

A Soft Approach to Providing Support to Parents with Cognitive Challenges

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Abstract

Today, many parents with varying cognitive abilities still are subject to disruption of their families by the child welfare system. Discriminatory attitudes by child welfare professionals and the courts that intellectual challenges equate to an inability to raise children effectively prevail. Efforts to prevent disruption or facilitate reunification generally require parents to participate in standard training programs and receive, at best, time limited supports that are not family-centered or individualized to what a given family needs. Efforts to acknowledge these parents' competencies have tended to focus on developing professionals' sensitivity to and skills for addressing these unique families. The result has been a distrust of the child welfare system by too many parents with varying cognitive abilities, both in requesting preventive services when needed and in low expectations for a positive outcome for them and their children.

Cognizant of this situation, a process was used that involved listening closely to what parents with these challenges said about their experiences with Connecticut's child welfare system in having their rights terminated, being denied contact with their children, forced participation in trainings they did not understand or were irrelevant, and other issues. To overcome the distrust they expressed, this project used a soft approach in which parents known to have cognitive challenges were invited to a stakeholder meeting. At that meeting, participants were introduced to the idea of using their experiences in a positive way to teach other similarly situated parents how to avoid family disruption. The result was a strong advocacy group which proved their competency by developing an accessible website in plain language, with visual supports, and covering almost every topic they knew had resulted in, or could invite, scrutiny by the child welfare system.

Keywords: Parents with disabilities, family support, child welfare, family preservation

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“Varying cognitive abilities” is the term we use specifically to assure that readers know ALL parents have cognitive abilities that vary. Those whose abilities are often overlooked tend to have diagnosed disabilities. These disabilities often include diagnoses of learning disabilities (LD) which can result in a range of difficulties, e.g., with information processing, reading, and comprehension; intellectual disabilities (ID) defined in most federal and state laws as “a disability characterized by significant limitations in both intellectual functioning (full scale IQ less than 70) and in adaptive behavior, which covers many everyday social and practical skills...that originates before the age of 22...” (American Association on Intellectual and Developmental Disabilities, 2021); autism (Pohl et al, 2020); mental health challenges (Wertheimer, 2019); physical disabilities (Becker et al, 2020); and other conditions that may affect a parent’s ability to meet commonly accepted practices of “good” parenting with additional support.

Although the focus of the article is on parents who have intellectual and developmental disabilities, the information and project now called *Proud Parents: Leadership and Encouragement for ALL Parents* (P.P.L.E.) can be applied in most, if not all, circumstances in which parenting by a person with any challenges is called into question including those with no disabilities at all.

Values Basis

According to the Ethical Standards for Human Services Professionals set forth by the National Organization for Human Services (2015), “The fundamental values of the human services profession include respecting the dignity and welfare of all people; promoting self-determination; honoring cultural diversity; (and) advocating for social justice.”

Additional values underlie this article and the P.P.L.E. project. These value statements come from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 , state policies that attempt to redress the wrongs of discrimination against parents with disabilities such as that of the Division of

Social Services and the Family and Children's Resource Program of North Carolina (2004), the parents involved in P.P.L.E., and the self-advocacy movement.

Federal law

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DDA), under which both the UCEDD and CCDD are authorized, states:

“...disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society (42 USC 15001. SEC. 101 (a)(1))” and that the purpose of the DD Act “...is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs. (DDA 42 USC 15001. SEC. 101(b)).”

Other DDA (2000) sections support the position of the UCEDD and CCDD that these words are intended to mean families in which a parent has “varying cognitive abilities” because those parents have the same rights as other parents as well as the added right to have needed services and supports they need to remain an intact family. Despite other federal laws that will be discussed later which can be used in lawsuits, the DDA is the only one that definitively states this federal policy. Even the federal *Family First Prevention Services Act* (P.L. 115-123) does not expressly prohibit this practice although discretionary prevention services are enhanced for all families. Removal from the family home and termination of parental rights for reason of disability is, by omission, still a *fait accompli*.

A State Policy

In January of 2004, the Division of Social Services and the Family and Children's Resource Program of North Carolina (NCDSS/F&CRP, 2004) identified four core values that apply to our CT project. These, and the corollary statements applying to how their needs should be addressed by the various systems they may encounter, are paraphrased as follows:

- Core Value 1: People with cognitive limitations are like other people—some will be good parents. Some won't. *Professionals should assess parents with cognitive limitations as individuals using appropriate assessment tools, hold them to the same parenting standards as other parents without cognitive challenges, and provide them with the education and other supports they need to meet those standards.*
- Core Value 2: Individuals with varying cognitive abilities have a right to have and to raise children. *Professionals should not presume a parent is incompetent simply because she is cognitively limited. Each family must be approached with an open mind focusing on the strengths of each individual and of the family unit.*
- Core Value 3: Most parents with cognitive limitations are poor and most have had limited learning opportunities. For example, they may not have had the same experiential opportunities to be hired as baby-sitters or been kept out of public -school classes in which sexuality and parenting topics may have been covered. *Professionals must understand that what appears to be neglect may be the result of poverty and/or these other factors, not the parent's disability.*
- Core Value 4: Provided the right supports and appropriate education, people with cognitive limitations who are struggling as parents can usually provide effective care for their children. *Agencies have a responsibility to provide what these families need to stay together.*

(NCDSS/F&CRP, 2004).

Despite North Carolina's leadership, 35 states as of 2018 still "...include disability as grounds for termination of parental rights (Parental Rights Foundation, 2018)."

The Self-Advocacy Movement

The value about "nothing about us without us" is the hue and cry of the disability self-advocacy movement in the U.S. and beyond. Although the term was borrowed from other social justice movements, it has been used by disability advocates for over a quarter of a century (Werner, 1998). A current and formal discussion of this mantra about participation in decision-making as applied to people with disabilities and their families can be found in the book, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Charlton, 2020). The title speaks for itself. This slogan is supported in the DDA which acknowledges that "...individuals with developmental disabilities often encounter discrimination in the provision of critical services..." (DDA, 42 USC 15001, Sec 101(a)(4)) and the DDA's insistence that families and people with disabilities be included in all decisions – major policy decisions as well as those involving families and individuals with disabilities – that affect them (DDA, 42 U.S.C. 15001 *et seq*).

Why Is an Article about Parents with "Varying Cognitive Abilities" Important Today?

Judging by the experiences of the parents involved in P.P.L.E., discrimination – whether actual or perceived – still exists in their worlds. It was not until 2021 that CT submitted its *State of Connecticut Family First Prevention Plan* formally acknowledging challenges faced by PwVCA and a setting forth a statewide commitment to include caregivers with disabilities in its effort (centered in DCF but inclusive of other state agencies) to emphasize front-end prevention services as a means of helping all families remain intact. That plan states:

"Based on the fact that caregivers and youth with disabilities are overrepresented in the child welfare system, Connecticut would like to extend prevention services to this population. CTDCF leads the Connecticut Parents with Differing Cognitive Abilities Workgroup, which is a statewide

partnership among public and private agencies and families seeking to promote system change and enhance capacity of professionals to serve parents of all abilities. Connecticut intends to continue to leverage the expertise of this workgroup to inform prevention planning. Connecticut will also collaborate with community partners to better support the particular needs caregivers and youth with disabilities may have outside of what Family First prevention services can address.” (State of Connecticut, 2021, p. 31).

Yet, at the 2020 annual meeting of the CT Parents with Differing Cognitive Abilities Workgroup (<https://www.pwclworkgroup.com/>) coordinated by the Connecticut Department of Children and Families (DCF), the breakout sessions and keynote speaker (Green, 2020) reflected only a focus -- albeit a necessary one given the horrific and public murder of an unarmed African American man, George Floyd, by a Minneapolis police officer earlier that year (Wamsley, 2021) -- on supporting parents of different racial and cultural backgrounds. Dr. Green did not mention disability, or the intersectionality of disability with race and culture, according to attendees directly affected by DCF’s involvement with PwVCA (Jossie Torres, personal communication, Nov. 5, 2020). Despite the good intentions of the Workgroup, which is comprised of representatives from “public and private agencies across Connecticut who serve adults, children, and families (DCF, 2002),” including eleven state agencies, has made little progress in walking the walk by only including one (1) Department of Developmental Services Self-Advocate Coordinator a member. “Nothing about us without is” would suggest that the Workgroup have substantial representation by PwVCA as members.

Whether intentional or not, CT practices to date have not reflected the values underlying this article and the P.P.L.E. project but instead have overtones of discrimination against PwVCA. Worse, on a national level, the current number of families of PwVCA is unknown since, as the National Council on Disability declared nearly a decade ago:

Parents with disabilities and their families exist in substantial numbers throughout the world, yet documentation of this population is extremely limited. A significant obstacle to ascertaining the number of parents with disabilities as well as their demographic characteristics is the absence of data. While some census data provide estimates of the number of people with disabilities or the number of parents within a given locale, almost no regional or national data consider the combination of these two characteristics. National estimates of the number of parents with disabilities are usually based on projections from much fewer data or estimated by complex extrapolations (National Council on Disability, 2012).

Thus, the most current estimate of the numbers of parents with any type of disability continues to be cited as approximately 4.1 million (Kaye, 2011).

What the Research Says about Discrimination Faced by PwVCA

We know that parents with intellectual disabilities have been at an increased risk for contact with child welfare services and of having their children removed but, surprisingly, little is known about the well-being or developmental health of children with a parent with intellectual disability (Emerson & Brigham, 2014; Tymchuk, 2009). This means there is no evidence base for assuming removal of children of PwVCA from their biological parents is in the best interests of those children. In fact, Krauss and Olkin (2020) recently reported an increased self-esteem in children of parents with ID when families were involved in social supports as well as spending time with other families with disabilities.

In the absence of such data, discrimination against PwVCA by child welfare systems around the world can be assumed and, indeed, has been documented in a number of research studies. Overcoming the prejudice resulting in this discrimination is essential for PwVCA to enjoy the rights that people without disabilities enjoy such as the rights to sexual expression, to love and be loved, and to have a family of their own. Yet many staff involved in child welfare systematically discriminate against PwVCAs simply because they believe that such a diagnosis automatically results in incompetence because of

limits to ability to learn. These staff believe that understanding what is in the best interests of the child is beyond the capacity of PwVCAs (Aunos & Pacheco, 2020).

Aunos and Pacheco (2020) reviewed child welfare case data behind the conclusions and recommendations of unfounded determinations by child welfare workers that PwVCA have limited to no parenting capacity. Their data confirms the prejudicial and erroneous assumptions that there is a positive correlation between IQ and parenting ability (i.e., the lower the IQ, the lower the ability and vice versa), that “objective” tests of parenting skills and professional opinions are predictive about risks to children (they are not), and that professionals with qualifications generally accepted by courts include sufficient training and experience to minimize the professionals’ own prejudices (they do not). In fact, the reports on the same PwVCA by child welfare workers incorporated sentences describing parenting shortfalls in their reports over five (5) times more frequently than specialists in the field of intellectual and developmental disabilities (I/DD) did and concluded that PwVCA were unable to adequately raise their child. This is in stark contrast to the I/DD specialists’ conclusions that all whose cases were reviewed could be adequate parents (Aunos & Pacheco, 2020). A related problem with child welfare workers’ prejudices was that some did not account for the demographic and environmental contexts that affect all families but, instead, attributed any difficulties to the parents’ disabilities (Krauss & Olkin, 2020).

Removal from a biological family by child welfare can be traumatic for both parents and children (Emerson & Brigham, 2014) but there are unique issues facing families and children when parental disability is identified as the only reason for removal. Children removed from these families spent significantly more days away from their natural families, spent more total days overall in foster care, were less likely to be discharged into permanency placements, and more likely to have their parental rights terminated (Lightfoot & DeZelar, 2016).

Higher Rates of Unfounded Referrals and Interventions

Based on a 14-state data set in which a total of 9,265 caregivers of children in the child welfare system were identified as having ID, DeZelar & Lightfoot (2020) found there were significant differences in who made referrals for these groups as compared to caregivers without disabilities and caregivers with other disabilities *after controlling for poverty* (emphasis added). Caregivers with ID were significantly more likely to be referred by medical personnel, foster care providers, nonparental relatives, and “other sources” than caregivers without disabilities and those with other disabilities. As one parent involved in the P.P.L.E. project declared, “I can be guilty of playing in the mud with my child and running so late (for a momentarily forgotten pediatrician appointment) that my child is filthy (but this is because) because I’m a GOOD mom (who plays with her kids). I’m not guilty of neglect. But that’s what they’d think and they’d never ask me” (anonymous, personal communication, March 16, 2021).

All parents with disabilities including ID had significantly higher odds of being referred by social services professionals. Some researchers have interpreted this as evidence of an exposure hypothesis – i.e., the more contact you have with professionals, the more likely they are to report maltreatment to authorities (c.f. DeZelar & Lightfoot, 2020).

McGaw et al (2007) found that risk factors for mental health challenges of parents with ID included sexual abuse (a strong correlation) as well as emotional abuse and neglect or physical neglect (weaker but still significant correlations). Traumatic events have also been reported in other studies as predictors of PwDCA’s involvement with child welfare services and receiving a psychiatric diagnoses (Ostrow et al., 2020). Emerson and Brigham (2014) reported that, despite some increased risks, there was no association between parental intellectual disability and either child behavior problems or frequent accidents and injuries. Although children of PwVCA were found to be more at risk for speech and language problems as well as overall developmental delays, they are, according to Through the Looking Glass, a California non-profit specializing in supported parents with disabilities

(<https://lookingglass.org/>), as responsive to early intervention as children of parents without disabilities at all.

Another finding from substantiated situations of abuse was that there was no significant difference in incidents of physical abuse, neglect/deprivation of necessities, or medical neglect among parents with ID as compared to parents without disabilities yet parents without disabilities were more than twice as likely to receive family preservation services (21.9% compared to 8.1%). Parents without disabilities also were much more likely to be referred to mental health and/or substance abuse services when these issues corresponded with substantiated abuse and/or neglect (Slayter & Jensen, 2019).

Removal from Family Home. The risk of a child being removed from their parent's care also has been associated with negative attitudes of child protection workers and judges towards parents with disabilities (Strnadová et al., 2019). This is supported by Arizaga and Morgan (2020) who reported that social workers who had more experience with individuals with ID had reported lower stigma about individuals with ID. Rates of substantiation of reports of maltreatment were higher for all caregivers with disabilities (Lightfoot et al., 2020), including when reports were made by an alleged victim (DeZelar & Lightfoot, 2020). Unfortunately, even when the abuse or neglect cannot be substantiated there is still a high risk for the children to be removed (Strnadová et al., 2019).

Extent of Discrimination. Perceptions among social services personnel that parents with cognitive limitations do not have the right or capability to parent their children appears to be a multi-national issue (Coren et al., 2018; Feldman & Aunos, 2020; Gur et al, 2020). This was also demonstrated by Emerson and Brigham (2014) who completed a study that looked at adverse child developmental outcomes and environmental adversity. Their data, however, was collected by health visitors who were not likely to be objective. In their article title, MacIntyre et al. (2019) refer to this as "the double-edged sword of vulnerability" faced by practitioners who hold dual loyalties to protect the well-being of vulnerable children living with parents who are also perceived to be vulnerable. Yet, despite what

appears to be a “victim-blaming” orientation, there still is evidence that parents, attorneys, and child welfare professionals all agree that there is a lack of expertise in disability issues in the child welfare system accompanied by a lack of adequate services (Albert & Powell, 2020).

Rights of PwVCA

Although no state currently has laws explicitly allowing the termination of parent rights solely by reason of disability, the Child Welfare Information Gateway of the federal Children’s Bureau, an office of the Administration for Children and Families, implies that, as of 2021, most still allow professional discretion in applying the criterion of “long-term mental illness or deficiency of the parent(s)” by not expressly forbidding it. Many states still direct courts – not disability professionals -- to consider how a parent’s intellectual or developmental disability, mental illness, emotional illness, or physical disability affects their ability to parent (Child Welfare Information Gateway, 2021; Lightfoot et al. 2020).

In general, parents have a right to raise children as they choose. All parents can have their rights terminated by the *parens patriae* doctrine in which a state may intervene in situations in the best interests of the child provided due process procedures are followed, the unfitness is individually determined (i.e., not based on a group identifier such as ID), and the decision is based on a high legal standard of “clear and convincing evidence” because of a strong presumption that family should stay together (Guerrero, 2021). For PwVCA, there is a strong case for inclusion of additional legal principles – i.e., those put forth by Title II of the Americans with Disabilities Act as amended in 2008 (P.L. 110-325) and the Workforce Innovation and Opportunity Act of 2014 (29 U.S.C. 794), still more commonly known as “Section 504 of the Rehabilitation Act of 1973” – which prohibit discrimination on the basis of disability and require reasonable accommodations, removal of various barriers including communication and transportation, and provision of auxiliary aids for PwVCA (Francis, 2019; Guerrero, 2021). Child welfare agencies at the state and federal level are included theoretically in these provisions protecting all people with disabilities, including PwVCA.

In fact, the U.S. Health and Human Services Office of Civil Rights and the U.S. Department of Justice Civil Rights Division (2015) has focused their efforts on two specific areas. One is that individualized interventions “...may not be treated on the basis of generalization or stereotypes...unsupported by individual assessment that people with disabilities are unable to safely parent their own children.” The second is that PwVCA are entitled to full and equal opportunity “...to benefit from or participate in child welfare programs, services, and activities that are equal to those extended to individuals without disabilities...(through) adaptation (and)....reasonable accommodations.”

Unfortunately, case law is inconsistent in applying these provisions to PwVCA if they are applied at all. And, despite a 2017 resolution of the American Bar Association (2017), CT is one of the states that still does not have a law a) incorporating rights of PwVCA, b) specifically prohibiting discrimination by DCF or mandatory reporters, or c) providing any definition of supported services that could keep such families intact. Rather, CT laws governing actions of the Department of Children and Family Commissioner (Connecticut General Assembly 17a-10a *et seq*; Sec. 45a-715 *et seq*) relate only to removal from the family home, termination of parental rights, and permanency planning. As some legal scholars have recently suggested, it is mandatory that DCF, courts, attorneys, and social services agencies need training by, e.g., disability advocacy organizations such as Disability Rights CT (also authorized by the DD Act), to change the issue from “lack of parent capacity” to “how parenting can be [optimized] through community supports” (Guerrero, 2021). Such training must address discrimination based on presumptions about the inability to learn parenting skills and “mental age” equating, e.g., to safety awareness, and how to maximize use of alternatives to family disruptions and termination or parental rights. Alternatives such as supported “family decision-making” arrangements, open adoptions in the event parental rights are terminated for the same reasons they may be for any parent, daily homemaker/housekeeping services, and other family-centered supports must be available to all (Francis, 2019).

Cultural Humility and Individual Differences

Exploratory research by Krauss & Olkin (2020) has shown that maternal disability does not impact the quality of the parent-child relationship, positive family activities or overall monitoring of their children. When pregnant, mothers with disabilities reported having similar fears to mothers without disabilities regarding their children's overall wellbeing. Another study found that mothers with autism that may or may not include ID had no significant differences in breastfeeding and many other aspects of parenting newborns but were significantly more likely to report they experienced depression; did not have the birth process adequately explained to them; and had greater difficulties being organized, with multi-tasking and completing household tasks, and putting effort into creating opportunities for their child to socialize outside the home (Pohl et al., 2020). Nearly half (41%) reported not receiving the kind of assistance they requested in addressing these challenges. They also reported significantly more difficulties communicating and interacting with professionals across a variety of domains as compared to non-autistic mothers.

In some situations, cultural and faith-based expectations around marital relationships leading, for example, to arranged marriages between men with ID and women without, may be at odds with some of the values held about self-determination and equity of parental responsibilities within a family (Gur et al., 2020; Gur & Stein, 2020). This can complicate the parenting by PwVCA, as can the myriad of other ecological influences including social factors, social support and services, parental history, and life crises that interact with parent and family characteristics, child heredity and early experiences, and parenting knowledge and skills sets to produce positive child and family outcomes (Feldman & Aunos, 2020).

Furthermore, like many families affected by the same ecological influences as chronic unemployment, poverty, and poor living conditions, PwVCA fear that involving the child welfare system

if and when they do need support automatically will result in loss of their child. Thus, they may not seek help (Collings et al., 2019).

What Kinds of Supports Work?

Prior to the 1980s there was little evidence-based information on effective child-care training programs for parents with intellectual disabilities (Feldman, 1994). Unfortunately, the child welfare system historically has not recognized the concept of supports for parents with disabilities or the notion of interdependent parenting. In the intervening years, however, siloed changes within the child welfare system occurred signaling that the concept of parental supports may be on the rise (Lightfoot & LaLiberte, 2011). Researchers report that assistance and supports are important factors in quality of life and participation for individuals with disabilities and their families. Specifically, when parental supports are provided parents are better able to care for their children (Krauss & Olkin, 2020; Lightfoot & LaLiberte, 2011; Tymchuk, 2009). Contrary to some beliefs, a large body of research also has confirmed that parents with intellectual disabilities can learn and retain parenting skills (Feldman, 1994; Strnadová et al. 2019).

Skill-building and Professional Supports. Tarleton and Ward (2007) reported that non-judgmental interventions such as regular assistance with a range of tasks (e.g., bill-paying, maintaining household routines, keeping appointments, play, saying “no”); plain language explanations (e.g., of court processes); help in overcoming bigger problems (e.g., living arrangements and living in poverty); emotional support; peer support and mentoring; and access to cash (e.g., to hire nannies or community mentors through self-determined services) were beneficial to parents. Supports provided to parents need to be available as required, not at pre-scheduled times. Parents in their study reported increased self-confidence, ability to self-advocate for what they and their families needed, motivation to remain involved with their children, and greater cooperation with formerly threatening child welfare workers

because of these supports. PwVCA also reported knowing they could still get help even if formal supports were faded was important (Tarleton & Ward, 2007).

Supports can and must be different based on an individual family's needs. Some parents benefit from attending structured programming while others benefit from consistent peer support. For example, participation in a structured 14-week relationship skills-building program coupled with home-based supports did not have any significant impact on participants' self-reported feelings about their children, perceptions of children's abilities, reported stress, or interactions with, e.g., professionals, but did result in improved self-concept and creation of an informal support group (McGaw et al., 2002). This was especially true for parents who had participated in prior group interventions. This combined intervention did not work for them.

Interestingly, parents who received only the home-based supports demonstrated significant increases in their perceptions of their children's abilities. The authors of the study posit that poor outcomes in the combined interventions may have been due to time conflicts between the two interventions, the greater focus on parental relationships than parent-child relationships in the group, or because "homework" was required (McGaw et al., 2002).

It is also possible that, in the McGaw et al.(2002) study, the instructional strategies used in the group sessions (i.e., skill rehearsal requirements, identification of behavioral A-B-C's, and some of the visuals used) were not individualized for or generalizable by participants to meet their unique needs. This is in stark contrast to the model of parent-centered planning and follow-up proposed by Lightfoot and DeZelar (2020) which embraces parent-centered planning focused on individual and family strengths, preferences, and desires. In practice, this model yielded minor short-term results in that the participants took some positive actions toward implementing their parent-centered plans. In the longer term, the study pointed out the fragility of social networks experienced by PwVCA despite parent-centered planning (DeZelar & Lightfoot, 2019). On-going person-centered support seems essential.

On the other hand, data from Project IMPACT (Improving Parenting Achievements Together) study that also attempted to validate a *Skills Assessment for Parents with Intellectual Disabilities* demonstrated significant improvement among some parents (Zeitlin et al., 2020). These parents were from intact families who completed the program. Improvements occurred for specific skill clusters that had been identified through assessment. A disproportionate number were parents of color. The skills clusters in which improvements *in describing OR demonstrating the skill* included activities of daily living, parent-child interaction, and overall safety. Presumably, this validates the prevention intent of Project IMPACT although there was no data comparing, for example, referral rates for those involved in this project as compared to those who were not.

Support Networks. In a scoping review involving 13 studies that met stringent criteria for inclusion, Gudkova et al (2019) found that strong informal networks of support (e.g., including siblings, extended family members, school friends, people in the neighborhood) and formal networks had the most positive impact as reported by adults who had been raised by PwVCA. Formal networks were successful to the extent they were connected to the parents and home life as well as being focused on the children's interests and needs in an age-appropriate way (e.g., through leisure opportunities, calling to make sure children got up in time for school, providing rides). Parents did not work well with professionals who focused on the parents themselves and who were disrespectful. This indicates that a peer-based model or disability support group may be more beneficial to the parents and their families (Gudkova et al., 2019; Krauss & Olkin, 2020; Collings et al., 2019). The disability community itself can provide supports to families with disabilities without any type of stigma, providing role models, assistance with problem solving, and shared strategies and adaptations for parents with disabilities (Krauss et al., 2020).

Peer supports also provide a number of benefits to families such as shared identity; exchanging information and learning from others; becoming empowered and motivated as well as more confident;

and a sense of being able to both receive and give support to others (Strnadová et al. 2018; Collings et al., 2019). Disability-Affirmative Therapy (DAT) was described by Krauss and Olkin (2020) as a way to improve one's disability identity and promote affiliations with a disability community. These results support the family-centered planning and practices model. Augsberger et al. (2020) did find these family- and person-centered relationships and community engagement significantly reduced out-of-home placements for PwVCA.

Need for Changed Roles of Professional Supports. The research suggests a strong amount of incongruity between opinions of some professionals and those with lived experience as PwVCA. On the other hand, research has also assisted in describing the characteristics of successful relationships with professionals that improvement family outcomes.

In a systematic review of 19 studies from various Western countries, none of the professionals perceived that PwVCA needed emotional support (Koolen et al, 2020). Few described successful informal supports. Instead, professionals focused on needs for daily living skills and for PwVCA to be connected with additional services. PwVCA, on the other hand, identified emotional support as a definite need. They also emphasized the importance of both informal and paid supports (e.g., to help them keep their child), and described their needs for assistance with basic tasks of child-rearing, dealing with services (e.g., for information to be in plain language), money, and materials. Both professionals and PwVCA concurred on the need for supports to be long-term and individualized, sensitive to what the PwVCA themselves said and needed, and clear about what they were offering by way of information and recommendations. Yet, professionals focused on their perceived need for PwVCA to be aware of their limitations whereas the parents themselves just wanted to be taken seriously as capable parents (Koolen et al., 2020).

Additional studies support the success of child welfare workers who do not equate learning challenges with neglect but rather see parents as needing more information, broken down into steps

they can understand, with positive regard for what they can do and learn in long-term supportive and empowering relationships with professionals who adapt their approaches when something either does not work or the family dynamics change (Tarleton & Turney, 2020).

Reaching and Teaching Opportunities. Even with supportive professionals, some instructional methodologies are more successful in supporting PwVCA.

Video Feedback. Hamby et al. (2019) make a compelling case for using video feedback (VF) in family homes (not necessarily possible at this writing during the COVID-19 pandemic) as teaching tools. Their comprehensive review of the literature on use of VF for parenting skills in general and as adapted for use with specifically parents with ID raise hope because VF:

- Highlights the parents' strengths and promotes an individual approach to building on these to address challenges these parents face;
- Is likely to be more compatible with the learning styles of many PwVCA than text (written) or verbal (spoken) instructions;
- Facilitates teaching of concrete skills and generalizability;
- Suggests positive attributes for child behavior; and
- Promotes a positive view of parent supports (Hamby et al., 2019).

Given the success of Zoom (<https://zoom.us/>) and similar platforms for connecting people with many types of disabilities with many different needs during the time of the COVID-19 pandemic, there is a likelihood that video feedback and coaching can be successful remotely as well.

Self-Instruction. Another strategy to reduce the risk of child neglect that appears successful is self-instruction. Feldman and Case (1999) did a series of studies using, e.g., illustrated parenting handbooks with accompanying childcare checklists and audiotapes. Their materials were made available in such a way that parents were not inundated with the entire collection but rather provided with information about priority topics for them. In some families, parents were prompted during home

visits to refer to the illustrations and checklists but the use of handbooks seemed to work equally well for parents whose only option was self-study of the materials they were given. Unfortunately, this practice of PwVCA to self-determine priority areas has not been widely adopted and the “one size fits few” approach in, e.g., court orders about reunification of children and their PwVCA, prevails (Francis, 2019).

Video Interaction Guidance. Although not specifically developed for parents with cognitive challenges, Video Interaction Guidance is an attachment-based parenting intervention in which a “VIG Guide” videotapes a parent interacting with their child and allows the parents to reflect on the filmed results. The guide supports the parent in identifying strengths and areas in which to make changes. This has been shown to be successful, too, especially when the targeted interactions relate to goals the parents themselves have set and materials are adapted to include plain language, visual aids such as comic strip conversations, supervised practice, modelling, and repetitions of information (Alghali, 2019).

The Cochrane review of interventions suggests that, although more efficacy research needs to be done, these interventions have been replicated sufficiently to conclude that PwVCA can indeed learn better parenting skills, especially when given options of what they feel they need to learn (Coren et al, 2018).

The Connecticut Parent Leadership and Encouragement Project

The shortcomings of the DCF-sponsored Workgroup in including PwVCA has already been described. According to the CT Clearinghouse (a program of the CT Center for Prevention, Wellness and Recovery funded by the CT Department of Mental Health and Addiction Services), the Wheeler Clinic has run a “Parents with Cognitive Limitations (sic)” workgroup since 2002 (Connecticut Clearinghouse, n.d.). Again, there is little indication that the Wheeler Clinic actively seeks input from PwVCA themselves. These programs, like the Healthy Start program in Australia’s Parenting Resource Centre (n.d.), exist to support “...professionals working with parents who have learning difficulties...(by providing) information

and resources for practitioners, managers, researchers and policy makers and aims to improve outcomes for both parents and children.” Such programs do not reflect the values basis for this article nor do they operate in accordance with best practices to support PwVCA.

A decade or so ago at the time of this writing, DDS received grant funding to engage PwVCA in devising their own supports (Marie Bennet, personal communication, March 24, 2021). Documentation of the results is limited but there is indication that DDS still has some regional support groups for PwVCA in the Norwich area and Southwestern CT (Advocates’ Corner, 2021). Despite the advocacy efforts of some CT professionals and self-advocates, activity in these groups seems to have all but disappeared of late.

CCDD Funding for a New Advocacy-Focused Project

Three factors led the CCDD to conclude that there was a need for some formal initiative to assure that PwVCA had the skills to deal with their children’s schools, to use community resources to optimize their and their children’s health and well-being, and to be able to advocate for systems changes (e.g., improved transportation). First, parent-staff relationships with public schools can be difficult when children have Individualized Education Plans under the Individuals with Disabilities Education Act (20 USC Ch. 33) or who present behavioral or academic challenges at school (c.f. Bennett et al., 2020). This is true for all parents but can be especially daunting for PwVCA. Second, there is an abundance of literature on the benefits of accessing community resources such as museums, recreational facilities, and the performance arts to the physical and mental health and well-being of both families as a whole and their individual members. Although there is no solid data to substantiate a differential benefit for families in which there are PwVCA, there is other evidence suggesting that people with disabilities in general (including PwVCA) have difficulty accessing community resources because of, e.g., transportation (Bezyak et al., 2020). Third, the CCDD was aware of the research on PwVCA already reviewed in this article that recognized “...the importance of social support (and)... teaching the parent

to build a support network, be more socially engaged, and participate in activities that promote parent, child, and family wellbeing (Feldman & Aunos, 2020).”

Thus, funding was allocated in FY 2019 to establish a self-advocacy group for PwVCA. This funding was awarded to The Arc of CT, consistent with its national policy and advocacy group, The Arc. The Arc’s position statement specific to “Parents with Intellectual and/or Developmental Disabilities” states:

The presence of an intellectual and/or developmental disability¹ does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities (The Arc, 2021).

Phase 1 (2019-2020). According to some self-advocates involved in the CT Arc’s initial attempt to develop a Parent Leadership and Encouragement Project in CT, the effort was not as successful as they had hoped it would be because of three factors. First, some of the more strident self-advocates complained that “Nothing about me without me” was ignored because the facilitator planned and organized the meetings. These were held in local Arc’s with dinner and transportation provided. Second, many prospective participants reported negative perceptions and general distrust of professionals. Third, materials and information were largely inaccessible (e.g., multisyllabic words, PowerPoints not using high contrast, multiple font types and sizes, no illustrations) (anonymous parents, personal communication, February 10, 2021).

Messaging in grant language or assurances that professionals were there to “do for” rather than “do with” participants, along with transportation and other logistical challenges including availability for meetings, resulted in drifting away from the original mission to create a self-advocacy group to support PwVCA in maximizing their engagement with their children’s school program and with community

resources towards more social get-togethers (Shannon Jaccovino, Arc CT, personal communication, November 20, 2020). Most likely, the culprit for initial lack of success was the onset of COVID-19 and the statewide quarantine which began in March of 2020.

This effort still was successful in reconvening a group of PwVCA as advocates (Arc CT, 2020) but was specifically instructive about how the second attempt to support CT PwVCA was conceptualized.

Phase 2 (2020 – 2021). For the 2020-2021 Fiscal Year, the CCDD agreed to change direction of the project to align with the self-advocacy mantra “nothing about me without me” and the approach taken by The Association for Successful Parenting (<https://achancetoparent.net/>). This organization strives to be strengths-based and solution focused, individualized, community based, and built on both formal and informal support systems that support meaningful connections of PwVCA to be strong, thrive, and have lifelong connections to family, identity, language, and culture.

The review of literature undertaken by the UCEDD provided ample evidence that involving PwVCA as consultants to this type of project was necessary for the project to be successful (c.f., Pohl et al., 2020; Tarleton & Ward, 2007). Involvement as consultants put the PwVCA on an equal level with professionals and their active role in decision-making in all phases of the work. For this reason, a Stakeholders group was established.

Methodology. The steps taken in Phase 2 has ultimately resulted in an extensive resource for all parents and that meets the need of PwVCA in CT as well as the various professionals and paraprofessionals who come into contact with them.

Staffing Support. Two professionals worked in collaboration to initially plan and implement the first steps of the project with the understanding that any decisions they made could be overridden by the PwVCA. The project coordinator, one of the co-authors of this paper, could relate to the experiences of PwVCA with DCF because of her long-established relationship and extensive experience with that agency as a foster parent. The coordinator worked under contract with The Arc. Technical

assistance was provided by the UCEDD. The other co-author of this paper had experience with DCF both as a recipient of services due to a child with significant behavioral health challenges and as a therapeutic foster parent. Both have extensive experience supporting people with disabilities and were easily accepted by the PwVCA who were recruited and were the mainstay of the P.P.L.E. project.

Initial Outreach. Outreach involved developing a flyer advertising in plain language, with visual supports, which encouraged any parents who felt they needed help raising their children to contact one of the support staff in order to be part of a “Stakeholder Group.” There were 650 flyers delivered during the COVID-19 quarantine to CT Community Health Centers (CHC) throughout the state for their pediatric departments. Electronic copies of the flyer were sent to DDS, DCF, affiliates of The Arc, and CT’s DCF-funded programs for Intensive Family Preservation (IFP) programs located throughout the state. These IFPs have as their mission to provide support to families in the positive, individualized manner described in the research.

Stakeholders. Twenty-five total recruits – i.e., 21 mothers and 4 fathers – came from The Arc’s initial list of those who had been involved in Phase 1, referrals from DCF, one from a CHC in one region of the state, and from people known to the organizers and participants. These represented six out of eight CT counties (New Haven 8; Hartford 7; Fairfield 4; New London 3; Windham 2; Middlesex 1).

Launch of the project. An initial virtual meeting was held of recruits on March 16, 2021. At this meeting, staff suggested that the project could hopefully result in a website with plain language and multi-media materials easily accessible to any parent including PwVCA. This proposal was met with enthusiasm by those in attendance. Stakeholders renamed themselves “Proud Parents – Leadership and Encouragement for ALL Parents (P.P.L.E),” in part to confirming the values described earlier in this article and also to eliminate the stigma they felt would be attached to any name related to differing abilities, disabilities, or cognitive differences. The P.P.L.E. project is the result of eight (8) months of hard work by CT parents who have been diagnosed with “varying cognitive abilities” at some time in their lives. This

work continues today. Each member also has been affected by the child welfare policies and procedures of DCF. The values members articulated at their first meeting, stated in plain language, are:

- Family First.
- No one parents alone.
- We CAN do it, even if we need support.
- Equity & fairness are what every family needs.
- Caras vemos, corazones no sabemos (English translation: Faces we see, hearts are unknown).
- Nothing about us without us! (P.P.L.E., March 16, 2021).

Vision and Mission. Flowing from these consensus values, the core group developed the vision statement, “For families to stay together with the support they want and need, and for children to grow up in safe, loving homes.” The mission, reflecting their experiences and the encouragement and support they strongly felt all parents need, is as follows:

- To be leaders for parents with disabilities to have the help they want and need so their families can stay together, and to fight against discrimination and unfair practices.
- To be leaders in decision-making to ensure "nothing about us without us."
- To create a user-friendly website to make it easier to find help and resources for parents and families.
- To have parents empower and encourage parents through peer support, other parents who understand what they are going through.
- To strengthen self-advocacy skills so parents can influence decisions make about them and about other parents with disabilities.
- To use strong self-advocacy skills to join advisory committees for DCF, DDS, the judicial system, advocacy groups, and local and statewide agencies to make needed changes.
- To advise professionals, like doctors, how to best help parents with disabilities.

- To change reading into plain language.(P.P.L.E., 2021).

To move toward the mission, P.P.L.E. held 14 additional meetings -- 12 on Zoom and two face-to-face – to develop their website (<https://www.proudparents.info/>). The project coordinator also met with four parents in person. All contacts were accurately billed as listening sessions in which the concerns, experiences, and advice from PwVCA were encouraged and valued. Over time, concepts from *Effective Support Strategies for Parents with Cognitive Difficulties* by Cathy Haarstad (2020) were introduced to obtain Stakeholders’ thoughts and ideas. The Haarstad concepts address specific life challenges, perceptions of effective supports and supporters, and overall approaches to helping families. “We are not here to judge...” was the support staff’s mantra for these listening sessions as participants are encouraged to find common ground in directing the contents, format, and other features of the website designed to make parenting materials accessible to PwVCA.

The Resulting Website

As the project progressed, needs were identified and materials collected (many of which were suggested by the Stakeholders). The skeleton of a website began to form. The Arc made the decision to use the “Wix” platform for website development because of its ease of use in addition new information, rearranging content, and removing materials that are no longer relevant. Originally, only links to existing resources were used. Then Stakeholders identified what revised information they wanted (e.g., things that may have been taught in a formal parenting class that did not use plain language or was not consistent with their learning needs).

Website Structure

The website content has now expanded and is grouped under nine (9) broad topic categories on the landing page. Each category has links to subcategories currently on the website or under development. Although the “drill down” from the broad categories to additional links had initially seemed confusing, Stakeholders felt it was not because of the overall colorful layout with large print,

visuals, and icons helpful to navigation. Stakeholders designed or approved all aspects of website development including accessibility, colors, font, and size of letters and images. Accessibility was also checked and meets or exceeds 508 standards for accessibility.

The website is available in Spanish and one of the Stakeholders, who is bilingual and fluent in the Puerto Rican dialect, is continuing to edit for other translation errors made by Google translate. The website can be easily translated into other languages upon request but may need to have a bilingual reviewer to check for complete accuracy.

The nine broad categories and subcategories are shown in Appendix A. Those that do not have subcategories listed still contain information and links but currently are not developed enough to divide the content further.

New materials are added frequently as the Proud Parents continue to meet. Page content varies somewhat but may include words of encouragement; links to videos and cell phone apps; definitions and FAQs written in plain language and explained; and links to services/other information that Stakeholders felt were important. Resources are cross-linked to other categories in the website “behind the scene” so users do not need to back out of the category they are currently exploring to get to related information. All categories and subcategories follow a similar lay-out.

In Appendix B, an example of the flow of some links from the first broad category (*I Need Support or Someone to Talk To: There are many different types of support that can help*) is shown. Clicking the link for that category brings you to a website with three basic sections. The first section links to two videos about general supports. The middle section allows website users to select what types of support applies to their current circumstances. They may choose 1) For parents, 2) In crisis, 3) Advocacy & School, or 4) For dads which, upon a click, brings them to other website pages. For Parents leads to a page containing words of encouragement; direct links and the ability to make direct phone calls to a variety of parent support groups; information about DDS with direct links; the ability to make

direct phone calls to various services DDS provides to PwVCA; and ways to connect to the DDS Helpline.

The website also has links to other pages within the website itself that are related to parent support.

Uses of the website. The major decision to construct this website came from Stakeholder feedback about other ways they have been given information. They had found many of these other ways unhelpful. Major reasons were that they covered general topics, the specific topics of trainings often included information they already knew and skills they had already mastered, and the content was not delivered in plain language. Usually, these experiences were the result of “parent training” required by DCF or the courts.

Website Applicability

The layout of the website intentionally has four purposes that work around the Stakeholder feedback of past training experiences while still meeting the needs for targeted learning – of knowledge and skill sets – the Proud Parents themselves want and need, including guidance to avoid what led the parent to be involved with DCF or the courts in the first place. These website purposes are:

1. Any parent, regardless of whether or not they have a disability, can identify what they feel they need to know and pursue information about the topic at their own pace. They may also return to review the information as needed. PwVCA are likely to do this independently, when they have access to the right technology, because they want to be good parents.
2. The website allows people involved with PwVCA to sit down with those parents, go through the website contents, and identify what it is the parents want and need to know about. There are also multiples ways each topic is addressed (e.g., plain language, pictures, videos, and links to training webinars). This individualizes any required parent training. Those reviewing this information may also work more intensively with the parents to assure content is understood, skills are practices and perfected under supervision, and families remain intact as a result.

Consistent with the research, practitioners may want to combine this with video feedback intervention (Alghali, 2019; Hamby et al., 2019).

3. The website allows anyone involved with PwVCA to learn approaches that are more likely to be effective because they have been recommended by people with lived experience. Again, this reflects “Nothing about me without me” and assures that the relationships between “helpers” and those parents are reflect “Plain language resources chosen by parents with disabilities to help parents be the best parents they can be!”
4. This website can be helpful to families affected by DCF child protective services because it includes the most common reasons referrals to DCF are made.

The website has been shared with DDS and DCF with the result that the Proud Parents received the annual advocacy award at the 2021 annual meeting of the CT Parents with Differing Cognitive Abilities Workgroup (<https://www.pwclworkgroup.com/>) in alignment with their topic, "Building a Connected Community: What we Need to Thrive."

Conclusion

Phase 2 of the CCDD-funded project to meet the needs of PwVCA has been extremely successful. The Stakeholders feel a strong sense of pride and accomplishment and, consistent with their stated goal for Phase 1, have become a support system for each other. They have requested specific information themselves, provided by the UCEDD and now posted on the website, on such topics as how they and their families can be more involved in their communities, how to best prepare for and support their children at meeting with school staff, and supported decision-making. They have become advocates in the process and now have a strong interest in changing CT laws that affect PwVCA; changing the DCF assessments to be more person-centered, strengths-based, and fair to all; improving state practices to increase family preservation; and educating others on how best to support parents with disabilities. They are now involved in several other groups where they continue learning and are

establishing a presence so others will learn from them. These groups include DCF's Parents as Experts for Family First, DCF's Child Safety Focus Group, the Self-Advocates Resource and Technical Assistance Center (SARTAC, <https://www.selfadvocacyinfo.org/>), The Association for Successful Parenting (TASP, <https://achancetoparent.net/>), and TASH (<https://tash.org/>). They plan to have a more active role in DCF's CT Parents with Differing Cognitive Abilities Workgroup (<https://www.pwclworkgroup.com/>) and closer ties to the Intensive Family Preservation providers (<https://www.intensivefamilypreservation.org/about/>) who have expressed interest in the website.

All in all, the Proud Parents, who themselves are PwVCA, have clearly shown their many strengths and, as the literature indicates, cannot and should not be underestimated or denied the right to parent with the support they need because of their intellectual challenges or cognitive disabilities.

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Appendix A

Nine Broad Categories and Subcategories on P.P.L.E. Website

- 1. I Need Support or Someone to Talk To: There are many different types of support that can help.**
 - a. For parents**
 - b. In crisis**
 - c. Advocacy & School**
 - d. For dads**
- 2. Help with Good Parenting: Parenting advice, tips, self-care (another section on Autism is under development)**
 - a. Good Parenting**
 - b. Parenting by age groups**
 - d. Training & Tips**
 - e. General Life Tips**
- 3. Self-Advocacy: Control of your life & future**
 - a. Self-advocacy Groups**
 - b. Person-centered Planning**
 - c. How to Make Things Better**
 - d. Advice for Professionals**
- 4. DCF CT: My rights, finding help & info**
 - a. Reasons/Abuse & Neglect/Prevention**
 - b. What if DCF contacts me or takes my children?**
 - c. My Rights as a Parent**
 - d. Who Can Help Me?**
- 5. My rights/My future: Disability rights, Planning my life.**

- a. Disability Rights**
 - b. Parents' Rights**
 - c. Person-centered Planning**
 - d. Employment**
- 6. Basic Goods & Services: Food, clothes, housing, rides**
 - a. Food**
 - b. Clothes**
 - c. Housing & Utilities**
 - d. Transportation**
 - e. Recreation**
 - f. Things for Babies**
 - g. Assistive Technology**
- 7. Health: Medical, mental health, insurance**
 - a. Taking care of your health**
 - b. General Health & Wellness**
 - c. Mental Health**
 - d. Medical Insurance**
 - e. Sexual Health**
- 8. Safety: Home, personal, children**
 - a. Safety at Home**
 - b. Personal Safety**
 - c. Healthy Relationships**
 - d. Child Safety**
 - e. Internet Safety**

9. Other: Agencies and general help websites

a. State of CT

b. Others

Appendix B

Example of Proud Parent Website Layers and Links

<https://www.proudparents.info/>

