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Practices Changes in the Child Protection System to Address the Needs of Parents With Cognitive Disabilities

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Abstract

Parents with cognitive disabilities (PCD) are over-represented in the child protection system. However, the current state of the child protection system is not well prepared for working with them. Biases that exist against their parenting, the need for accommodations in assessment and intervention practices, and specific training in staff and cross systems barriers need to be addressed. This paper argues for changes that will ensure such parents are more effectively served and that child protection staff and contract providers are better equipped to work with them. Specific changes are discussed in assessment and intervention practices. These changes will require human capacity building and organizational restructuring. Although empirically based behavioral approaches with PCD will be emphasized, recent empirical work suggests that social information processing and neurocognitive problems occur in PCD. Approaches to working with such problems are emerging and must also be considered and integrated into a blueprint for change.

Keywords

parents; social information processing; disabilities; child welfare

Parents with cognitive disabilities (PCD) may include individuals who have official developmental disabilities labels, have IQs in the Borderline to Mentally Retarded range, and/or have learning disabilities or selective neuropsychological difficulties or traumatic brain injuries. Each can have implications for the quality of parenting and the requirements of everyday family life. Although there has been an increase in empirical work regarding antecedents of parenting difficulties and practice with PCD, the required adaptations have been slow to be implemented consistently across the child protection services (CPS) system

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(Azar, Robinson, & Proctor, 2012; McConnell, Feldman, Aunos, & Prasad, 2011). Our discussion outlines suggestions for changes in systems-based practices that are meant to increase the effectiveness of work with PCD and to make available needed extra-organizational supports for those who work with this population. The adaptations will require changes in the methods used to assess PCD for service planning and changes in the implementation of interventions for these parents. These changes will require building human capacity to optimize staffs' ability to communicate with parents and to reduce barriers between systems.

Recent efforts at the federal level on the behalf of disabled parents (e.g., National Council on Disability, 2012) suggest that there is a new window of opportunity for systems change. Thus, our blueprint for changes in practices in CPS is timely. It integrates recommendations put forward by early task force efforts (President's Committee on Mental Retardation, 1999; Tymchuk, 1996, 1999) and more recent calls for changes that have occurred (e.g., Azar, Robinson, & Stevenson, 2012; Benjet, Azar, & Kuerston-Hogan, 2003; Lightfoot & Laliberte, 2011; McConnell, et al., 2011; Tymchuk, 2006).

Finally, although we describe specific adaptations for PCD, we strongly advocate for universal design efforts such that CPS will better serve the needs of all parents. A universal design approach is "a framework for the design of places, things, information, communication, and policy to be useable by the widest range of people operating in the widest range of situations without special and separate design" (Institute for Human Centered Design, 2011). Universal design attempts to create an inclusive environment that anticipates a wide variety of needs (e.g. ramps to assist those with disabilities become beneficial for others entering a building; Scott, McGuire, & Shaw, 2003). It encourages flexibility and alternatives to meet diverse needs (Rose, 2000). Thus, this approach argues for CPS programming to stretch and adapt its service provision and necessitates specific staff skills and providers to better serve the needs of all parents.

Parents with Cognitive Disabilities and CPS Caseloads

The exact number of PCD in the CPS system is difficult to estimate for a variety of reasons (e.g., lack of common definitions, variable screening, inconsistent record keeping; Special Interest Research Group on Parents Parenting with Intellectual Disabilities, 2008). Evidence from a range of international studies suggests that these parents might constitute between 9 and 22% of CPS cases (Booth, Booth, & McConnell, 2005; McConnell, Feldman, & Aunos, 2008; Taylor et al., 1991). These figures are striking in comparison to the rate of intellectual disabilities in the general population (1% of the population; Fujiura, 2003). Cognitive impairments especially the more subtle ones that we discuss later may also remain hidden and so these figures may be underestimates.

Indirect evidence signals that even greater attention is needed for special programming. For example, studies with parents who are on public assistance, which is common in CPS caseloads, suggest as many as 30% have learning disabilities (US General Accounting Office, 2001) and these would include sensory processing problems. Head injuries also appear to be common in disadvantaged populations and thus, may appear in higher numbers

in CPS caseloads as well. Other evidence exists of failures in the care of traumatic brain injuries within minority populations, another group over represented in CPS caseloads, and thus, their functional impairments may not be identified or addressed. Further, the consequences of the co-occurrence of traumatic brain injuries in individuals with intellectual disabilities, especially if it occurs early in life, have been seen as going undetected (McKinlay, McLellan, & Daffue, 2012). Finally, we are seeing a rise in head injuries with returning military and they may appear in greater number in CPS caseloads. This too argues for attention to PCD.

Once reported to CPS, PCD are more likely to have child maltreatment substantiated, to remain active CPS cases longer, and to have a greater risk of having their parental rights terminated (Booth et al., 2005; McConnell et al., 2011). Typically, these cases are reported for child neglect, and we know that chronic neglect cases use nine times the social service dollars than other cases (Loman & Siegel, 2006). This fact alone suggests the need to focus on being more effective with such parents. If not identified as having cognitive challenges, these parents may attempt to avoid identification, stigma, and further attention by adopting “a cloak of competence” (Edgerton & Bercovici, 1975) and thus, they may not divulge their difficulties processing information to their caseworkers. Most importantly, even if identified, *a priori*, negatively biased judgments in those that work with these parents occur (Proctor & Azar, 2012) and may set into motion decreased engagement of workers and parents and less aggressive efforts to help. Indeed, the parents’ failure to follow through on instructions due to their cognitive problems may be labeled as non-cooperation and carry with it negative consequences in terms of case disposition. PCD have erroneously been seen as less amenable to intervention than are other parents (McConnell, Llewellyn, & Ferronato, 2000) and assumed to be a greater risk to their children.

Other welfare systems have acknowledge their difficulty in working with individuals with cognitive disabilities and made systemic changes (Scheepers et al., 2005). The welfare system, for example, found that PCD had difficulty meeting requirements for newly instituted welfare to work programs. In response, this system instituted better identification procedures and adapted programming (Center on Budget and Policy Priorities & Center for Law and Social Policy 2007; US General Accounting Office, 2001). Such changes have not occurred in any widespread way in CPS.

As noted earlier, there has been a call for changes in CPS to ensure the needs of this population of parents are addressed (National Council on Disability, *Rocking the Cradle Report*, 2012). Some preliminary efforts to improve services have already occurred with regard to children with disabilities (National Symposium on Abuse and Neglect of Children with Disabilities, 1995) and CPS has made efforts to address unmet needs in its caseloads in some states (Parents with Cognitive Limitations Work Group (CT), 2007). However, these efforts are still very limited in number and in reach. Further action is needed to address the specific needs of PCD in a more system wide basis. Work groups and coalitions of service providers and CPS have been formed within states, across regions, and more recently nationally and internationally (e.g. The Association for Successful Parenting, www.achancetoparent.net). National agencies have also focused attention on this topic area (The Arc, <http://www.thearc.org/page.aspx?pid=3195>).

Social Information Processing and Neurocognitive Factors and Parenting Risk

Much of the systemic changes that are required involve the implementation of better behavioral assessment strategies and interventions specifically designed for persons with cognitive problems, and especially those that have been empirically supported with PCD. As we have begun to study the antecedents of parenting difficulties within this population, however, more nuanced views of the nature of the cognitive problems that underlie parenting difficulties are beginning to emerge beyond simply that denoted by an IQ test score (Azar, Stevenson, & Johnson, 2012b). Before we discuss essential changes, therefore, we briefly describe this work as it will inform better and more focused practice.

Advances in theory and research in child maltreatment have begun to implicate social cognitive and neurocognitive problems in its etiology (Azar, 1997; Azar & Weinzierl, 2005; Azar, et al., 2012b; Crittenden, 1993; Milner, 2003). That is, social information processing (SIP) frameworks argue that parenting quality is determined by parents' internal capacities to learn from their environment and previous experiences, in combination with the physical and social resources available to them. Thus, differences in SIP that interfere with appropriately attending to environmental cues, problem-solving, and learning may account for the persistent failures in judgment and inept care-giving viewed as characteristic of abusive and neglectful parenting (e.g., harsh parenting, inattentiveness to child illness, lack of vigilance in supervision). Unlike prevailing views of IQ, SIP is not assumed in current thinking to be unamenable to interventions (e.g., cognitive training, cognitive behavioral work).

Research evidence has begun to show difficulties in CPS parents' encoding of social information (Azar, Read, Biancaniello, Callen, & Martinez, 2011; Azar, Read, Proctor, & Arnett, 2011; Azar, Robinson, Hekimian, & Twentyman, 1984; Hildyard & Wolfe, 2007), identifying and solving childrearing problems and cognitive flexibility (Azar, Read, & Proctor, 2009; Azar, et al., 1984; De Paul, Perez-Albeniz, Guibert, Asia, & Ormaechea, 2008), and mis-appraising their children's behavior (Bugental & Happaney, 2004; Larrance & Twentyman, 1983). SIP difficulties have also been found to characterize some individuals with intellectual disabilities, but have been shown to predict maltreatment over and above IQ scores (Azar, et al., 2012b). These more nuanced difficulties may present barriers to learning (social and non-social) and thus, would affect interactions outside of parenting (e.g., with other adults) and everyday functioning. The latter may have a negative impact on general parenting abilities in ways that contribute further to maltreatment including less parental social support and more stress (e.g., inability to follow physician's directions; decreased ability to access personal supports in the community; inability to cope with stressors; difficulties managing finances; challenges to identifying children's signs of medical need or distress). Relevant to the CPS system, unless special programming is done (specific scaffolding to provide instruction and staff training to accommodate), it has been argued that these more specific cognitive problems may interfere with parents' making progress and benefiting from services (Azar, et al., 2012a). Furthermore, unless workers are able to adapt

their approaches, interpersonal missteps on parents' part can lead to communication problems with CPS staff and other service providers (Azar et al., 2012b).

CPS staff and providers at agencies have cognitive systems that determine their effectiveness. There is evidence of negative biases in caseworkers' information processing when they encounter PCD toward seeing greater risk even when the facts of a case are held constant (Proctor & Azar, 2012). This may act as a barrier to seeking more information for risk determination. Further, the flexibility of professional's cognitive system and typical training is often taxed when they encounter clients' whose needs are greater than normal and whose needs exceed their expertise (Kroese, Dagnan, & Loumidis, 1997). Unlike other providers of services to individuals with disabilities that have specific training and that have materials such as individual educational plans to help guide their work, CPS workers and parenting agency providers may not have the necessary resources to provide more effective services to this population. In addition, barriers to cross system collaborations exist that act as obstacles to acquiring need expertise. Thus, the potential for helping parents is hindered.

Assessment for Service Planning

Although we have discussed the importance of having methods for identification of such parents elsewhere, our focus here is to highlight more comprehensive methods for assessing parenting skills and capacities once PCD have entered the system. Adequate assessment allows caseworkers and providers to interpret the source of parental difficulty, tailor services to be more effective and when needed, to triage cases to other appropriate supports (e.g. Department of Mental Retardation, dual diagnosis mental health, adapted parenting skills groups) (Azar, 2013; Azar et al., 2012a). There is evidence of the poor quality of parenting assessments generally in the CPS system (Budd, Poindexter, Felix, & Naik-Polan, 2001; Grisso, 1986) and this may be especially problematic for PCD as having a good grounding for service provision is essential to guide work.

Given a history of laws allowing actions to be taken when parents have severe cognitive deficits, evaluators typically turn to IQ testing rather than a towards a fine grained look at the more nuanced cognitive capacities that may underlie parenting and performance in everyday tasks or behavioral abilities to parent directly (Azar, 2013; Lightfoot & LaLiberte, 2011). IQ testing may support eligibility for specialized services, but does not elucidate specific parenting skills that interventions may target. Further, even parents with an IQ that is not low enough for a diagnosis might still benefit from adapted services. IQ assessments, therefore, should never be used alone.

We argue for a developmental-functional-contextual approach to assessments of PCD by CPS. This approach links parents' individual skills/deficits with their capacity to parent a particular child within the specific contexts that are available to them (Azar, 2013; Azar, Lauretti, & Loding, 1998). Such assessments might include assessment of *neurocognitive and social cognitive capacities* that are linked to parenting or may create barriers for engaging in services (e.g., impulsivity), behavioral assessments of parenting skills, assessment of comorbid psychopathology, screening for medical problems that may interfere with parenting, and inventorying of social and environmental barriers and supports and

resources for effective parenting. Each area is relevant in understanding the complex interplay of factors that determine parenting risk (Belsky, 1984; Feldman & Aunos, 2010).

Assessments of *social and neurocognitive skills* are one alternative to IQ tests for evaluating cognitively based strengths and weaknesses. That is, we see IQ as simply a proxy for a narrower range of cognitive capacities only some of which serve as the foundation for competent parenting (Azar, et al., 2005). These cognitive capacities include expectations, attributional biases, and executive functions such as problem-solving, planning, cognitive flexibility, inhibition, attention, and working memory (Azar et al., 1984; Azar et al., 2012b). These factors have been shown to be associated with inappropriate & harsh parenting (Azar, et al., 1984; Deater-Deckard et al, 2010), specific elements of neglect (home hygiene, supervision attitudes, physical environment qualities, parent-child interactions such as intrusiveness and disengagement), and the severity and level of involvement in CPS for abuse (Azar et al., 2012c). Links with tasks that support family life have also been found (e.g., financial planning; Willner, Bailey, Parry, & Dymond, 2010). Measures such as the open-ended interview the Parent Problem Solving Instrument (Wasik et al., 1981) assess problem-solving capacity and cognitive complexity in parenting situations. Other measures assess more general problem solving in domains such as finances and parenting stress management (Hansen, Pallotta, Christopher, Conaway, & Lundquist, 1995) and more general cognitive flexibility (the Wisconsin Card Sorting Test). Measures such as this can provide more concrete domains of disability in these parents and lead to more focused intervention. The application of neuroscience to parenting risk and to everyday functioning is still in its infancy, thus more research needs to be conducted to identify and validate additional measures for use with PCD. For example, cognitive scientists have linked executive functions to tasks like shopping using computerized assessments which might be adapted for use with PCD (Laroi, et al., 2009).

Assessments of cognitive capacities that may be prerequisites to engage in cognitive behavioral treatments may also be worth using. Although, less evidence is available for cognitive as opposed to behavioral strategies with individuals with learning difficulties, empirical work is available that suggests they can be efficacious. For example, cognitive behavioral techniques to address anger, co-occurring depression, and the self-management regulation skills for smooth interpersonal life have been utilized with this population (Kroese et al., 1997; Veroonghe & Langdon, 2013). Frameworks have begun to appear for assessing readiness for such approaches. Cognitive capacities that are thought to be important in addressing these emotional difficulties include receptive language ability, the abilities to identify and differentiate emotions, to link cognitions to emotional states, and to recognizing the mediational role cognition may play in emotion (Dagnon & Chadwick, 1997). Studies validating instruments to assess these elements have begun to occur and hold promise (e.g., Oathamshaw & Haddock, 2006).

Attention should also be paid not only to the type of cognitive capacity assessment given, but also how the assessment is given. Assessors should have experience with adults with disabilities and follow recommendations made for accommodating testing to such individuals (see *Standards for Educational and Psychology*, American Educational Research Association, 1999). For example, during a parenting evaluation, the first author observed a

mother stating “I can’t” or “I don’t know” to multiple questions. Though this mother was eventually able to do more on the test than she believed she could, her answers were described as resistance and used as an example of her deliberate oppositionality and parenting risk. Care in these evaluations should also be taken to ask open-ended questions or questions with fewer choices due to the increased tendency for PCD to acquiesce. Attention should be paid to assessing for differences in learning style. Individuals with learning disabilities vary between visual, auditory, kinesthetic (active learning), and multimodal learning preferences (Lisle, 2007).

The ability to enact *specific parenting skills* is the most directly related to the concerns of CPS (e.g., child safety, home hygiene) and here our methods are better developed. The more defined specific skills in the assessment are, the more precise the intervention can be (Feldman & Aunos, 2010; Tymchuk, Lang, Doylniuk, Berney-Ficklin, & Spitz, 1999). Precision also allows for baseline information to be collected about a parent's caregiving abilities against which change can be evaluated once supports/interventions have been in place. The field does not yet have standardized norms, but local norms can be developed allowing for comparison with other parents. Large scale intervention randomized trials will soon provide evidence of the range of scores that occur within CPS caseloads in areas such as safety knowledge, child care skills (e.g., proper feeding), family routines, and home hygiene (Lutzker & Bigelow, 2001). A few exemplar tools will be described below. These are carried out in parents' home environments rather than in professionals' offices.

Feldman and Case (1997) developed a self-instructional parenting book that includes child-care checklists and step-by-step pictorial manuals for children between newborn and toddler age (feeding, bathing, diapering, safety and accident prevention, recognizing and treating common childhood illness, and preventing and handling child aversive behavior). As an assessment tool, parents are observed conducting each step of a particular skill. For other domains such as safety skills, the parent must identify and eliminate potential hazards. Accommodations such as the use of pictorial prompts to increase comprehension, the permanency of written materials facilitating maintenance of skills, and the self-learning aspect might promote parents feelings of self-confidence (Feldman et al., 1997).

Other measures have been developed to specifically assess parent's awareness of safety and dangers in their home. The Home Inventory of Dangers and Safety Precautions (HIDSP-2) (Tymchuk, Lang, Doylniuk, Berney-Ficklin, & Spitz, 1999) was designed to help staff, including CPS workers, in developing home safety plans for addressing 14 home dangers (e.g. fire, suffocation). Parents are asked about the presence of dangers and what precautions they have taken in their home. The evaluator then conducts a home observation to identify the dangers. An illustrated version was developed to assist parents with reading difficulties or those who prefer illustrated materials (Tymchuk, Lang, Sowards, Lieberman, & Koo, 2003). Similar to the checklist book, both of these measures are examples of instruments that have been designed specifically to accommodate the needs of PCD.

Beyond assessing specific parenting skills and knowledge, other domains may need to be addressed in assessment. It must be acknowledged that many measures used with PCD are typically adaptations of measures designed for individuals without disabilities. As such, they

require more validation and adaptation (e.g., simplifying instructions, visual cues, large print for visual impairments) before they become reliable for everyday use. The following examples were chosen to illustrate the types of assessments and concepts that can be considered. PCD tend to have higher rates of *psychopathology* such as depression and anxiety (McGaw et al., 2007). Some PCDs are motivated to mask a comorbid condition, thus instruments designed to assess for psychopathology can be helpful in identifying diagnoses and connecting parents to interventions designed specifically for adults with cognitive disabilities (Matson et al., 1993). One such measure is the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD), this screener was designed specifically for people with cognitive disabilities and helps to identify problems with depression, anxiety, sleep, appetite and psychosis (Moss et al., 1998). Another area of concern involves *medical problems* as PCD are more likely to have medical problems than the general population (Jansen, Krol, Groothoff, & Post., 2004). Resolving medical problems may serve parent's interests by alleviating parenting difficulties (Azar, 2013). A well-established measure for assessing health, the SF-36 has been adapted for screening individuals with intellectual disabilities (Ruddick et al., 2005). It assesses several domains such as general health, physical functioning, pain, vitality, and sensory functioning.

Finally, it is essential that PCD's *supports and resources* be evaluated as both are more limited in PCD. Although not designed for PCD, the Social Support Inventory (Crnic et al., 1983) is useful in gathering information about parents' satisfaction with practical and emotional support from family and friends. Parenting is stressful even for parents without disabilities and CPS workers may benefit from understanding sources of support that PCD can use when engaging in interventions as well as sources of stress that may affect their compliance with or success acquiring more effective parenting skills. Stress has been associated with increased child maltreatment (Egeland, Breitenbucher, & Rosenberg., 1980). The Life Stress Scale (Egeland et al., 1980) examines whether a number of stressful events have occurred and its items are especially relevant for parents who are lower in socioeconomic status. See Feldman & Aunos (2010) for a detailed discussion of these domains of assessment with PCD.

In summary, comprehensive assessments are essential to linking PCD' skills and capacities to the appropriate professional and non-professional supports. The assessment approach we suggest is an improvement beyond typical approaches, which often fail to assess parents within their context, rarely include home visits, and rarely use behavioral methods (Budd et al., 2001). In addition, assessments beyond the direct domain of parenting can aid in understanding the barriers to effective implementation of plans and provide a context under which the family is operating. Care must be taken, as many of our typical assessment measures were not initially designed for PCD. Identifying ways to adapt how they are administered or to meet parents at their preferred learning style are essential. It goes without saying that evaluators who have training in assessment with individuals with disabilities are crucial and argues for organizational shifts to train/hire and utilize such professionals for this work. Further work needs to be done to develop assessments with better validity and norms for PCD with attention to potential ethnic/racial variation. We call upon researchers in this area to take up this task as they are in the best position to develop appropriate approaches.

Funding for measurement validation and development is needed. Existing measures should be better disseminated so staff interested in conducting these evaluations can use them.

Interventions

Despite erroneous beliefs that PCD do not benefit from parenting interventions, reviews of multiple studies have demonstrated that PCD are able to learn, use, and retain parenting skills (Azar et al., 2012a; Benjet, Azar, & Kuerston-Hogan, 2003; Feldman, 1994; Tymchuk, 1999; Wade, Llewellyn, & Matthews, 2008). Interventions that are delivered in multiple modalities, that occur within the home, that are skill-focused, and that utilize behavioral strategies have been shown to be most effective with PCD. Interventions need also to attend to common background factors that may influence a family's access to resources such as lower educational attainment, poverty, and uncertain incomes (Tymchuk, 1996). Selecting the parenting skills to address and tailoring the method of delivery rests on conducting the careful assessment just described.

Effective behavioral interventions with PCD

Effective programming requires the modifications that support and scaffold the learning of PCDs. Three evidence-based behavioral programs for PCD that include such modifications and that have demonstrated gains in parenting skills include: the UCLA Parent Child Health and Wellness Project (Tymchuk, 1996; 2006), the Parent Education Project (PEP; Feldman, Case, & Sparks, 1992; Feldman, Ducharme, & Case, 1999; Feldman, 2004), and SafeCare (Lutzker et al., 1998; Lutzker & Bigelow, 2001). These interventions focus on teaching PCD very specific basic caregiving (e.g. safe bath practices, medical literacy) and parenting skills (e.g. child management skills). They work on assisting parents by breaking down tasks into identifiable and more manageable components. Within these interventions, PEP utilizes self-instructional materials, while the other two utilize modeling of skills, and all three use consistent practice and reinforcement of previously acquired skills (Azar et al., 2012a). These strategies may be important in helping CPS workers to scaffold PCDs development of parenting skills (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003; Wade et al., 2008).

Common to these programs is that work is done in the home. This allows parents to practice skills in the environment in which they may most often use them, requires less organization on the part of the parent (e.g. arranging transportation), and allows feedback and refinement as problems occur which requires less generalization from an outside environment into the home (Azar et al., 2012a; Galanter et al., 2012; Llewellyn et al., 2003; Wade et al., 2008). This method of in-the-moment coaching has been used in a home based Parent-Child Interaction therapy (PCIT) intervention with parents at-risk for maltreatment; results showed that it led to a reduction in child-abuse risk as measured by observations and a risk instrument (Galanter et al., 2012). This live coaching is suited to use with PCD.

These programs also use materials that are reflective of PCD's individual learning styles and that empower parents. Examples of such materials include self-teaching materials with visual checklists and audio recordings which compensate for some parent's literacy issues (Feldman, 2004). Written information provided to PCDs should be clear, presented in a sequential and logical order, and should relay information in a manner that parents can

quickly understand (tips for doing so can be found through the Parents with Cognitive Limitations Work Group, 2007).

Another consideration for intervention with PCD is the duration of the intervention. Typical parenting programs are time limited and PCDs may require longer interventions to accommodate their individual pace of learning (Llewellyn et al., 2003; Wade et al., 2008). This requires a fundamental organizational change for CPS which is oriented toward crisis intervention where involvement is time limited. Booster sessions also may be required to maintain effects and to teach new skills as parenting demands and children's needs change over time (Feldman et al., 1997b). Before a child is born, PCD may need assistance navigating health and safety concerns related to pregnancy and childbirth. After infancy, children's entry into school appears to be related to an increase in parenting stress for PCD. This change is coupled with increased interactions with the school system (Feldman et al., 1997b) and highlights the need for PCD skill building on how to work with teachers so that they may stay involved in the academic lives of their children (e.g., role playing parent-teacher conferences). Different periods of parenting may require different forms of intervention and strategies to help parents address their changing roles as parents and to address the needs of their children. A strengths based approach is crucial given parents' have encountered negative evaluation across their life time and fear regarding competency may be higher.

Cognitive interventions with parents

Beyond behavioral strategies, interventions with PCD may need to address core cognitive difficulties (less flexible and abstract thinking, poor problem solving, and difficulties with generalization and maintenance of learning) that may present obstacles to effective parenting. Adopting a rehabilitation stance, that uses strategies to help PCD work around these issues, is optimal (Azar et al., 2012a; Wilson, McKenzie, Quayle, & Murray, 2013). Interventions that target specific cognitive difficulties, including problem solving and effective decision-making, have been developed for PCD. Cognitive work with PCD should utilize familiar materials, practice concepts often, over practice, limit the number of things parents have to remember to three things, and group items based on similarity (Tychuk, 1985).

There is an emerging literature on executive function training that suggests that interventions that focus on these specific skills may be beneficial to this population. Executive functions describe a group of processes that help an individual to pay attention and concentrate and include inhibition, working memory, and cognitive flexibility (Diamond, 2013). Van der Molen et al (2010) found that computerized working memory training led to significant improvements in verbal working memory in adolescents' with mild to borderline intellectual functioning (Van der Molen et al., 2010). This demonstrates that PCD may be able to improve in these skills which can aid in their ability to remember more items at the same time, a skill that may be important for completing more complicated parenting tasks.

Helping PCD learn how to more effectively problem-solve may also be an important component of a parenting intervention. Nezu, Nezu, and Areal (1991) found that a problem-solving treatment that taught problem orientation, problem definition and formation,

generation of alternative solutions, and solution implementation led to improvements in problem-solving skills and assertive responding in a group of individuals with mild mental retardation. Similarly, cognitive training work with an elderly sample showing cognitive decline found that those that received reasoning training reported less difficulty in instrumental activities of daily living 5 years after the intervention (Willis et al., 2006). Such elements have been included in parenting interventions with CPS parents and are promising (Azar, 1989) and are worthy of trying with this population.

Those that intervene with PCD may also have to consider the mental and physical health of the parent. It has been found that the prevalence of psychopathology in individuals with cognitive difficulties may be much higher than that in the general population (e.g., high rates of anxiety and/or depression; Aunos, Feldman, & Goupil, 2008; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Lindsay, Howells, Pitcaithly, 1993; McGaw, et al., 2007). One study found that mothers with cognitive difficulties reported clinically elevated levels of stress (Feldman, Varghese, Ramsay, & Rajska, 2002), suggesting that these mothers may benefit from individual or group interventions that address their own mental health struggles as these may impact their ability to parent. This is particularly important as well as, in some cases, symptoms of mental illness such as apathy, disorganization, and lethargy may be misconstrued as parental noncompliance (McConnell et al., 2011). With regard to physical health, individuals with intellectual disabilities are estimated to have similar-to or higher-than normal levels of obesity than non-intellectually disabled populations (Rimmer & Yamaki, 2006). Obesity places individuals at risk for poorer health outcomes including heart disease, diabetes, and hypertension (Rimmer & Yamaki, 2006). These health consequences are important as parents may be less able to meet the physical demands of parenting; a lack of nutrition knowledge may also affect decisions that PCD make about the food that they serve to their children. PCD, therefore, may benefit from work with CPS workers that address nutrition and eating habits (Lutzker, et al, 1998).

These interventions require human capacity building where service providers and caseworkers are trained in how to work with disabilities and with PCD in particular. New hiring should be done in CPS that increase the number of service providers who have been trained in these specialized skills. The Institute for Human Services in Columbus, Ohio (Rycus, 2006) has developed a list of competencies required for work with special needs adults and their families that provides a starting point for skills involved. Joint training and consultations with organizations serving the intellectually disabled can be useful. For example, University Centers for Excellence located in every state are charged with providing such training and consultation in this domain (Association for University Centers on Disabilities, 2010).

Collaboration between agencies in interventions and service provision

Increased collaboration between CPS and other systems with whom PCD are involved may benefit this population as many are involved in multiple, complicated systems. An example of such a program is the Peer Navigator Program of the Vermont Family Support 360 Project (Legal Services Law Line of Vermont, 2008). This program provides mentors for PCD when attending legal and medical appointments. Widely disseminated public health programs that

provide similar supports may exclude PCD who are involved in CPS and efforts to include such parents are needed. Wrap around services that help PCD to navigate the increasing number of services or agencies that parents can become involved with as children age can be important in helping reduce parents' feelings of confusion and stress (Azar et al., 2012a). Such supports are needed to empower parents to obtain their self-defined goals and to learn about and understand how to operate in these systems.

This increase in collaboration between CPS and the systems with which PCDs may interact may be accomplished by CPS establishing connections with community-based agencies that work with adults with cognitive challenges. PCD often have smaller support networks and report being socially isolated (McGaw, Ball & Clark, 2002; Feldman et al., 1997b; Feldman et al., 2002; Wilson et al., 2013). Promoting a community of other parents with similar challenges can help to normalize experiences and difficulties. Participation in a group intervention aimed at relationship skill building (e.g. listening, communication skills) resulted in a significant increased parents' self-concept and led to positive changes in their social and family interactions (McGaw et al., 2002).

Breaking down systems barriers to jointly serving parents is needed and might include formal agreements, joint training, and sharing funding streams. Such efforts may initially encounter resistance, but it must be viewed as a normal part of the "growing" of such connections and has potential for innovation to occur if handled correctly. The organizational change literature has experimented with a variety of such approaches to produce change and these approaches might be adapted here (e.g., transformational leadership, Aarons, 2006; Green, Miller, & Aarons, 2011; culture change workshops, Thomas, Sargent, & Hardy, 2011).

Interventions with children of PCD

Currently, empirical work around the children of PCD is limited, but efforts here are needed. Based on work with other populations including children of mothers with mental illnesses, potential targets for intervention may be feelings of isolation from peers and family, anger about the lack of acknowledgement of their experiences, feelings of guilt and extreme loyalty to their mothers, and difficulties working with service providers (Dunn, 1993). CPS workers may seek to find services including social skills trainings, activities with same-age peers, and support groups (e.g. similar to Al-Anon for children of alcoholics; see: www.al-anon.org) that work to help these children address and process feelings of isolation, anger, or guilt. Finding programs that connect children with adults that can be advocates or mentors may also be beneficial. Examples of such programs include the Big Brother and Big Sister Program (www.bbbs.org) and "Shared Family Care" in which mothers and children live with a host caregiver (Arc of Franklin & Hampton Counties, 2007; Barth & Price, 1999). CPS workers may also find that PCD express feelings of concern about their child's functioning and shame about their limitations (Pihkala et al., 2008). CPS workers may need to help bridge communication between parents and children about these issues.

Like their parents, children of PCD may also require more long-term support services, especially as they enter the school system. Multiple factors affect the relationship between parental IQ and child IQ and these children themselves are not always cognitively disabled

(Benjet et al., 2003). However, children of PCD often receive less cognitive stimulation and are themselves at risk for developmental delays (Feldman et al., 1993). CPS might do routine early intervention screens for infants and toddlers and assist parents in accessing services for early child interventions. Families may benefit from CPS workers working more closely with schools to ensure that children are receiving services and assistance that address their own level of need, and to assist parents in advocating for their children. Again, this requires cross systems service provision.

Intervening with PCD requires attention to individual learning styles and difficulties. PCD profit the most from behavioral interventions in which significant adaptations are made to address the parents' individual learning style and needs. Cognitive training and cognitive behavioral work may also be useful. Additionally, CPS staff should work to bridge gaps between agencies that work with individuals with cognitive disabilities to help these parents form stronger communities as well as to provide more resources across the multiple systems in which these families exist (Azar et al., 2012a; Tymchuk, 1999).

Aspirations for Full Inclusion: What Will It Take

The American with Disabilities Act (ADA) (1990) was intended to produce the kinds of accommodations and adaptations we have described, but it has been slow to be applied PCD in the child welfare system. This system has had the difficult task of balancing the best interests of children with strongly held societal bias against parenting by PCD. Yet, this is an untenable position in which to operate a government funded agency charged with both assisting families and protecting children. Changes have already occurred in the educational and welfare systems to accommodate individuals with special needs. The recently released "Rocking the Cradle Report" by the National Council on Disabilities (2012) outlines the areas where better implementation of the ADA's tenets needs to occur with regards to PCD. Although external pressure, such as laws like the ADA, is often a catalyst for organizational change, CPS agencies across the U.S. have been uneven in their operationalizing the intent of the ADA. To fully implement the approaches we suggest three domains need to be addressed.

First, formal organizational change is required. There has throughout history been a common ethos of pessimism and rejection in work with individuals with cognitive disabilities and this is exacerbated when children are involved. It becomes a self-fulfilling prophecy (Kroese et al., 1997). For CPS, fully implementing ADA and the changes we outline will require commitment of leadership to new policy and procedures for serving PCD and their children, collaborative case management with other governmental and non-profit organizations, and removal of cross system service barriers.

Second, it will involve equipping current caseworkers and contract agency staff with skill-set enhancements and hiring administrators and supervisors who have specialized training in this skill set from the start (for more information see: Azar & Read, 2009; Azar et al., 2012a; McConnell et al., 2011; President's Committee on Mental Retardation, 1999). Funding provisions will be required to implement such changes, but cost saving will accrue with more effective approaches and with the stopping of the revolving door of CPS involvement.

Finally, research is needed to improve our understanding of mechanisms that may play a role in parenting difficulties that may occur in PCD, the development of better measurement to improve our assessment of their needs, and foster the wide dissemination of behavioral approaches to intervention and to further the emerging work being done with cognitive training and other cognitive approaches to intervention. Research is also needed to identify better the needs of children in such families and effective ways to address them.

Chronic CPS cases use up to nine times the social service dollars (Loman & Siegel, 2006) and we have argued elsewhere that PCD may be a substantial proportion of such cases (Azar, et al., 2012a). Our blueprint for changes advocates for creative approaches to meet the special needs of PCD in contrast to forcing them to fit within the borders of traditional “business as usual” child welfare services. Many of these same recommendations were made over 2 decades ago by the Presidents’ Committee on Mental Retardation (1999) and by writers since then. A new window of opportunity has opened for the hopes outlined in the 1999 report to be realized for full inclusion PCD.

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