

Lightfoot, E., & DeZelar, S. (2020). Parent Centered Planning: A new model for working with parents with intellectual and developmental disabilities. *Children and Youth Services Review*, 105047.

Parent Centered Planning: A new practice model for working with parents with intellectual and developmental disabilities

This article discusses the need for more models and interventions that focus on the broader support systems of parents with disabilities. Parent centered planning is introduced as a potential model for helping parents with intellectual and developmental disabilities to begin to build the formal and informal parental supports needed for parenting their children. This model builds on the person centered planning model, but focuses on planning in regards to an individual's parenting role, including an individual's parenting desires and goals, along with the needs of the parent's child. The article discusses the potential uses of this model, including as a standalone planning process, a part of the ongoing provision of supports, or as a support for referral from child protection services.

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People with varying types of disabilities, including intellectual and developmental disabilities, are increasingly becoming parents. There currently are few formal supports to assist them with their parenting, as the support and service system for adults with intellectual and developmental disabilities focuses on supporting people with disabilities as individuals, rather than as parents or caregivers. While there have been a number of promising interventions developed to assist people disabilities in parenting, these tend to focus on parent training to increase parenting skills (Knowles, Macheilcek & Van Norman, 2015, Feldman & Tahir, 2016, Coren, Ramsbotham & Gschwandter, 2018). These types of programs are vital, as learning parenting skills is important for good parenting for any parent. However, there has been less emphasis on the role of developing or enlisting broader family and community supports to assist parents with disabilities in their parenting. This article proposes Parent Centered Planning, based on the person-centered planning approach ubiquitous within disability services, as a potential practice model to assist parents with intellectual and developmental disabilities, along with their families and supportive community members, to envision how a person can positively parent his or her children with appropriate parental supports, and to put a plan into place that draws on these supports. The purpose of this article is to describe this potential practice model and to suggest implications for its use in working with parents with disabilities.

Background

There has been an increased attention to parenting by adults with disabilities. Until recently, our knowledge about the scope of parenting by adults with intellectual and developmental disabilities was mostly anecdotal, without any population-based studies. While we still do not have access to prevalence rates of parenting by people with intellectual and developmental disabilities, we can estimate the fertility rates of people with intellectual and developmental disabilities, which gives us a snapshot of how many parents may have an intellectual or developmental disability. For example, a large study in Ontario, Canada calculated the general fertility rate of mothers with intellectual disabilities. In this study, Brown and colleagues (2016) found that the fertility rate for mothers with intellectual was just over 20.3 live births per 1,000 women ages 18-49 in Ontario in 2009, which is just under half (43.4 per 1,000) of the general fertility rate of women without an intellectual disability. A subsequent study from the same authors found that mothers with intellectual and developmental disabilities were also more than twice as likely as mothers without intellectual and developmental disabilities to have a second child within a year of their first child (Brown et al 2018). These findings are within the range of another large study conducted in Massachusetts, using older data, which examined birth over from 1998 to 2009. This study found that .076% of births during the study timeframe were to mothers with intellectual and developmental disabilities (Mitra, Parish, Clements Cui & Diop, 2015). If we extrapolate from either of these studies, we can estimate that there are tens of thousands of children born annually to mothers with intellectual and developmental disabilities

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in the United States. While these studies do not include fathers due to methodological constraints, it is likely that there are also thousands of new fathers with intellectual and developmental disabilities a year as well.

People with intellectual and developmental disabilities historically have experienced extreme forms of discrimination or oppression related to parenting; such as through the widespread forced sterilization of people with disabilities in the eugenics movement that was common in many countries in the twentieth century and still happens to some extent now (O'Brien, 2011). While more people with intellectual and developmental disabilities are now having children, many parents with intellectual and developmental disabilities are involved in the child welfare system at high rates and have their parental rights terminated (Slayter & Jensen, 2019; McConnell, Aunos, Feldman, & Prasad, 2011; LaLiberte, Piescher, Mickelson & Lee, 2017). This occurs despite a number of studies showing that having an intellectual or developmental disability does not necessarily correlate with the likelihood for abuse or neglect (McGaw, Scully & Pritchard, 2010; Emerson & Brigham, 2014). This high rate of involvement in child welfare could have multiple causes, ranging from negative attitudes of child welfare workers (Proctor & Azar, 2013) to lack of appropriate supports (Llewellyn & McConnell, 2002) to state laws which explicitly named intellectual disability as one of the grounds for terminating parental rights (Lightfoot, Hill & LaLiberte, 2010). There has been growing international concern regarding the experiences of parents with disabilities (National Council on Disability, 2012; Llewellyn, McConnell & Ferronato, 2003; McConnell, Aunos, Feldman, & Prasad, 2011). The increased attention has led to changes in child welfare statutes in several states in the United States, with some states not only eliminating discriminatory language, but also requiring courts to consider the availability of parental supports when assessing parenting (Lightfoot, Hill & LaLiberte, 2010). The National Council on Disability in the United States, as part of its *Rocking the Cradle Report* (2012), called for federal laws to be changed to require parental supports to be considered when assessing parents with disabilities in child welfare.

There have been a number of models or programs developed to increase the parenting skills of parents with intellectual and developmental disabilities in response to the recognition that there are a substantial number of parents with intellectual and developmental disabilities and that they are more likely to be involved in the child protection system. These include intensive in-home parent training for parents of infants or young children (McConnell, Matthews, Llewellyn, Mildon & Hindmarsh, 2008; Rao, 2013; Llewellyn & McConnell, 2005; Wade, Llewellyn & Matthews, 2008; Feldman & Tahir, 2016) or parents of school-age children (Glazemakers, I., & Deboutte, D. 2013) as well as support groups (McGaw, Ball & Clark, 2002). There also have been innovations involving incorporating technology to support parent with intellectual and developmental disabilities, such as the use of video-feedback interventions (Hodes, Meppelder, de Moor, Kef & Schuengel, 2017). The evidence for the effectiveness of these types of parent trainings is currently mixed (Coren, Ramsbotham & Gschwandter, 2018), but there are many promising practices. There has not also been a corresponding attention to developing contextual supports and services for parents with intellectual and developmental

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disabilities, despite research showing that support networks among parents with intellectual and developmental disabilities are limited (Mayes, Llewellyn & McConnell, 2008). The only extensively studied intervention was a 12-week structured support group, tested in both Australia and Canada, which found that participants had increased psychological wellbeing and perceived social support (McConnell, Dalziel, Llewellyn, Laidlaw & Hindmarsh, 2009; McConnell et al, 2016). There have been some other innovative programs that haven't been rigorously tested, such as the Vermont 360 Program (Holsopple, 2010), which used peer navigators to serve as allies in helping parents with disabilities navigate through the system. While participants in the Vermont 360 program had very low rates of termination of parental rights (Yuan, 2013), and it has been replicated in other settings, it is not clear what elements of these programs work without rigorous evaluation.

It is somewhat surprising that more models focusing on providing social supports for parents with disabilities have not been developed tested, as in the general population, contextual factors such as social supports and social networks, are strongly linked with positive parenting outcomes, such as reduced parental stress, increased parental efficacy and improved parent-child interactions (Lee, Anderson, Horowitz & August, 2009; Simons, Lorenz, Wu & Conger, 1993; Jennings, Stagg & Connors, 1991; Boyd, 2002). Further, parents with disabilities have expressed a strong desire to receive informal supports for their parenting (Lightfoot, LaLiberte & Cho, 2018). Such an emphasis on contextual factors, such as the development of a broad range of informal parenting supports, can complement the emphasis on developing parenting skills.

A Parent Centered Planning Approach

One potential approach to planning for and enhancing supports of parents with intellectual or developmental disabilities is to use parent centered planning, which is an adapted person-centered planning process that is geared toward parents with intellectual and developmental disabilities and their families. Person-centered planning emerged in the field of intellectual and developmental disabilities in the 1980s and fits within the broader ideological framework of normalization and inclusion (O'Brien & O'Brien, 2002). Person-centered planning's central purpose is to develop a plan for individualized supports through a process that assists people with disabilities and their social networks to plan, by focusing on a person's strengths and preferences rather than on formal assessments or services available. It is commonly used in both services and support planning for people with intellectual disabilities (O'Brien, 2013), and has been used to plan services and supports related to educational planning (Keyes & Owen-Johnson, 2003), transition planning (King, Baldwin, Currie & Evans, 2005), career planning (Menchetti & Garcia, 2003), and later-life planning (Heller, Factor, Sterns & Sutton, 1996). There are many variations of person-centered planning, such as Personal Futures Planning (Mount, 2000), Planning Alternative Tomorrow's with Hope, which is commonly known as PATH (O'Brien, Pearpoint, & Kahn, 2010), Making Action Plans, which is commonly known as MAPS (O'Brien, Pearpoint, & Kahn, 2010), or Support Plans (Duffy, 2004).

There have been several recent systematic reviews of person-centered planning for individuals with intellectual and developmental disabilities. Claes and colleagues (2010) found

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that person-centered planning for individuals has been associated with increased social networks, frequency of contacts with family and friends, and levels of knowledge about choices. Ratti and colleagues (2016) conducted a slightly more recent systematic review on the same topic. Their findings were more mixed, determining that there is currently little evidence that person-centered planning leads to radical changes, primarily due to the low-quality of the study designs rather than necessarily a lack of effectiveness of the intervention. Nonetheless, Ratti and colleagues did find studies that showed some limited impacts, particularly concerning community participation, participation in activities, and daily decision-making. Both reviews indicated that there were only a handful of high-quality studies of person-centered planning, which limits our understanding of the effectiveness of this widely used intervention, and called for further study of this intervention (Claes et al., 2010; Ratti et al., 2016). However, as there is evidence that person-centered planning leads to improved decision-making, which is an important part of parenting, and person-centered planning is a widely used approach for working with persons with intellectual and developmental disabilities, developing a well-specified person centered planning model for working with parents with disabilities can be useful both for practitioners and future research.

The Parent Centered Planning Model

A proposed model for working with parents with disabilities to help them build their parental supports is the *parent centered planning* model. This proposed model draws on the person-centered planning approach, but broadens the focus from the individual to the parent with an intellectual or developmental disability and his or her child(ren), with a specific focus on the parent in his or her parenting role. The purpose of this paper is to describe this potential model, which will need empirical support for it to become adopted as a promising practice in work with parents with disabilities.

Similar to the person-centered planning approach for individuals, all aspects of parent centered planning focus on the parenting desires and preferences of the parent, and the supports needed to achieve his or her parenting and family goals. However parent centered planning also includes an emphasis on the needs of the parent's child or children as well, with the children participating as appropriate based on their age. A facilitator, ideally a person skilled in group facilitation with persons with intellectual and developmental disabilities, knowledgeable about a wide range of community services, and experience in supporting people with disabilities, coordinates this planning process, but the parent makes all decisions, in consultation with his or her supportive community. While traditional person-centered planning processes often use peer facilitators or minimally trained facilitators, this model proposes using more highly skilled facilitators, such as licensed social workers, to ensure that this complex group meeting is run effectively.

The primary purpose of the person-centered planning process is for the parent and his or her supportive community to understand the parenting desires and goals of the parent and the needs of his or her children, and to make both short and long-term plans to achieve these goals, drawing on informal and formal supports. There are four phases to the proposed parent centered

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planning model: Preparation, Scheduling & Inviting, Parent Centered Planning Meeting and Transition. The following describes the four phases of this proposed parent centered planning model.

Phase One: Preparation

The first phase of the model is a preparation phase, where the facilitator meets with the parent, along with one or two close supporters if desired, to plan the upcoming parent centered planning meeting. In this meeting, the facilitator describes the concepts of parent centered planning and parental supports in simple terms, and provides an overview of what the meeting will look like. This preparation will assist the parent to begin to think about the support that they need about parenting. The facilitator also asks the parent and her supporters to identify support persons to invite to the planning. A simple relationship map is used to help identify these key and potential support persons from various domains of their lives, including their home, family, work, church, child's school/daycare, child's other parent and relatives, child's activities, friends and/or child's friends. The facilitator and the parent determine who will make the initial invitations to the meeting. Parents might have partners, spouses, ex-partners or ex-spouses, who may or may not be a biological or stepparent of one or more of the parent's children. Parents who are co-parenting could certainly do the process as a couple. In parent centered planning, the potential for complicated relationship dynamics are possible, and the facilitator must be aware of the dynamics between the parent and his or her relatives and the co-parents' relatives, and plan accordingly. As each situation is different, the facilitator must consult with the parent regarding who is important to be included both in the preparation meeting and the parent centered planning meeting, and to help the parent navigate these various relationships as they relate to the parent centered planning meeting.

Phase Two: Scheduling and Inviting

The second phase involves scheduling the person-centered planning meeting and inviting potential participants. The facilitator's role in this part of the process is to help determine where the meeting is going to be held, such as at the parent's home or other location, and the timing of the meeting. An important consideration for a parent centered planning meeting includes determining whether the parent's child or children will attend, depending on age, and if not, arranging for childcare. Regardless of who makes the initial invitation to the parent centered planning meeting, the facilitator makes individual contact with all attendees to explain the purpose of the meeting and sends a reminder.

Phase Three: Parent Centered Planning Meeting

The parent centered planning meeting is the heart of this process. At this meeting, the parent and his or her supporters participate in a series of pre-planned activities led by the trained facilitator to develop a parenting support plan, which will include an emphasis on parental support needs and increasing a parent's social network, though will follow the parent's lead. The facilitator first makes introductions and explains again the purpose of the meeting, particularly how the meeting is focused on the parent's needs and wishes. The meeting is guided by a graphic flow chart inspired by the PATH model (O'Brien, Pearpoint, & Kahn, L, 2010) which aids in the

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breakdown of big dreams into attainable action steps. The facilitator captures the participants' discussions graphically on the flowchart, beginning with the parent-driven identification of realistic future goals and a vision for his or her family, and the identification of strengths and challenges that the parent has surrounding parenting. If resources allow, the facilitator could have an assistant aid in doing the graphic drawings. After goals and visions for the future are broken down into attainable short-term goals for the next three to six months, the parent and his or her supporters then develop action steps, identifying how the supportive community can assist in making these steps, as well as the need for additional needed resources. The final outcome of the meeting is the development of a Parental Support Plan, with commitment from the attendees for specific roles and actions. Included within this plan are the identification of several bold steps that the parent agrees to undertake within the following week, that demonstrates action towards one of the parent's short-term goals, with the potential assistance of one of the parent's support persons, if desired and appropriate. For example, if the parent identifies a goal of having his son involved in more regularly scheduled activities, the parent may decide to call about enrolling his child in scouts as one of his bold steps. The purpose of identifying bold steps is to increase the confidence in both the parent with intellectual and developmental disabilities and their support community in the ability to take action towards goals and to increase the likelihood of follow-through on action steps agreed to in the meeting. The entire plan needs to be captured graphically, but also needs to be written down in easily understandable steps, as graphics alone can be confusing for referencing in the future. If resources permit, this plan could also be recorded or entered into an appropriate smart phone application.

A strengths-based focus is also essential throughout this planning process. Parents' personal strengths are identified from the parents and their support community, and are highlighted prominently in the graphic display. The parent centered planning process recognizes the aspects of parenting and individual functioning that the individual with intellectual and developmental disabilities excels at and builds upon those skills to expand into other areas. For example, a mother might have a goal to increase outdoor active play experiences for her son while also getting herself in informal social situations with other parents. If one of her strengths is keeping track of and adhering to her personal part-time work schedule and medical and therapy appointments with use of the calendar feature on her smart phone, a goal for parenting could be for her to schedule weekly park visits using her smart phone.

While the entire emphasis is on helping the parent realize his or her vision and desires regarding parenting, the actual steps could involve anything that assists with parenting, as long as it helps the parent reach his or her parenting goals. For example, the parent and her supportive community might agree that the parent obtaining a part-time job in the community would assist in her parenting, as a job would assist the parent in providing structure to her day, help her serve as a role model for her daughter and also provide some additional spending money that enables the family to engage in more community activities. Likewise, while this model is not focusing on parental skill building, the parent might have a goal of increasing his parenting skills, and thus one of the goals might be to find an adapted parenting skills training program. The focus on

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parenting differs from most traditional person-centered planning meetings in that the emphasis is on parenting and the needs of the parent and his or her child, rather than solely on the individual's desires or well-being. However, this is appropriate for parents, as this is similar for parents without intellectual and developmental disabilities who must take their family's well-being into account when making plans.

This model also differs from some other traditional person-centered planning meetings in its length. While person-centered planning is often scheduled to last for an entire day or even several days (O'Brien, Pearpoint & Kahn, 2010), this is a much briefer meeting that only takes a few hours. This planning process is brief both to accommodate the busy lives of parents and of their identified support persons, and for the hopes that it could be more easily adopted by systems that have few services for parents with intellectual and developmental disabilities overall.

Step Four: Transition

The parent centered planning process includes a transition or follow-up phase where the facilitator meets two or three times over the next two months with the parent and his or her supportive community to help them take the first steps of the plan. The facilitator acts as a resource guide and sounding board for the parent, helping to problem solve and break down specific action steps into small tasks. For example, if one of the action steps was to get the parent's child signed up for the same dance lessons as his cousin, the facilitator would check back with the parent to see if they had taken this step, and what supports they needed to do this, such as contacting the cousin's mother for assistance. Similarly, if one of the supportive community participants was a member of the clergy who had agreed to find a mentor for the parent within the religious community, the facilitator could contact the clergy person to see if this had happened. The goal of this transition phase is not for the facilitator to take action herself any of the steps on behalf of the parent or the supportive community participants, but rather to assist the parent in using his or her support team, and to remind all of them about this process. If a parent was attending a program with ongoing supports, this transition plan could remain ongoing as part of the parent's care plan. However, this model could also be used in a one-time planning process, for which the follow-up and transition process would end after one or two months.

Implications

The proposed parent centered planning model needs empirical evidence to ascertain its feasibility and effectiveness. However, this parent centered planning model has the potential to be used by those working with parents with intellectual and developmental disabilities in a range of contexts. Disability service providers or advocates could use the parent centered planning model as a tool to assist a new parent in planning for their new role or to assist a parent with planning for new stages of their child's development. Likewise, child welfare professionals who were trained in working with parents with disabilities could use it with a parent with intellectual and developmental disabilities that is referred to the child protection system as part of an

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alternative response approach to child protection, or could make referrals for this type of planning process. As the United States Department of Justice and Department of Health and Human Services (2015) has recently issued a call for child protection agencies to provide appropriate accommodations to parents with disabilities, echoing a previous call by the National Council on Disability (2012), child welfare agencies might welcome this type of tailored model for parents with disabilities. Moreover, social service providers in a variety of community settings beyond disability-specific programs, such as housing program case managers and early childhood programming, could use this type of planning process if they serve parents with intellectual and developmental disabilities in their service settings, to support the parenting of the families they serve.

The parent centered planning model also has the potential to be used as a standalone brief process, or incorporated as part of ongoing provision of services. As there are not a lot of services for parents with disabilities, disability or child welfare organizations could use parent centered planning as a brief, one-time tool to help parents organize their planning. However, it also could be incorporated into other types of supports a parent is receiving, either to support them as an individual, or if parental supports were available, to support in parenting. As some entities are now requiring person-centered planning to be included as part of formal assessment processes, a parent centered planning module could perhaps be streamlined into this process and offered concurrently with assessment. Even if the entire model is not used, the concept of person-centered thinking, along with an emphasis on planning for formal and informal parental supports, should be included when working with parents with disabilities.

Parent centered planning is not meant to be a replacement for building and expanding the formal support system for parents with intellectual and developmental disabilities. There is still a great need for the development of a range of services to assist parents with intellectual and developmental disabilities who are raising children, including the development of effective adapted parenting skills training programs, co-housing programs, respite programs or even the provision of family-focused personal care attendants. The aim of the parent centered planning model is to increase and enhance existing informal support for parenting, which mirrors the common parenting experience of parents without intellectual and developmental disabilities, and to help parents connect with both formal and informal supports. Further empirical testing of this model, which is currently underway, will help determine whether such a planning process is feasible, whether parents feel that participating in such a planning process is beneficial, and whether parent centered planning leads to better social supports for parents.

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