu/10.1038/s41598-021-97551-6

Martin, A.-M., & Carey, E. (2009). Person-centred plans: empowering or controlling? *Learning Disability Practice*, *12*(1), 32–37.

Office for People With Developmental Disabilities (2022). *Become a Direct Support Professional*. https://opwdd.ny.gov/career-opportunities/direct-support

Office for People With Developmental Disabilities (2022). *What is the Life Plan?* https://opwdd.ny.gov/providers/what-life-plan

Racino, J.-A. (1999). Statewide approaches to community integration: moving toward technical assistance strategies that make a difference. *Journal of Vocational Rehabilitation*, *13*(1), 31.

Reimann, M. (2017). Willowbrook, the institution that shocked a nation into changing its laws. *Timeline*. https://timeline.com/willowbrook-the-institution-that-shocked-a-nation-into-changing-its-laws-c847acb44e0d

Schalock, R. L., & Luckasson, R. (2021). Enhancing research practices in intellectual and developmental disabilities through person-centered outcome evaluation. *Research in Developmental Disabilities*, *117*, N.PAG. https://doi-org.proxy.wexler.hunter.cuny.edu/10.1016/j.ridd.2021.104043

Shogren, K. A., Bradley, V. J., Gomez, S. C., Yeager, M. H., Schalock, R. L., Borthwick-Duffy, S., … Wehmeyer, M. L. (2009). Public Policy and the Enhancement of Desired Outcomes for Persons With Intellectual Disability. *Intellectual and Developmental Disabilities, 47(4), 307–319.* doi:10.1352/1934-9556-47.4.307

Thomas, D. R., & McGuire, P. S. (1988). Balancing Right to Treat with Intrusiveness: The Psychotherapist Judgment Rule. *Behavioral Residential Treatment*, *3*(3), 211–222. https://doi-org.proxy.wexler.hunter.cuny.edu/10.1002/bin.2360030305

Weiser, B. (2020). Beatings, Burns and Betrayal: The Willowbrook Scandal's Legacy.

The New York Times. https://www.nytimes.com/2020/02/21/nyregion/willowbrook-state-school-staten-island.html