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Chronic Neglect and Services Without Borders: A Guiding Model for Social Service Enhancement to Address the Needs of Parents With Intellectual Disabilities

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Abstract

Child neglect has negative effects throughout the lifespan. Although an argument for a link between intellectual disabilities and neglectful parenting can be made, this paper argues for a more fine grained view of the cognitive problems that underlie child neglect perpetration and provides evidence for a social information processing model of etiology. Based on this model and what is known about the efficacy of behaviorally-based interventions, implications for enhancements to the social service system to adapt to the needs of parents with intellectual disabilities are presented. The areas covered include improvements to screening and assessment of parents; provision of adapted services; and changes in selection processes and training of staff. Future directions for integrating social information processing elements into interventions are discussed with examples from empirically tested prevention programs.

Child neglect has pervasive negative effects on children's health, social, and academic outcomes (English et al., 2005; Hildyard & Wolfe, 2002; Shipman, Edwards, Brown, Swisher, & Jennings, 2005) and its impact is felt throughout the lifespan (Currie & Spatz Widom, 2010). Rates of its occurrence have remained high (ACYF, 2010), despite reported decreases in other forms of maltreatment. The lack of evidence-based etiological frameworks for neglect has hampered the development of effective support services (Azar, Povlatis, Lauretti, & Pouquette, 1998; Wilson & Horner, 2005), thus contributing to a revolving door of many neglectful families' involvement in the child protection system (CPS). Little is known about neglect's causes except for broad links to poverty, substance use, and psychiatric problems (Azar et al., 1998; Slack, Holl, McDaniel, Yoo, & Bolger, 2004; Wilson & Horner, 2005).

Neglect involves what may be described as an extraordinary inattentiveness to children's needs (e.g., parents' inability to recognize children's immature capacities; poor planning and monitoring; failure to flexibly adapt to environmental risks). Cognitive processes are inherently involved in such disturbances and thus, cognitive problems may be a causal factor in many cases of neglect. Parents with intellectual disabilities (PID)¹ are one group of adults

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¹PID may carry official developmental disabilities labels, have IQs in the Borderline to Mentally Retarded range, and/or have learning disabilities or selective neuropsychological difficulties (e.g., sensory processing problems).

who may be more likely to evidence consistent problems in attending and appropriately responding to their environments. We argue that because of these problems, such parents may be more likely to be labeled as neglectful. This article will make a case for more specific cognitive processes as playing roles in parental neglect of children. These problems may become more salient for individuals with lower cognitive abilities; however, we contend that IQ may be merely a marker of these cognitive problems and intellectual disability in and of itself is not an indicator of parenting quality. In addition, given that PIDs may have special social service needs when it comes to improving their parenting capacities (e.g., behavioral skills training), this article will also build a case for systematic social service enhancements to address PIDs' needs thereby reducing incidents of child neglect.

Parents with Intellectual Disabilities and Neglect

Direct and indirect evidence suggests that PIDs come to the attention of CPS for neglect more often and are involved more chronically than parents without such disabilities. First, families involved with CPS often live in poverty and high proportions of such adults both have IQs below 79 (between 25 and 35% of cases) and learning disabilities (close to 50% in large scale studies, US GAO, 2001). Second, findings suggest that a higher than expected proportion of low IQ parents find themselves in the CPS system, with estimates ranging from 33 to 78%, most involved for neglect (Aunos, Goupil, & Feldman, 2003; Ethier, Couture, & Lacharité, 2004; McGaw, Shaw, & Beckley, 2007; Mørch, Skår, & Andersgård, 1997; Schilling, Schinke, Blythe, & Barth, 1982; Tymchuk & Andron, 1990). Third, although CPS does not routinely conduct intellectual assessments, one court-based study of CPS cases (sampling from a select group representing more severe cases) found that 15% had severe cognitive limitations (Taylor et al., 1991); this is a striking number given the estimated percentage of adults with such limitations, IQ of 70 or below, is 8% in the general population (Wechsler, 1997). Finally, one Canadian study found 78% of PID involved in social services had *chronic* CPS involvement (Ethier et al., 2004), a higher figure than is seen generally in CPS (e.g., in Washington State, 16.6% of all families had chronic involvement; Braddock & Ahluwalia, 2003). Most convincing are findings from a prospective study, which followed a large sample of mothers from pregnancy onward and found that "learning difficulties" predicted later neglect (Slack et al., 2004). Although more systematic epidemiologic data within US CPS caseloads are needed to establish the disproportionate prevalence of PID in CPS neglect caseloads, this preliminary evidence suggests intellectual disabilities may be linked to neglect and greater attention to intellectual disability should be considered as part of inclusive programming for CPS.

Advances in theory and research about neglect also implicate cognitive problems in its etiology. In social learning theory and social information processing (SIP) frameworks, 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 neglect (e.g., inattentiveness to child illness, lack of vigilance in supervision; Azar & Twentyman, 1986; Azar & Weinzierl, 2005; Crittenden, 1993).

Supporting such theorizing is research evidence showing difficulties in neglectful 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 (Azar, Read, & Proctor, 2009; Azar et al., 1984; De Paul, Perez-Albeniz, Guibert, Asia, & Ormaechea, 2008), and misappraising their children's behavior (Bugental & Happaney, 2000; Larrance & Twentyman, 1983). Figure 1, taken from Azar & Weinzierl (2005), illustrates a model of how these disturbances may lead to neglect. These SIP problems and social difficulties characterize groups that are over-represented in neglectful populations (e.g., adults who are domestically violent (Holtzworth-Munroe & Hutchinson, 1993; Makin-Byrd & Azar, in press; Marshall, Robinson, & Azar, in revision), mentally ill (Penn, Corrigan, Bentall, Racenstein, & Newman, 1997), and substance abusing (Spieker, et al., 2001). SIP difficulties have also been found to characterize individuals with intellectual disabilities. These difficulties may negatively influence 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 neglect including less parental social support and more stress (e.g., inability to follow physician's directions or consultation as needed; decreased ability to access personal supports in the community; inability to cope with stressors; difficulties managing finances; challenges identifying children's signs of medical need or distress).

Individuals with intellectual disabilities have been shown to evidence these narrow, parenting specific SIP difficulties and also show broader SIP difficulties as well as more general chronic social problems at higher rates (Azar, 1996; Azar & Robinson, in submission; Walton-Allen & Feldman, 1991; Wilson, 1999b). Beginning in childhood, intellectual disabilities are linked to deficits in SIP domains. Children with lower intellectual abilities are more likely to misappraise the intent of others (e.g., attribute hostile intent to even benign acts; Leffert, Siperstein, & Millikan, 2000; van Nieuwenhuijzen, Vriens, Scheepmaker, Smit, & Porton, 2010), and the extent of such misappraisals relate to inappropriate social responses (Jahoda, Pert, & Trower, 2006). This bias may be linked to negative interpersonal experiences associated with a schema that includes the expectation of others as not being helpful and potentially hurting them (Jahoda, Pert, Squire, & Trower, 1998). Additionally, children with lower intellectual abilities show difficulties in generating multiple and appropriate solutions to social problems, instead most frequently choosing passive ones (i.e., to get help from an adult; Leffert et al., 2000). Evidence of greater difficulties with perspective-taking, problem recognition, working memory, and emotion recognition have also been documented (van Nieuwenhuijzen et al., 2010). These deficits in "peer-related social competence" found in children with ID are likely due to increased difficulty in focusing on, encoding, and integrating the types of social information necessary to navigate every day social situations and may result in greater social isolation (Guralnick, 2006; van Nieuwenhuijzen et al., 2010).

Many of these same difficulties persist in adulthood. Adults with lower intellectual abilities show increased reliance on others (Bybee & Zigler, 1998), and this may generalize to "expecting" too much from their children as well. They tend to have difficulties with social problem solving and may be more likely to persist in using ineffective solutions (Wilson,

1999). Their exposure to negative evaluation by others (stigma) and greater likelihood of experiencing “social defeat” across their lives (Jahoda & Markova, 2004; Reiss & Benson, 1984) may lead them to monitor their social behavior more actively and to make negative appraisals (i.e., seeing others as negatively evaluating them and having negative intent), including their own children). Resulting chronic social anxiety may lead to a greater tendency to stereotype (e.g., less complexity and more rigidity in thinking; Broadbent & Broadbent, 1988; Mandler, 1975). Preliminary evidence in the parenting realm have shown PID to have more rigid and unrealistic expectations regarding children, poor parenting problem solving, and biased negative appraisals of their children’s behavior (Azar, 1996; Azar & Robinson, in submission).

Overall, more specific cognitive difficulties that occur disproportionately among individuals with intellectual disabilities may play an etiological role in neglect. It is these difficulties that may need to be identified and considered as professionals interact with parents and that may require adaptations of services as they are delivered.

Intellectual Disabilities and Adequacy of Typical CPS Service Provision

The CPS system has had difficulty successfully treating neglect cases with a portion of them becoming chronic (i.e., going in and out of the system) (Loman, 2006). SIP difficulties may explain why it has been less successful with such cases. Attentional processes, organizational skills, problem solving, and social skills linked to these cognitive capacities are required to negotiate and follow service plans. Caseworkers without knowledge of parents’ disabilities or routine procedures to screen for them may misinterpret PID’s difficulties as resistance or lack of motivation. In addition, individuals with intellectual disabilities may attempt to avoid stigma by adopting “a cloak of competence” and thus, may not divulge their difficulties processing information to their caseworkers. Even if identified as PID, *a priori* negatively biased judgments are believed to occur regarding PID that may set in motion decreased engagement of workers and parents and less aggressive efforts to help. For example, using an experimental design, when caseworkers were given vignettes of potential neglect situations, parents labeled as having mild intellectual disabilities were more likely to be judged as placing their child at greater risk than if they were labeled as not having an intellectual disability (Proctor, 2011); thus PIDs may have strong reasons to withhold divulging their status. In addition, PIDs are seen as less amenable to intervention than are other parents (McConnell, Llewellyn, & Ferronato, 2000); an erroneous assertion, yet one that may further lead to less aggressive service provision.

Of most concern is that SIP difficulties may interfere with service utilization and ongoing interactions with caseworkers, thus making chronic involvement more likely. Individuals with cognitive challenges have demonstrated a poor response to services in other welfare systems (Scheepers et al., 2005). The TANF system, for example, found that PIDs had difficulty meeting requirements for newly instituted welfare to work programs. In response, this system instituted better identification procedures and adapted programming (CBPP & CLSP, 2007; US GAO, 2001). Such changes have not occurred in the CPS system with any frequency. Using what is known about SIP difficulties and adults with intellectual disabilities, we will suggest ways in which the social service system’s traditional service

delivery might be enhanced to break down barriers for PIDs. Such enhancements could reduce the potential for chronic neglect to children by more effectively serve the needs of affected families.

SIP: Implications for CPS

Viewing the risks for neglect as in part related to parental difficulties in learning may mean that CPS view parents through a different lens. Typical crisis-oriented responses and traditional didactic parenting classes designed for parents without intellectual limitations are less likely to work with PID. We argue for modifications in three areas. We recognize that these are “perfect world” suggestions and that there are limitations to putting these in place. Nonetheless, we suggest that for true inclusion such efforts in these directions are warranted and will improve system effectiveness and overall efficiency. First, appropriate screening, identification, and evaluation are crucial to identify the need for adapted services and build upon parents’ functional capacities. Second, parenting interventions within CPS need to be multi-systemic both to improve parents’ capacities and to enhance the support network around the family. Adaptations based on learning style are needed including appropriate modalities for skill training (e.g., the use of visual aids), the rate at which material is presented and time frames in which change is expected, and the duration of and types of supports needed to maintain parenting capacities over time. PID may also require changes to the *processes whereby* services are provided (e.g., determining the literacy level of forms, attention to comprehension difficulties, and recognition of potential for bias) (Tymchuk, 2006). Finally, sharing strengths in intervention capacities across other disability agencies and with community professionals (e.g., reducing system based barriers or silos; Azar & Read, 2009) would streamline services and reduce the burden on individual agencies. We suggest this greater integration of services and use of family-centered approaches to intervention (Wade, Mildon, & Matthews, 2007) is necessary for the well-being of PID and their families. Finally, these first two areas of change will require human capacity building that would require selecting and equipping caseworkers and other CPS staff with a different skill set that we will describe below (for a fuller discussion see Azar & Read, 2009).

I. Screening and Parenting Assessments

Enhancements in skills sets are needed for CPS workers to engage in cognitively sensitive identification and in-depth evaluation of parents’ functional capacities (strengths and weaknesses). This would allow for better triaging of cases and development of adapted service plans for parents who need them; ensuring that the services available are comprehensive enough to address the needs of cognitive differences. Identification tools could be added to intake procedures.² Protocols and the staff training created for the TANF system might be adapted for CPS use (*see* Table 1 for sample tools). [At the systemic level, collating data from this type of surveillance would also allow the tracking of numbers of cases to aid in directing resources appropriately and provide the evidence needed to justify forging partnerships with other systems of care (e.g., with the Department of Mental

²The CT Workgroup suggests a more *Universal Design* approach focusing on behavioral functioning as opposed to obtaining IQ scores (see Renzaglia, Karvonen, Drasgow, ... Stoxen, 2003 for a discussion of universal design for the disabled).

Retardation for adjunct services; allocating funds for contract work for special parenting programs, and special training of CPS staff)]. Instituting screening, however, should be considered cautiously. Without adapted follow-up services and skilled intervention staff available, screened parents are likely to languish without assistance. Although sample tools exist from the TANF system, these tools could be improved with further validation for this population (Azar, Benjet, Fuhrmann, & Cavallero, 1995). New tools may be needed that ask questions to identify disability history that are less open to impression management (e.g., what was the smallest class you attended in school; did you take a big or small bus to school) or that take place over a period of time as the parent becomes comfortable with social service treatment agents. Screening by CPS case workers early in cases would allow for triaging identified parents to more specific psychological evaluations designed both to validate identification and/or uncover specific needs for remediation (e.g., learning style) and adaptations in service delivery: therefore, offering targeted services instead of mislabeling these parents as noncompliant or nonamenable to change. Effective identification can help ensure decisions are not made based on misappraisals (e.g., missed appointments being seen as due to a lack of motivation instead of inability to tell time) and would improve the effectiveness of CPS interventions or prompt referrals to specialized services.

When individual needs are identified during initial assessment, the CPS worker may begin to target services toward those needs more quickly and begin to disrupt the cycle of child neglect. For some parents, a referral for a more detailed evaluation of intelligence, specific disabilities, and neuropsychological impairment may be useful (e.g., for qualifying them for state subsidized programs). For the vast majority of others, an assessment of functional capacities that are required to parent competently may be most beneficial (e.g., medical literacy; Tymchuk, 2006). This could include assessment of skills such as basic child care (e.g., reading thermometers; Lutzker, Bigelow, Doctor, Gershater, & Greene, 1998), problem solving, safety (e.g., using appropriate safeguards while bathing babies; Feldman & Case, 1999; Feldman, Case, & Sparks, 1992) and hygiene (Lutzker et al., 1998). In addition, observations of interactions, measurement of stress and social support, and interviews with collateral contacts (Aunos et al., 2003; Benjet, Azar, & Kuersten-Hogan, 2003; Tymchuk, 1998) should occur to identify strengths and areas needing improvement, parents' optimal learning style (Tymchuk, 2006) and potential resources (e.g., professionals and community resources already in the parent's life whose support might be enlisted or improved).

Multi-informant, multi-modal protocols have been developed for CPS staff to assess parenting skills and might form the basis for larger systems-based evaluation protocols (Table 1). Other protocols are available for PID that focus on specific areas such as decision-making, home safety and hygiene, medical care (Lutzker et al., 1998), and daily routines and parent-child interactions (Haarstad, 2002). Given higher rates of mental illness among adults with ID (Borthwick-Duffy, 1994; Hudson & Chan, 2002; McGaw et al., 2007) and that intellectual challenges may mask their occurrence, psychopathology instruments and protocols designed specifically for this population should also be used by the social workers connected to the case. If a diagnosis is identified and linked to parenting, then interventions for treating mental illnesses that are designed for adults with ID need to be accessed (Matson & Barrett, 1993). Medical problems have also been identified as linked to ID (Steen, 2009).

Resolution of medical/mental illness problems may serve to alleviate parenting difficulties (e.g., illnesses such as poorly treated diabetes or depression can lead to inattentiveness and lack of energy needed to engage in supervision and child care). Therefore screening and identification that focus on functional capacities in addition to the co-occurring conditions associated with ID may give CPS workers the tools necessary to address the specific needs of these families.

II. Intervening with the Parent with Intellectual Disabilities

PIDs often have difficulties with responding well to traditional didactic parent education, frustrating both parents and service workers (Whitman, Graves, & Accardo, 1989). Multimodal approaches that include auditory, visual, and kinesthetic strategies, using concrete examples and in-home work to promote generalization tend to work best (Feldman, 1994; Green & Cruz, 2000). Evidence based adapted approaches that target both behavioral and SIP elements exist for PID (see review by Wade, Llewellyn, & Matthews, 2008). Although the research evidence here has some limitations (e.g., small sample sizes), they provide starting points for interventions that could be incorporated into CPS practice. Attention in their implementation should be given to allowing PID an active role in determining their parenting goals. (Table 2 provides examples of effective parenting programs for PID).

Although the amount of evidence based interventions for parents with intellectual disabilities still remains small, Wade and colleagues' review (2008) suggests that behaviorally-based interventions for PID that use strategies such as task analysis, can be successful in increasing parenting skills and improving child outcomes. Three behavioral programs for PID worthy of attention are the UCLA Parent Child Health and Wellness Project (PCHWP; Tymchuk, 1996; Tymchuk, 2006), the Parent Education Project (PEP; Feldman et al., 1992; Feldman, Ducharme, & Case, 1999), and Project SafeCare (Lutzker et al., 1998). Each is home-based and uses pictorial materials to communicate information. Neglect relevant issues are targeted, such as home safety, hygiene, medical care of children (e.g., taking children's temperature), and basic care giving tasks (e.g., toilet training, diapering, bathing). Studies have shown effectiveness lasting up to six years (Feldman & Case, 1999), both in changing the level of skills trained (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003) and in reducing child maltreatment (Gershater-Molko, Lutzker, & Wesch, 2002). One intervention (PEP) is partially self-directed by the parent. The others use home educators who use modeling, role-playing, and providing feedback (i.e., positive coaching). Efforts to integrate Project SafeCare into Georgia CPS are currently underway.

In addition to behavioral work, cognitive strategies have been applied in other areas of functioning with adults with cognitive challenges (e.g., dual diagnosis with anxiety, Dagnan & Jahoda, 2006); social skills, (Loumidis & Hill, 1997; Rusch & et al., 1985); anger management, (Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005). Cognitive strategies have been used recently to enhance parenting work (Barmish & Kendall, 2005; Costin, Lichte, Hill-Smith, Vance, & Luk, 2004; Johnston, 1996; Stern & Azar, 1998). Further, cognitive strategies have been integrated into intervention with maltreating parents and prevention efforts with at-risk parents (Azar, 1989, 1993; Azar et al., 1984; Bugental et al.,

2002; Kolko, 1996; Sanders, 1999; Stern & Azar, 1998) (See Azar, Nix, & Makin Byrd, 2005 for a discussion of such techniques). There have been some extensions to parenting work with PID (Heinz & Grant, 2003; Tymchuk, 2006). These address elements of the SIP model such as improving challenging rigid schema, problem solving, and changing appraisals.

All intervention may need to be ongoing with booster sessions, as changes in children's developmental needs may create new challenges for PID. This would be the most radical change for CPS where services are by their very nature time limited. Alternative timelines for PID treatment are crucial. Dissemination of these intervention programs has begun to occur (Horwitz, Chamberlain, Landsverk, & Mullican, 2010; McConnell, Matthews, Llewellyn, Mildon, & Hindmarsh, 2008), however, more widespread adoption is needed.

Collaboration with behaviorally trained staff in Departments of Mental Retardation (DMR) or private agencies where existing staff have proficiencies in functional analytic approaches (i.e., a step by step task analysis and graded training of skills) should occur. CPS caseworkers, however, still need skills training to reinforce the work done elsewhere and to facilitate more general interactions with parents who do not process social information in typical ways. For example, as service planning takes place, elements need to be broken down into smaller steps and each step carefully gone over with parents and members of the social service team (e.g., very specific direction to other service caregivers' offices, numbers to call, and following up with reminders or prompts to schedule other services). PIDs (and others) often need assistance with navigating this initial step, when to call, what information to have, what supports are needed, etc.

Along with adapted services, CPS workers should focus attention on client engagement strategies and building networks of support within existing systems for this population. PID are often socially isolated (Hassiotis et al., 2008), experience greater exploitation by others (Feldman, 1998), and at the same time interact with multiple service systems (e.g., housing, welfare, schools, and courts; US GAO, 2001), which can cause confusion and even fear on their part. Although distrust may pervade all parents' responses to CPS workers generally, for PID there are added elements. Integration of multiple services is needed; fewer service providers along with faster service implementation has been linked to satisfaction with CPS generally (Chapman, Gibbons, Barth, & McCrae, 2003) and may be more crucial for PID. CPS partnering with community agencies for adults with cognitive challenges (e.g. Arc) will help integration of efforts, reduce the burden for case workers, and connect PID with the community and other individuals both with and without cognitive challenges. Cross training for these other agencies' staff in the nuances of child maltreatment and risk assessment may be crucial for this to work well. Social networks that might be gained by such integration of services will help reduce social isolation, build parent empowerment, help with the sharing of resources and information, and increase treatment engagement (i.e., community agency-based support is viewed by PID as less judgmental and more helpful than support from CPS; Tarleton & Ward, 2007).

Risk factors associated with being an individual with cognitive challenges and with general parenting inadequacies are largely the same: poverty (Emerson, 2007), mental health and

substance abuse (Clay & Thomas, 2005; Whitaker & Read, 2006), low educational attainment (Hassiotis et al., 2008), single parenthood (Llewellyn, 1995), and high parental stress (Feldman, Varghese, Ramsay, & Rajska, 2002). This suggests the need for taking an ecological approach by addressing other domains beyond parenting (e.g., mental health, vocational, marital, community-living, intrapersonal, and interpersonal). Indeed, PID themselves report needing more services addressing vocational needs and self-improvement skills and report being “over-serviced” in the child care area which CPS prioritizes (Walton-Allen & Feldman, 1991). Interventions with individuals with intellectual disabilities have addressed other areas (e.g., vocational skills; Greenspan, Shoultz, & Weir, 1981; Steed & Lutzker, 1999). Moreover, individuals with cognitive challenges may be more likely to be victimized (Nettelbeck & Wilson, 2002), physically, sexually, economically, and emotionally. Therefore, including education on identifying abusive situations and avoiding risky situations would be extremely important not only for parent safety but also for children’s safety (see Boyle & Lutzker, 2005 for an example of pictorial behavior training that could be extended to PID).³

Working with the community to develop resources is also needed. Community-based networks of professionals with expertise relevant to cognitive challenges are necessary (e.g., medical professionals who can provide more appointment reminders and patiently translate medical jargon). Programs that combine community mentors who can help parents navigate in the community and provide residential placements for entire families have shown effectiveness in increasing self sufficiency and family preservation (Barth & Price, 1999).

Altogether, coordination with these public/private entities would reduce the intrusion into these families’ lives, provide the long-term ongoing support they require, make service workers more available for crisis management, and reduce feelings of parenting in isolation. Possible ways to improve agency coordination include providing opportunities for common training experiences (e.g., workshops) and routine inter-agency meetings. Ultimately, these extended supports could reduce recidivism of neglect by increasing connections to individuals who can serve as community resources in times of crisis and reduce barriers related to PID biases (Tymchuk, 1999). Cross training across these systems in child protection issues may ensure that children remain protected while building relationships across agencies.

III. Building Capacity – Training from the Trenches Up

Capacity building, as briefly mentioned above, is a crucial element of system change. It needs to take a continuum approach from improving pre-professional training to setting new priorities in hiring standards for staff, continuous enhancement, and ongoing supervision with established personnel. Skills on empowering parents to participate in program development are crucial (Haarstad, 2002; Kennedy Krieger Institute, 2008; McCusker & Irwin, 2002). Continued system enhancement also requires staff skills in implementation and

³Some preventive efforts to reduce risk of victimization might occur early with adolescents who have special needs (e.g., Youth Relationship Project; Wolfe et al., 2003). A classroom based curriculum with special needs high school students prior to parenting is also being done by the Positive Parenting Resource Center (Arc of Franklin ... Hampshire Counties, 2007) called “Baby Think It Over.”

evaluation. Key agencies also must be full participants in development (Tymchuk, 1999). Although we have touched on this topic in earlier sections, we want to end with a more organized discussion of what capacity building would entail (see Azar & Read, 2009).

The Institute for Human Services in Columbus, Ohio (2006) has developed a list of competencies required for work with special needs adults and their families that provides a starting point (see <http://ici.umn.edu/products/impact/191/191.pdf>). Examples include the ability to use observation and interviews to identify possible disabilities and refer a family for further assessment; knowing how the characteristics of an adult's disability impact their physical, social, emotional, and cognitive functioning and parenting activities; and the ability to coordinate services for parents with mental, emotional or developmental disabilities, to promote their ability to provide safety and permanency for their children. Given high rates of dual diagnosis within PID, the list also argues for understanding how more than one disorder (e.g., seizures, cerebral palsy, or mental health problems, including substance abuse) affects parenting and the complications for case planning and treatment. As noted above, priority needs to be given to skills to conduct work in multiple modalities so that information is communicated effectively to PID that may have sensory processing and other deficits. Ability to work with literacy issues is also crucial (see <http://plainlanguage.gov>).

As new administrative staff and caseworkers are recruited, training and experience with adults who have cognitive differences should be a priority. Supervisors might require additional certification and/or pre-professional training to improve their day-to-day supervision of staff. Ongoing training or, in some cases, re-training with experienced staff in CPS and related systems, needs to occur. First, values assessments and discussions are crucial to begin to challenge biases toward PID. This work can involve exposing them to professionals who might act as role models for the kinds of slow and methodical work required to affect change. Changing biased schema regarding stigmatized groups is still in its infancy, but programs in other professions (e.g., physicians, mental health staff) might be adapted here (e.g., McDowell et al., 2003). Initial training of CPS caseworkers and continuing education trainings should be inclusive of attention to intellectual disabilities (much like efforts regarding diversity). Second, attention to assessment capacities for learning style would go far to ensure adaptations in service delivery and appropriate referrals for further intervention. Individuals involved in interventions would need training in behavioral and cognitive-behavioral strategies as they apply to interactive capacities and in the implementation of adaptations when failures occur. Capacities in functional assessment (task analysis) and direct observation of parenting behaviors, as described in the screening section, are needed. Third, abilities to do more than crisis management are required, such as balancing the handling of immediate crises with identification of the need for more long term planning, intervention, and perhaps life time supports. Finally, triage and referral skills are needed. Deep understanding of multiple systems of care (DMR, MH, EI) is needed such that consultation and assistance can be sought respectfully (e.g., professions' differences in views/language used) and with the right level of specificity of referral information and careful follow-up.

Final Thoughts

Our discussion advocates for creative approaches to meet the special needs of PIDs, in contrast to forcing them to fit within the borders of traditional child welfare procedures and services. We argue that SIP difficulties, which may characterize PIDs, play both a causal role in neglect and signal the need for diverting from “business as usual” in CPS procedures and services provided. We have made recommendations for systems changes to address the needs of these parents. In focusing on cognitive differences, we do not intend to diminish attention to other predictors of neglect: poverty, substance abuse, and mental illness. We are merely focusing additional attention on a set of more chronic, overlooked cognitive deficits that may interfere with parenting in systematic ways, even if traditional supports are provided.

The system enhancements we suggest will require funding (e.g., staff capacity building; specialized service provision). Currently, chronic neglect cases use up to nine times the service dollars of other CPS cases (Loman & Siegel, 2006). However, the cost saving in constructing a system that is more effective and stops the revolving door of involvement with CPS would be great. For example, implementing interventions such as shared foster care (residential community placement for entire at-risk families) is less expensive and usually shorter in duration than traditional intensive family preservation (Barth & Price, 1999). These types of interventions can draw funds from Title IV-E & B, TANF, and state and federal family preservation funds, along with cost sharing with systems already providing services to disabled individuals. Ultimately, taking the proactive as opposed to reactive stance to intervention with PID would demonstrate large cost savings, as other effective preventative efforts have shown (see Foster, Prinz, Sanders, & Shapiro, 2008).

Funding for intervention far outweighs that for prevention in CPS (CDF, 2008). Prevention programs that have effectively addressed parenting may be adapted for use with PID (e.g., Nurse Family Partnership, (Olds, Henderson, Chamberlain, & Tatelbaum, 1986); the Triple-P Positive Parenting Program, (Sanders, 1999); these programs use cognitive techniques in aspects of parent training (e.g., re-attribution training; Sanders et al., 2004). For example, Bugental and colleagues (2002) found problem solving and reattribution training more effective than a home visiting program alone for preventing harsh physical punishment among mothers with preterm infants. The addition of cognitive strategies to empirically validated prevention programs would likely be even more beneficial for PID.

In summary, prolonged involvement of families with the social services system has led to discussions of “untreatable families.” This has precipitated a move toward speedier termination of parental rights rather than a focus on providing supportive services earlier in the process, to meet the special needs of some families within the child welfare system. Tailoring services as we have suggested may reduce the neglect of children and recidivism in CPS involvement. The reduction of neglect through adoption of evidence based interventions for PID and systemic change activities is ultimately a societal issue. Adoption of these recommendations requires that we open up a new dialogue about the importance of family support in the face of neglect scenarios that challenge everyone to look deeper and manage differently. Such a dialogue might address the need for a “Universal Design” approach,

which advocates for accessibility for all and therefore includes attention to parents with cognitive differences.. The emerging public health perspective of disability supports the dual role of inclusion of individuals with disabilities in general services along with providing accommodations to their special needs (Krahn & Campbell, 2011); the recommendations we have provided here for CPS address both these roles.

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Figure 1.
The social information processing model (adapted from Azar & Weinzierl, 2005).

Table 1**Instruments**

	Instrument	Source	Description
Identification	Washington State TANF Screener	(Washington State Dept. of Social and Health Services, 1998)	Asks questions such as past special education status, grade retention, and difficulties learning
	Interview Assessment Guide	(Connecticut Department of Children and Families, 2008)	Interview tool that could be used to identify functional capacity issues, including parenting
Assessment	Parent Assessment Manual (PAM)	(McGaw, Beckley, Connolly, & Ball, 1998)	Incorporates parent and professional's perceptions, observations, structured interviews, and questionnaires designed to meet the needs of PID specifically (e.g., written and visual aids)
	Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD)	(Moss et al., 1998)	Tool for assessing psychopathology that is validated for individuals with cognitive challenges
	North Dakota Center for Persons with Disabilities a University Center for Excellence for Persons with Developmental Disabilities at Minot State University	(Haarstad, 2002)	Assessment and intervention protocol for PID that focuses on decision-making, home safety and hygiene, medical care, daily routines and parent-child interactions

Table 2**Interventions**

Type	Program	Source	Description
Behavioral Interventions	UCLA Parent Child Health and Wellness Project (PCHWP)	(Tymchuk, 1999, 2006)	Home-based interventions that use pictorial materials to communicate information.--targeting neglect relevant issues such as home safety, hygiene, medical care of children, and basic care giving tasks (e.g., diapering). PEP is partially self-directed; PCHWP and Project SafeCare have home educators who use modeling, role plays and feedback (i.e., positive coaching).
	Parent Education Project (PEP)	(Feldman & Case, 1999; Feldman et al., 1992)	
	Project SafeCare	(Lutzker et al., 1998)	
	Project 12 Ways	(Lutzker & Rice, 1984)	Individualizes behavioral interventions to address challenges to family's optimal functioning (e.g., couples work, medical, recreation needs).
	Parenting Forever Program	(Heinz & Grant, 2003)	Includes multiple components, which address self-esteem, self care, crisis management, and parenting taught mostly through problem solving training.
Community Supports	Arc of Franklin & Hampshire Counties Family Friends Program	(Arc of Franklin & Hampshire Counties, 2007)	Intensive Supported Family Living program that offers families structured living arrangements adjacent to a "host" family (culturally similar community mentors) who provides on-going support and weekly home visit parenting intervention.
	Peer Navigator program of the Vermont Family Support 360 Project	(Legal Services Law Line of Vermont, 2008)	Community mentors and lay advisors who accompany PID to appointments, help "translate" legal and medical information.