Research

Reducing 'Challenging' Behavior By Training
Support Staff to Promote Dignity and Respect

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Reducing 'Challenging' Behavior By Training Support

Staff to Promote Dignity and Respect

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Abstract

The occurrence of 'challenging' behavior is commonly documented amongst people with intellectual and developmental disabilities (IDD). Since behavior is not only a form of communication, but often in response to environmental conditions, it stands to reason that one mechanism to reduce 'challenging' behaviors would be to draw attention to people's environmental conditions and well-being, such as people's physical and mental health, and lack of opportunities and exclusion, and by treating people with dignity and respect. This research study aims to explore the relationship between 'challenging' behavior, and dignity and respect, particularly by exploring the role support staff can play in promoting dignity and respect. We had the following research question: what is the relationship between support staff being trained to promote dignity and respect and 'challenging' behaviors? To explore this research question, we analyzed Basic Assurances® and 'challenging' behavior data from 74 human service organizations that supported 6,982 unduplicated people with IDD annually. Our findings revealed that, regardless of the agency size or geographic location, when support staff were trained to promote dignity and respect and to recognize each person as a unique individual, the number of 'challenging' behaviors people with IDD exhibited reduced significantly. While not all 'challenging' behavior may be reduced by staff being trained to promote dignity and respect alone, findings from our study suggest this training may be one mechanism to reduce the incidence of 'challenging' behaviors, and by extension, the need for behavior intervention services which can be controversial and costly.

Keywords: dignity and respect; people with intellectual and developmental disabilities; challenging behavior; outcomes; social determinants of health

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'Challenging' or 'problematic' behavior exhibited by people with intellectual and developmental disabilities (IDD) is typically defined as "'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'" (Poppes et al. 2010). The occurrence of 'challenging' behavior is commonly documented amongst people with intellectual and developmental disabilities (IDD), especially people with more severe impairments (Poppes et al. 2010). However, the etiology of 'challenging' behavior is not necessarily clear cut – the locus is not necessarily internal or due to people with IDD's impairments (Poppes et al. 2010). Instead, the etiology of 'challenging' behaviors is multidimensional, and often environmental.

'Challenging' behaviors exhibited by people with IDD may actually be caused by a slew of conditions. For example, 'challenging' behaviors can be a way for people to express that they are experiencing a medical or dental condition (Poppes et al. 2010; De Winter et al. 2011; Gentile 2019). 'Challenging' behaviors can be the result of people having psychological disabilities or conditions, such as a result of people having depression, anxiety, or sleep disorders (Poppes et al. 2010; Gentile 2019). People may also be participating in 'challenging' behaviors because they are being abused, neglected, mistreated, or exploited (Gentile 2019).

Simply put, behavior is a form of communication – it can be a means of expressing people are frustrated, in pain, experiencing abuse, that their needs are not being met, and/or that they are unhappy (Poppes et al. 2010; Brown et al. 2013; Gentile 2019). For example, traumatic life events may result in 'challenging' behaviors; "ordinary life event trauma may include:

feeling different; not being accepted; not being able to do what others do; moving or other big changes at home; having a disability and feeling 'different' than others; being ignored; being misunderstood; [and] failing at tasks" (Gentile 2019, n.p.). Moreover, having a lack of experiences and opportunities, as well as facing isolation, can lead people with IDD to participate in 'challenging' behaviors (Poppes et al. 2010).

Not only is it problematic that 'challenging' behaviors are often a result of negative life events or circumstances, and/or needs that are not being addressed, but it is also problematic because people with IDD with 'challenging' behavior are more likely to be institutionalized, and re-institutionalized (McIntyre et al. 2002; Lulinski 2014). In addition, rather than the environmental causes being addressed, people with IDD with 'challenging' behaviors tend to be overmedicated and/or treated with behavioral interventions (De Winter et al. 2011; Friedman 2020b).

However, since behavior is not only a form of communication, but often in response to environmental conditions, it stands to reason that one mechanism to reduce 'challenging' behaviors would be to draw attention to people's environmental conditions and well-being, such as people's physical and mental health, and lack of opportunities and exclusion, and by treating people with dignity and respect. Furthermore, recent research suggests that people with disabilities who are treated with respect have better quality of life, have more choices and opportunities, and are more integrated into their communities (Friedman 2018b). Respectful practice includes: ensuring the person has opportunities to participate in interesting and challenging activities; recognizing a person's personhood; supporting the person to control their life; recognizing complexity regarding choice, judgements, wellbeing, and dignity; and, ensuring

interactions reflect concern for the person's opinions, feelings, and preferences (Bigby et al. 2014; The Council on Quality and Leadership 2017).

Indeed, preliminary research suggests a link between 'challenging' behavior and dignity and respect. For example, one study found people with IDD who were respected had lower behavior intervention services expenditures than those who were not respected (Friedman 2020b). Another study found that when organizations participate in respectful practices, such as listening to people's concerns and responding accordingly, people with IDD express fewer 'challenging' behaviors (Friedman 2018a). This research study aims to follow this line of inquiry – explore the relationship between 'challenging' behavior and dignity and respect – particularly by exploring the role support staff can play in promoting dignity and respect. We had the following research question: what is the relationship between support staff being trained to promote dignity and respect and 'challenging' behaviors? To explore this research question, we analyzed secondary Basic Assurances® and 'challenging' behavior data from 74 human service organizations that supported 6,982 unduplicated people with IDD annually.

Methods

Data

This study was a secondary data analysis – the data were originally collected from one state developmental disabilities department. Specifically, the data were from human service organizations who provided services to people with IDD receiving the state's developmental disabilities department service programs. As part of their quality assurance program, the state conducts Basic Assurances® reviews (described in more detail below) each year with a random sample of human service organizations that provide services to people with IDD. This data, as well as incident reporting data (e.g., behavior event data) about the sample that human service

organizations in the state are required to provide them, were transferred to the research team. The state developmental disability department first removed all personal identifiers and then coded the data with identifiers; the data were then transferred to the research team.

In total, the secondary dataset included 74 human service organizations that supported 6,982 unduplicated people with IDD annually. The majority of organizations (50.68%) were located in both urban and rural areas, with fewer organizations serving in only urban (26.03%) or rural (23.29%) areas (Table 1). The majority of organizations were a medium agency size (51 to 400 people supported annually; 54.05%), while 41.89% were a small agency (1 to 50 people), and 4.05% were a large agency (401+ people).

[Table 1 approximately here]

Variables

Dependent variable: 'Challenging' behavior events. The dependent variable (DV) for this study was 'challenging' behavior events per person supported. These data were included as part of the incident reporting data agencies are required to submit to the state. Behavior events included any time there was a documented behavior event, regardless of the type of incident, where the incident occurred, or if the incident resulted in an injury. The data represented the aggregate number of behavior events for each agency. While the data comprised three years of data (2016 through 2018), since some agencies did not operate in all years, we averaged agencies' total behavior events across the years (the data thereby represents average annual behavior events). In addition, since organizations supported different numbers of people with IDD, behavior events data was converted into an average rate per person supported (doing so also minimized collinearity). The final DV was the average annual behavior events per person supported.

Independent variable: Dignity and respect. The independent variable (IV) for this study came from the Basic Assurances®. The Basic Assurances® is an organizational assessment that ensures health, safety and human security of human service organizations – they are non-negotiable requirements for service and support providers (The Council on Quality and Leadership 2015). The Basic Assurances® contain 10 factors: (1.) Rights Protection and Promotion; (2.) Dignity and Respect; (3.) Natural Support Networks; (4.) Protection from Abuse, Neglect, Mistreatment and Exploitation; (5.) Best Possible Health (6.) Safe Environments; (7.) Staff Resources and Supports; (8.) Positive Services and Supports; (9.) Continuity and Personal Security; and, (10.) Basic Assurances® System. Underneath the 10 factors, are 92 indicators which include approximately 400 different probes.

Within Factor 2, Dignity and Respect, the Basic Assurances® (2015) examines: Are support staff trained to promote dignity and respect and to recognize each person as a unique individual? To determine if probes, including this one, within the Basic Assurances® are present, expert reviewers, in this case from the state developmental disabilities department, collect a number of data points from multiple sources including focus groups with people with IDD and direct support professional staff, interviews with organizational leadership and people with IDD, data and record reviews, reviews of organizational policies and regulations, and observations of a variety of the agency's settings. All of these data are then utilized to determine if the probes are present or not. The expert reviewers, which are trained and certified by the Council on Quality and Leadership (CQL), typically work in teams of two or three; all decisions are made as a team utilizing interrater reliability.

Utilizing the data collected, the expert review teams determined if the "support staff are trained to promote dignity and respect and to recognize each person as a unique individual" (yes

(1); no (0)). In doing so, the reviewers consider if training curriculum addresses the concepts of dignity and respect with staff, but also is designed to treat people with dignity and respect by promoting people's inherent value, granting them opportunities, and not reducing them to their impairments (K. Dunbar personal communication, February 13, 2019; A. Rapp Kennedy personal communication, February 13, 2019). To gather this evidence, reviewers often examine the training curriculum, examine how staff talk about people with IDD, observe people with IDD's homes and work environments, and observe interactions between staff and people with IDD. Of the agencies in our sample, 84.51% of agencies ($n = 60$) trained support staff to promote dignity and respect and to recognize each person as a unique individual, whereas 15.49% did not ($n = 11$).

Control Variables. Two variables were utilized as controls (CVs). The first variable was agency geographic location – the agency being located in a rural setting, urban setting, or both urban and rural settings. Geographic location was utilized as a CV because there are potential differences in terms of resources, infrastructure, and opportunities for human service agencies in different settings (i.e., rural versus urban).

Our second CV was agency size, as agency size can impact an organization's ability to provide services and its ability to take risks. As a proxy for the size of the agency, we utilized the number of people with IDD served, which fell into the following categories: small (1 to 50 people supported); medium (51 to 400 people supported); and large (401+ people supported). However, because only two agencies fell into the large agency category, they were removed from the sample. Therefore, only small and medium agencies were compared.

Analysis

We had the following research question: what is the relationship between support staff being trained to promote dignity and respect, and 'challenging' behaviors? To explore this research question, we utilized a multiple linear regression model, with the DV 'challenging' behavior events per person supported, and the IV support staff being trained to promote dignity and respect, while controlling for agency size and geographic location (CVs).

Results

Agencies had on average 0.47 'challenging' behavior events per person supported per year ($SD = 0.80$). The number of behavior events ranged from 0.01 per person supported to 4.37 per person supported.

[Table 2 approximately here]

We ran a multiple linear regression model to explore the relationship between behavior events per person supported (DV), and support staff being trained to promote dignity and respect (IV), while controlling for agency size and geographic location (CVs). The model was significant, $F(4, 61) = 3.51$, $p < 0.012$, $R^2 = 0.20$. The following variable was significant: support staff are trained to promote dignity and respect and to recognize each person as a unique individual ($t = -2.89$, $p = 0.005$; Table 2). According to the model, controlling for all other variables, when support staff were trained to promote dignity and respect and to recognize each person as a unique individual the average annual number of behavior events was 0.52 per person supported (Figure 1). Whereas when support staff were *not* trained to promote dignity and respect and to recognize each person as a unique individual the average annual number of behavior events was 1.32 per person supported. For example, if two agencies both supported 250 people, one that does not train staff to promote dignity and respect would be expected to have

330 behavior events in one year, whereas the agency that did train staff to promote dignity and respect would be expected to have 130 behavior events in one year.

[Figure 1 approximately here]

Discussion

Many 'challenging' behaviors exhibited by people with IDD are motivated by environmental causes (Poppes et al. 2010; De Winter et al. 2011; Gentile 2019). For this reason, the aim of this study was to explore the relationship between 'challenging' behaviors and being treated with dignity and respect. Our findings suggest that, regardless of the agency size or geographic location, when support staff are trained to promote dignity and respect and to recognize each person as a unique individual, the number of 'challenging' behaviors people with IDD exhibit reduces significantly. Moreover, in our study, when organizations trained support staff to promote dignity and respect and to recognize each person as a unique individual, the number of behavioral events per person supported was 61% lower than organizations that did not train support staff to promote dignity and respect and to recognize each person as a unique individual.

Our findings add to past research that indicates increased staff training benefits both support staff and the services they provide. Currently, staff who provide the most support often have the fewest qualifications (Hewitt 2014). In addition, the federal government only requires support staff have a high school diploma or equivalent, pass a criminal background check, and have a driver's license (Hewitt 2014; Wachino 2016). Although many states have additional standards, most states do not provide guidance regarding training, leaving organizations to figure out training curricula and protocols (National Direct Service Workforce Resource Center 2013).

Yet, training can lead to increased self-efficacy, improves the quality of the services support staff provide, and improves the health and safety of people with IDD (National Direct Service Workforce Resource Center 2013; Ejaz et al. 2008; Britton Laws et al. 2014; Friedman 2020a). As such, support staff would not only benefit from increased training, but, our findings suggest, they would also benefit from training particularly about treating people with dignity and respect.

Respect "is how we show our regard for each other. Respect indicates that we believe someone is a valued person. Everything we do and say to people makes a statement about their perceived importance… Respect means listening and responding to the person's needs" (The Council on Quality and Leadership 2017). In order to train support staff to promote dignity and respect and to recognize each person as a unique individual, organizations must ensure training curricula addresses the concepts of dignity and respect, including how to see and interact with each person with IDD as an individual – not reduce them to their impairments or believe they are a problem that needs fixing (K. Dunbar personal communication, February 13, 2019; A. Rapp Kennedy personal communication, February 13, 2019). Language should be discussed as part of that training, and how people are treated and referenced should reflect respectful language. How staff talk about people with IDD can not only reinforce stigma, but can also be internalized by people with IDD; "language encodes discriminatory stereotypes and scripts that are associated with inequalities and assist to normalize discrimination in everyday life… language is power; and discrimination cannot be alleviated nor fully understood without language" (Gendron et al. 2016). Finally, respectful practice also includes recognizing people's inherent value, appreciating people's strengths, and people with IDD being afforded opportunities to grow as a person.

We theorize that staff that are trained to, and thereby promote, dignity and respect, will be better at providing supports more effectively as a function of respecting the unique values and

choices of each person. They may also be more likely to present people with opportunities to participate in interesting and fulfilling opportunities. As a function of dignity and respect, they may also be better at interpreting people's behavior, and less likely to problematize it – less likely to interpret people's behavior 'the way a person is,' or as bad or problematic, but rather seek alternative causes and solutions. All of these changes – when the person is being treated with respect – will likely reduce not only the number of 'challenging' behaviors people exhibit, but also what is deemed to be 'challenging' behavior.

Limitations

A number of limitations should be noted when interpreting the findings from our study. All of the agencies in the sample represented a single state. Furthermore, all the agencies in the sample provided services to recipients of the state's developmental disabilities programs. In addition, this was a secondary data analysis. As such, we did not have the ability to add additional questions or variables. We would like to remind readers that correlation does not equal causation. Also, we also did not explore possible confounding variables.

Conclusion

While not all 'challenging' behavior may be reduced by staff being trained to promote dignity and respect alone, findings from our study suggest this training may be one mechanism to reduce the incidence of 'challenging' behaviors, and by extension, the need for behavior intervention services which are costly (Oliver et al. 2012), and, in some forms, controversial (Autistic Self Advocacy Network 2015, n.d.; Kupferstein 2018; Gardiner 2017; Sparrow 2016; Magiati et al. 2007). However, regardless of if, or how, dignity or respect reduces incidences of 'challenging' behaviors, all people with IDD are entitled to respect – "to say that persons… are

entitled to respect is to say that they are entitled to have other persons take seriously and weigh

appropriately the fact that they are persons" (Darwall 1977).

Compliance with Ethical Standards

Conflicts of Interest: The author declares that they have no conflicts of interest.

Funding: This study was not funded.

Ethical approval: This was a seccondary data analysis of existing data. As such, our Institutitional Review Board granted an exemption from human subjects review. All applicable guidelines for the use of secondary data were followed.

Informed consent: Informed consent was obtained in the initial data collection from all individual participants included in the study.

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Table 1

Demographics of Agencies in Sample (n = 74)

Variable	n	%
Geographic location (*n* = 73)		
Both urban and rural	37	50.68
Urban	19	26.03
Rural	17	23.29
Agency size		
Small (1 to 50 people supported)	32	43.24
Medium (51 to 400 people supported)	40	54.05
Large (401+ supported)	2	2.70

Table 2

Behavioral Events: Results of the regression Model

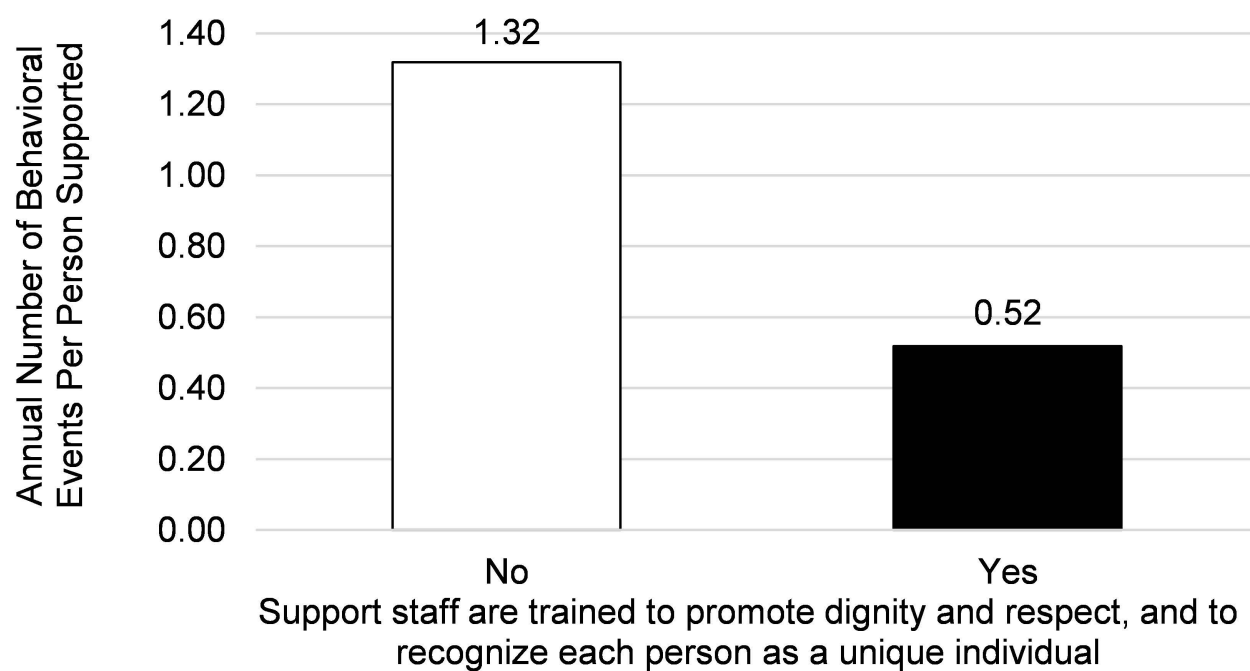| Variables	*B*	*SE B*	*β*	*t*
(Constant)	1.32	0.32		4.11***
Support staff are trained to promote dignity and respect, and to recognize each person as a unique individual	-0.80	0.28	-0.34	-2.89**
Agency size (ref: small)				
Medium	-0.23	0.21	-0.14	-1.07
Geographic location (ref: both rural and urban)				
Urban only	0.30	0.25	0.16	1.21
Rural only	-0.35	0.26	-0.18	-1.36

Note. **$p < 0.01$. **$p < 0.001$.

Fig 1 The relationship between staff being trained to promote dignity and respect, and the annual number of 'challenging' behavior events per person supported (controlling for agency size and geographic location).