Coordinated Future Planning to Prevent Homelessness in Adults with Developmental Disabilities

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Executive Summary

In response to the Grand Challenge of Social Work, End Homelessness, Coordinated Future Planning (CFP) seeks to prevent homelessness for adults with intellectual/developmental disabilities (I/DD) by ensuring appropriate future planning occurs before the loss of a primary caregiver, usually a parent. Adults with I/DD have significant support needs and most frequently live with family caregivers. Research shows that planning team meetings, coordinated by I/DD professionals, are not resulting in functional plans that prepare adults with I/DD for the inevitable loss of their primary caregiver. When that caregiver dies or is incapacitated the adult with I/DD becomes homeless.

In describing the conceptual framework, CFP represents a sustaining innovation, an improvement over an existing social work practice, that effective future planning will reduce the risk to homelessness if developmental disability services agencies take the following steps: Identify those at risk to homelessness due to having an aged caregiver and no caregiver succession plan identified. Conduct trainings, developed in partnership with adults with I/DD and their families, to increase the competencies of service coordinators in discussing future planning. Finally, during annual planning meetings, require an assessment for risk to homelessness as well as a discussion as to if an adult with I/DD wants to live in a home of their own. Annual planning documents will illustrate what services and supports adults with I/DD need to meet these future goals.

CFP will be immediately piloted at Alta California Regional Center (ACRC), a non-profit agency coordinating services for over 26,000 individuals with I/DD, in ten Northern California counties. The target implementation date is January 1, 2021, with the first step gathering a CFP Task Force to develop the training materials.

The task force will evaluate data collected about the impact of CFP. The goal is for this data to demonstrate that CFP leads to the development of more caregiver succession plans and that regional center clients experience less incidences of homelessness due to caregiver incapacity. Evaluation data will demonstrate that ACRC staff implemented CFP as intended and that CFP effectively meets the stated goals. Further. this data may lead to modifications to the implementation steps and will provide justification for replication beyond ACRC.

CFP aligns with current research on the topic of planning and person-centered service delivery and can serve as an innovative model to be scaled up to serve a much larger population of adults receiving disability services. Looking beyond just Northern California, the other 20 regional centers in California can replicate the well-defined implementation steps. Nationwide, social workers assisting with planning for adults with I/DD will also benefit by locally implementing CFP to increase their competencies in working with clients and families to develop future plans that represent the desires and choices of their clients.

Conceptual Framework

Problem Statement

Coordinated Future Planning responds to the Grand Challenge of Social Work, End Homelessness by addressing the social problem of homelessness and risk for homelessness among adults with intellectual/developmental disability (I/DD). Studies have shown the presence of an intellectual disability increases the risk factors for homelessness. The primary cause of homelessness for adults with I/DD is the death of a caregiver (Backer & Howard, 2007; Stone, Dowling, Cameron, 2019). Despite holding a great fear of what will happen with their child after they die, aged parents of adults with I/DD are not participating in caregiver succession planning (Burke, Arnold, & Owen, 2018). The Grand Challenge of Social Work, End Homelessness, notes

the value of interventions that prevent individuals from becoming homeless (Padgett & Henwood, 2018).

Research has shown that there are two phases of life when individuals with I/DD are at greatest risk of becoming homeless. The first is during the transition period to adulthood, when many formalized special education services end. The second is when their primary caregiver, a commonly a parent, dies (Backer & Howard, 2007; Shaw, Parish & Lutwick, 2005; Cartwright, & Craig 2011). CFP intervenes in the second critical period in the life of an adult with I/DD, preparation for the death or incapacity of their primary caregiver.

CFP addresses the practice problem that service coordinators facilitating supports for adults with I/DD and their family are not assessing risk to homelessness or offering opportunities for independent living to adults with I/DD and their families therefore limiting housing options. In a study of how service coordinators manage their job duties, one of the crises requiring immediate intervention by service coordinators is the death or incapacity of a client's primary caregiver (Association of Regional Center Agencies, 2013). As will be described in detail later, CFP was developed by assessing the norms that lead to homelessness or a risk of homelessness for adults with I/DD, as well as analyzing the four domains of innovation to determine what kind of innovative change can best mitigate the risks caused by insufficient future planning (Leitner, 2019; Satell, 2017). The result is the development of an evidenced-based innovation that is in line with current research on effective future planning.

Analysis of the Social Problem

Individuals with I/DD include those diagnosed with autism, cerebral palsy, epilepsy, and intellectual disability. These developmental disabilities occur prior to age 18, are likely to continue throughout the lifespan, and significantly impact physical ability, learning, capacity for

independent living, behavior, and language skills (Center for Disease Control and Prevention, 2019). Adults with I/DD require significant amounts of supports throughout their lifespan. Families are vital in meeting these support needs, serving typically as caregivers for their child into adulthood (Freedman, 2000; McGinley, 2016; Hewitt, et al., 2010).

Current Environmental Context

The urgency to address this practice problem is related to the growth in numbers of adults with I/DD that are increasingly relying on aged caregivers. Improved health outcomes and a move away from institutionalization have led to adults with I/DD living longer lives. Most adults with I/DD will have a likelihood of mortality similar to the typically developing population (McGinley, 2016). As an example, the mortality rate for Down Syndrome, the most common chromosomal disorder, has improved drastically from 10 years old in 1960 to 60 years old in 2007 (Bittles et al., 2007).

The federal government raised the alarm about the risk to homelessness for individuals living with aged caregivers twenty years ago. The Developmental Disabilities Bill of Rights (2000) noted that developmental disability service systems and communities were ill-prepared to support the nearly 480,000 individuals with I/DD living with caregivers over age 60. To illustrate the increase in risk to homelessness, by 2018, The Arc of the United States (2018) estimated approximately 900,000 individuals were living with caregivers over age 60.

Stakeholder Viewpoints on the Problem

Walker and Hutchinson (2018) describe a sense of helplessness felt by families engaging in the future planning process. The Family & Individuals Needs for Disability Support survey conducted by The Arc found that more than half (54%) of caregivers do not have a plan for when they are no longer able to provide care (Anderson et al., 2018). Additional research identified

that one of the largest reasons that caregivers of adults with I/DD gave, as to the status of their future planning, was that they were not ready or willing to begin planning. The same study found that eleven of fifteen sole caregivers over age 80 indicated they were unwilling to plan for the care needs of their adult child (Bowey & McGlaughlin, 2005). The National Core Indicators (2018) In-Person Survey captures the viewpoints of adults with developmental disabilities by conducting face to face interviews. The results from Alta California Regional Center for 2017 – 2018 were determined after achieving a sample of 400 interviewees. Results showed only 86% of clients indicated their service coordinator asked them what they want and only 66% felt that they had input into choosing the services they get as part of the Individual Program Plan.

Problem Space

To develop an effective intervention for the practice problem, it is necessary to understand what research says about how future plans are made for adults with I/DD. Equally important is what researchers say about innovative frameworks that currently exist that promote successful planning.

Supported Decision-Making & Substitute Decision-Making

Inherent in the question of choice for adults with I/DD, is their ability to provide consent. When ability to consent is in question, supported decision-making (SDM) or decisions made by guardians, substitute decision-making, are the two methods of future planning (Zhang, Walker, Leal, Landmark, & Katsiyannis, 2019). Well regarded by adults with I/DD and advocacy groups, SDM maintains the legal rights of individuals while still aiding in making challenging life decisions. Court ordered guardianship removes some or all legal decision-making rights of adults with I/DD and gives those rights to a person or persons identified by the court (Shogren et al,, 2017).

SDM is broadly defined as any planning process which includes assistance from family, friends, advocates, and professionals to make informed choices (Blanck & Martinis, 2015). One vital component to SDM is providing information on the practical implementation of a client's wants, as well as consequences that may occur. Specifically, the developmental disability professional and the rest of the team are responsible for making the decision understandable to the client, conducting research on the requested goal or services, and presenting both the positive and negative aspects of the decision (Douglas & Bigby, 2018).

Research states that SDM is grounded in the principles of self-determination. The most important component of self-determination is "personal control" defined as "direct exercise of civil and individual rights through personal choice, with the goal of exerting control over one's daily life and future plans" (Stancliffe et al., 2000). The benefit of utilizing self-determination as the construct for future planning include increased access to opportunities to make major life decisions, most notably, where adults with I/DD live and what type of staff are supporting them (Heller et al., 2011).

Coordination of Services

In the United States, developmental disability services are the responsibility of state agencies. Some state agencies employ service coordinators or case managers to monitor and assist adults with I/DD and their families. In many states, non-profit social services organizations are responsible for coordination of services (Cooper, 2006). The purpose of coordinating services is to increase positive outcomes for adults with I/DD. The goal is for services to respond to the totality of client needs with the benchmark for quality being clients receiving the services that they want (Bunger, 2010). The literature on effective coordination of services speaks to the need for training. Research shows that professional development enhances the effectiveness of service

coordination in offering family and person-centered planning. It is recommended that training needs to be specialized to the issues facing individuals with I/DD and their families (Childress et al., 2013). Effective planning helps meet both the needs of the adult with I/DD and their families (Hole et al., 2013).

Plan Early

Studies have shown the benefits of effective future planning include both empowering adults with I/DD as well as assisting in preparing them for the loss of their caregiver. The development of a future plan ,which is created during a period when the adult with I/DD's housing is not in jeopardy, will increase positive outcomes after their caregiver passes away (Bibby, 2012; Bowey & McGlaughlin, 2005).

To illustrate what is currently being done to address the need for effective planning, in 2018 the federal government passed legislation creating the National Family Caregiver Strategy. The provisions of this legislation speak directly to the challenges faced providing support to adults with I/DD in future planning. This strategy seeks to "promote person and family-centered care, family involvement in assessment and service planning, information sharing and care coordination with service providers, respite options, financial security and workplace issues, and efficient service delivery" (The Arc of the United States, 2018). The results of the strategy will come in a set of recommendations at the federal, state, and local level for developmental disability service systems.

Person-Centered Planning

Person-Centered/Family-Centered Planning (PCP) is the recommended philosophy for goal development and coordination of services for individuals with I/DD and their families (Kirkendall et al., 2012). The United States Department of Health and Human Services,

Administration for Community Living (2019) recommends the utilization of person-centered planning and describes the key elements of it. Paramount is that the adult with I/DD directs the planning process. PCP assists in developing and articulating future plans, evaluating success and challenges, and making any needed changes to the plans. PCP defines the individual's positive attributes, future wishes for themselves, needs for services and preferred outcomes. An individual's culture is included in the planning process. Key is the role of the service coordinator, as they are there to assist in the identification of services and to aid in putting those services in place.

Social & Medical Models of Disability

Person-centered planning is based in the social model of disability which replaced the medical model of disability during the latter half of the 20th century. Whereas the medical model of disability looks at the symptoms of disability as problems to be fixed, the social model seeks to eliminate barriers to access experienced by those with disabilities (Goodley, 2010). The difference between these models, in the context of CFP, is the example of individuals with safety awareness issues walking down a city street. The medical model of disability would state that the individual would need to be trained sufficiently before walking down a busy city street. The social model of disability would be to have a support person assist an individual in accessing their neighborhood immediately. Substitute decision making arises historically from the medical model of disability (Parker, 2016).

Inclusion

The proposed outcome of CFP is for individuals with developmental disabilities to live the most included way possible in a community of their choosing, reducing their risk to homelessness. The Institute for Community Inclusion (2019) defines inclusion as "all people,

regardless of their abilities, disabilities, or health care needs, have the right to be respected and appreciated as valuable members of their communities." Settings for inclusion include, but are not limited to, recreational activities, education, and employment. Research has shown social inclusion is key to treating homelessness (Substance Abuse and Mental Health Services Administration, 2020).

Theory of Change Overview

As informed by the evidenced-based models above, this CFP seeks to change the approach and behavior of individuals with I/DD, families, support staff and service coordinators during annual planning meetings. There are three components of CFP to address the social problem of adults with I/DD being at risk of homelessness due to reliance on aged caregivers. The first component is quantifying the problem, the second is training service coordinators to provide effective support to clients and families, and third the intervention of holding mandatory discussions about adults with I/DD living in homes of their own with needed supports. As shown A logic model (see Figure 1) summarizes the activities, outputs, and outcomes of CFP described herein. Below is the justification of why this theory of change will be effective.

Social Norms & Deviant Development

Developing an effective intervention requires an analysis of the norms that hold the practice problem in place (Leitner, 2018). Social norms are the unwritten guidelines that govern our behavior in social environments (Bicchieri, 2017; Leitner et al., 2017). In the context of CFP, the social environment is the annual Individual Program Plan meeting held with adults with I/DD and their circle of support. A review of the literature shows several norms exist that hinder planning for opportunities for independent living. Norms related to the practice problem include embarrassment, fear, and frustration experienced by members of the planning team toward

participating in future planning (Bowey & McGlaughlin, 2007; Dimitriadou, 2018; Fullana et al., 2019). Some note it being worthless to participate in future planning because of lack of resources that were present when the topic was brought up previously. Others state a discussion of moving into a segregated care home was already determined in advance by the developmental disability professionals prior to planning by the team being completed (Bigby et al., 2011).

Leitner (2018) describes deviance as a behavior that can subvert the social norm. To meet the goals described in the literature regarding supported decision-making, self-determination, person-centered planning, and inclusion, then it is necessary to subvert the norms that exist in planning meetings. The proposed deviant is, during the annual Individual Program Plan meeting, to require service coordinator hold a discussion of caregiver succession and adults living in homes of their own at annual planning meetings.

Trainings Informed by Social Role Valorization

Training materials will be developed with a basis in the theory of Social Role Valorization (SRV) popularized by Wolf Wolfensberger (1983). SRV posits that everyone fills a social role and that some roles are perceived to be positive and some negative. People have better outcomes in life if they are viewed by others as fulfilling a positive social role (Blakely & Dziadosz, 2014). An example would be an adult with I/DD not living independently, not competitively employed or participating in the social activities of their typically developing peers being seen in a negative social role. The goals of SRV, which will be incorporated into the trainings for service coordinators, are enhancing the image and the competencies of adults with I/DD (Osborn, 2006). The trainings will highlight the need for explaining the positive social roles that adults with I/DD can play in our society while living independently. The literature about SRV speaks to the power of imagery in influencing the expectations of service

coordinators and families toward adults with I/DD (Mann, Moni & Cuskelly, 2016). The training materials will also be developed to enhance the competencies of adults with I/DD in how to choose and direct support staff and direct their finances.

Innovation Domain

A tool is available to determine the appropriate type of innovation to address the practice problem. Satell (2017) describes four classifications of innovations. Basic research, disruptive innovation, breakthrough innovation and sustaining innovation. Two questions, "how well the problem is defined" and "how well is the skills domain defined," determine the classification of an innovation. As both the problem and the skills domain are well defined, the innovation domain classification is sustaining innovation. Sustaining innovations make incremental changes to existing products. CFP, by changing the way planning meetings occur to more fully address the risk to homelessness, will improve an already existing process. Literature shows that sustaining innovation works well in large organizations, such as a regional center with over 500 employees, and lends itself to strategic road mapping (Kadar, Moise & Colomba, 2014).

Problems of Practice and Solution

Implementation of the Theory of Change – Alta California Regional Center

As informed by the Theory of Change, CFP seeks to implement a sustaining innovation to planning for the future of adults with I/DD. The logic model (Figure 1), displays the implementation steps that will modify the behavior of planning teams to reach the stated aims of CFP. The discussion of implementation below includes both the proposed components as well as corresponding research justifying it's inclusion in the overall intervention.

Implementation Overview

CFP will piloted at Alta California Regional Center (ACRC), one of twenty-one non-profit regional centers providing assessment and coordination of services and supports for the over 350,000 children and adults with I/DD in California (Department of Developmental Services, 2019). This doctoral student is a member of the executive management team, serving as the Director of Community Services and Supports for ACRC. Service Coordinators at ACRC will, at every annual Individual Program Plan meeting, assess risk to homelessness as well as discuss the adult with I/DD living independently. Resources identified in the logic model include agency staff, stakeholders, including adults with I/DD, families, service providers, and advocates that can help create training curriculum for service coordinators. This curriculum will include how to talk to resistive families about independent living, how to access currently available affordable housing resources, how paid professional support staff aid individuals to live in homes of their own, and the risk to homelessness if caregiver succession is not planned for. The development of training materials addressing these topics is in line with the need for information, which family members describe is as a major barrier to future planning (Bibby, 2012; Deville, Davies, Kane, Nelson & Mansfield, 2019).

Based on the aforementioned research describing the problem and the proposed innovative solution, the service coordinator training will have three main learning objectives. First, service coordinators will increase their understanding of the social norms present in planning team meetings and the impact on client's access to services. Second, service coordinators will learn of the benefits to themselves and our clients of participating in future planning as opposed to responding to emergency housing requests. Third, service coordinators will increase their competencies in discussing access to affordable housing, offering

opportunities for independent living, and developing caregiver succession plans. The CFP Task Force will provide input on these learning objectives and may modify them as deemed appropriate by the team.

Quantifying the Problem

During the development of training materials, service coordinators will quantify the number of adults in immediate need of housing due to having caregivers over age seventy that have no caregiver succession plan. The age of seventy was chosen to mirror the United Kingdom model described in the Valuing People White Paper (Bowey and McGlaughlin, 2006; Department of Health, 2001). In this statement of government policy, the United Kingdom required the development of future plans for all individuals with I/DD living with caregivers over aged seventy. The State of Connecticut also chose the age of seventy in prioritizing their waitlist for residential services. (Fifield, 2016) Neither the California regional centers, nor the Department of Developmental Services, have a firm number of this at-risk population (California State Council on Developmental Disabilities, 2018). CFP, using administrative data, will initially target the over 500 ACRC clients with I/DD age 52 or older living with family caregivers. ACRC already has an existing needs assessment tool that service coordinators are required to complete after every annual IPP meeting. ACRC will add additional questions to the tool. “Do you have a primary or sole caregiver over age 70? Do you have a caregiver succession plan?”

Modification to Individual Program Plan Requirements

After training, service coordinators will be required to ask questions in the IPP meetings for adults with I/DD living with aged caregivers about caregiver succession and if the client is interested in living in a home of their own with needed supports. If they answer in the affirmative or express interest, the service coordinator will identify the needed supports to help them reach

their goal in the IPP. With the proliferation of person-centered planning, supported decision making, and self-determination with a goal toward inclusive living, why then create strict new requirements for how service coordinators hold annual planning meetings? A 2010 study speaks to the reason. This study examined the decision-making process for placement into care homes. The results showed, though at a policy level there are strong requirements for person-centered planning and supported decision making, social workers gave little importance to the preferences of the adult with I/DD. Families felt guided toward segregated care home placements for their loved one – expressing that it seemed the social worker already made the decision prior to holding the planning meeting (Bigby et al., 2010).

Outputs

Outputs of these activities include over 500 adults with I/DD being assessed for needing an immediate housing plan if they reside with a caregiver over age 70 and do not have a caregiver succession plan in place. Additionally, over 100 service coordinators that work with adults will be trained. Finally, annually, over 500 adults with I/DD will be assessed as to their desire to receive services to support a move into a home of their own with needed supports.

Outcomes

Immediate short-term outcomes of this framework include adults with I/DD and their families having increased access to affordable housing resources as well as increased knowledge about independent living with needed supports. Additionally, they will have improved caregiver succession planning. Service coordinators will increase their competency in determining who on their caseload needs immediate housing planning, discussing independent living, as well as making referrals to affordable housing resources. The entire planning team will have an increased acceptance of adults with I/DD living in homes of their own as a viable future option.

Intermediate outcomes associated with this framework include increased utilization of independent living and supported living services for adults with I/DD in homes of their own. Having assessed risk to caregiver incapacity, there will be reduced crisis/emergency placements needed and an overall reduction of incidences of unsheltered homelessness. Also, ACRC can use data on the need for affordable housing to request funds from the government including capital funding for multi-family housing projects as well as for rental vouchers.

The long-term outcome sought by implementing this sustaining innovation is adults with I/DD living in the most included way possible in a community of their choosing. Care home vacancies will increase as those that choose to move out to independent living do so. Finally, the other regional centers can use this pilot as a model to scale up this innovation to serve a much larger population of adults with I/DD.

Likelihood of Success

CFP represents an innovative solution to the devastating social problem of homelessness in adults with I/DD. By addressing the practice problem that contributes to the social problem, research supports that following the operationally defined steps will reduce the likelihood that this vulnerable population will experience homelessness. Narrowly defining the practice problem allows for development of an actionable intervention that is both easily understood and replicated by others with similar concerns. The assessment of impact, as described below, will be the true measure of success and will provide the strongest argument toward replication elsewhere.

Project Structure, Methodology, and Action Components

Prototype

To visualize the process and illustrate the theory of change, a storyboard (Figure 2), was developed that displays the current process of planning for adults with I/DD and the revised process with the inclusion of the tenets of CFP. This prototype illustrates the practice problem and the risk posed by adults with I/DD that do not have a caregiver succession plan. Additionally, the prototype describes the CFP process of quantifying the problem, receiving training from stakeholders, and implementing required changes to the annual Individual Program Plan meeting. The prototype exhibits the output of developing a person-centered Individual Program Plan and its role in preventing homelessness. The goal of the prototype is to show both the benefit of implementing CFP as well as the disadvantages of continuing the same insufficient planning processes. Research speaks to the power of identification in persuading others (Cialdini, 2009). The prototype allows the client, the family members, and the service coordinator the ability to identify with the characters visualized on the storyboard.

Market Analysis

CFP modifies an already existing process, the development of the Individual Program Plan, to enhance outcomes for adults with I/DD. The State Council on Developmental Disabilities (2018) released a strategic framework for expanding housing for adults with I/DD. In their framework they describe the impact of adults with I/DD living with aged caregivers and indicate there is insufficient housing to support those individuals when their caregivers become incapacitated. Several nationwide best practices are identified including increasing tax credits for the development of affordable housing, expanding rental subsidies, assisting people in finding and keeping their housing, and increased usage of accessory dwelling units to name a few. Each

of these proposals have merit for replication in California, however they do not address the practice problem that contributes to the social problem of homelessness for adults with I/DD.

Implementation Strategy Methods

As to methods of implementation, CFP utilizes a number of evidenced based strategies including involving clients and family members in both the project development and implementation, making CFP mandatory for service coordinators and modifying report writing requirements and gathering feedback about implementation of the project (Powell et al., 2012). The application of these strategies will not only facilitate more effective implementation of CFP, but also provides a research foundation when describing the program to clients, stakeholders, and regional center staff both during the development and dissemination phases.

The EPIS Framework (Aarons et al., 2012) assists in identifying barriers and facilitators in each phase of the implementation - Exploration, Preparation, Implementation, and Sustainment. Each of these phases has both outward and inward forces that impact implementation the researchers identify these as the inner context or outer context. In the inner context of the Implementation Phase a barrier is adding additional work to service coordinators that already have high caseloads. In the inner context of the Sustainment Phase, staff turnover at the agency represents a barrier. In the outer context of the Preparation Phase, client advocacy groups that support person-centered planning and self-determination, two foundational aspects of CFP, will serve as facilitators to the project. Additionally, in the outer context of the Implementation Phase the requirements to receive federal funding, which our system relies on, supports practices that are person-centered and rely heavily on the client making choices for their own future. The CFP Task Force will use this framework as an aid to identify and overcome barriers to implementation, some of which will not be known until the project begins.

Leadership strategies for CFP will conform with the theory of Transformational Leadership (TFL) as put forth by Burns (1978) and Bass (1985). Ng (2017) describes TFL as, "inspiring followers to believe in or identify with the leader's vision beyond their own self-interest". The four key aspects of TFL, idealized influence, inspirational motivation, intellectual stimulation, and individualized consideration will be the foundational approach of the management staff working on CFP.

The Director of Community Services and Supports at ACRC, this USC doctoral student, will be responsible for project oversight, recruitment of the CFP Task Force, development of training curriculum, service coordinator training, and assessment of the impact of the project. Completing these duties will equal 10% of this positions time during the first year of CFP and 5% of the time thereafter. Other regional center management and line staff will participate in project implementation also at a rate of 10% of their time the first year and then 5% thereafter. These positions include at least one associate director of client services, the training manager and the home and community-based services specialist. This specialist already has extensive training and experience regarding person-centered planning. The salary and benefit costs of these ACRC staff members represent the majority of the cost of implementation of CFP.

Financial Plans

Implementation of CFP at Alta California Regional Center is ideal as it is a non-profit corporation with access to significant revenue and resources. Alta California Reginal Center publishes its annual independent audit reports in the transparency and public information page on the website altaregional.org. A review of the 2019 fiscal audit showed revenue of $453 million, largely due to a $448 million contract with the State of California. Of these dollars, $404 million is used to fund the annual services for the clients served by the regional center. The regional

center uses the remaining $49 million to fund the operations costs of the regional center, including salary and benefits of staff, lease costs, equipment, and other fees (AGT, 2019).

As described in the CFP budget (Figure 3), ACRC's existing operations budget will fully fund the implementation of CFP. It is likely that remote video platforms will be used both for task force meetings as well as training of staff, reducing the overall cost of implementation. The estimated personnel expenses in the first year, figuring a benefit percentage at 30% is $71,370 for the first year and $35,685 thereafter. Personnel costs may increase in the future due to both longevity and merit increases staff may receive.

Assessing Impact

ACRC will assess the impact of the implementation of CFP in several ways. The CFP Task Force will use the results to refine the materials and improve the experience for the beneficiaries.

Process Measures and Outcome Measures

In evaluating this project, we can look both at the process we have developed and the desired outcomes. An easily quantifiable metric is that the implementation of CFP leads to an increase in the number of caregiver succession plans. To determine this, a simple pre-test, post-test will be conducted that queries planning teams both before and after the Service Coordinator has received CFP training. The purpose is to ascertain if additional training and discussion about caregiver succession planning leads to an increase of the development of caregiver succession plans. As teams are required to meet annually to develop Individual Program Plans, there will be many opportunities for service coordinators to gather this information.

An additional outcome measure is less incidences of ACRC clients becoming homeless due to caregiver incapacity. ACRC primarily learns of homelessness due to caregiver incapacity

from hospitals where the client is at risk of beginning a protracted stay. ACRC has an existing process of activating regional center management, clinicians, and resource specialists when a client is at risk of, or on a, protracted stay in a hospital. This group of regional center staff is known as the Hospital Emergency Assessment Review Team. Reviewing these records before implementation will provide baseline information on the prevalence of clients at hospitals due to caregiver incapacity. The CFP Task Force will view this data again a year after full implementation and annually thereafter to gauge the effectiveness of CFP at impacting the problem. ACRC stores this data on an internal server that will not be accessible to non-regional center staff. Therefore, one of the ACRC task force members, the HCBS Specialist, will be responsible for gathering the data and presenting it to the CFP Task Force.

Service coordination managers, that review Individual Program Plans, will be charged with monitoring the quality of the documentation. An example of this monitoring is making sure that service coordinators include names of prospective or identified caregivers in the Individual Program Plan document. Quality documentation is specific and actionable as it relates to the services and supports that will be provided to meet a client's goals. To begin, regional center staff on the CFP Task Force will examine administrative data and provide managers with lists of clients age 52 or older that live with family and are served by a case manager in their units. Managers will report at minimum annually on these individuals as well as other adults in their unit identified through the needs assessment process.

As to measuring the process, the regional center will use two methods. First, an evaluation form will be given to service coordinators after they complete their training session that measures the quality of the training and the service coordinators readiness to engage planning teams with their newly gained CFP skills. The second will be a client and family

survey, modeled on the National Core Indicators Adult Family Survey (National Core Indicators, 2017). CFP Task Force members will finalize these questionnaires. Qualitative data adds a richness to health care information, providing deeper insight into the experiences of stakeholders and beneficiaries (Bradley et al., 2007). Both the evaluations of the training and the feedback sought from families will include a qualitative data component.

Evaluation Procedure

Alta California Regional Center plans to use The Stages of Implementation Completion (SIC) tool to evaluate the implementation milestones. This model is useful because it focuses on easily observable activities. Though there are eight stages to the SIC broken up into three areas, pre-implementation, implementation, and sustainment. The implementation stage begins with the hiring and training of staff to implement the intervention and sustainability begins during the Competency stage (Chamberlain & Saldana, 2011).

Using a tool like the SIC, will aid in disseminating and scaling CFP. As the authors stated, SIC can evaluate "implementation activities, the length of time taken to complete activities, and the proportion of activities completed" (Chamberlain & Saldana, 2011, p. 2). Dissemination of CFP may require convincing executive leadership, financial staff, and social work supervisors that will be responsible for overseeing the project. Regional center staff can use the data gathered in the SIC to explain to these different leaders the challenges and opportunities faced in the various stages.

Stakeholder Input

Alta California Regional Center will seek regional center clients, family members, advocates, and service providers to form the CFP Task Force. Task force members will develop the training, deliver the training to service coordinators, and evaluate the impact of the project.

Regional centers in California are required by Section 4622(h) et seq. of the Welfare and Institutions Code to have appointed advisory committees of both clients and service providers. Alta California Regional Center will send an email solicitation for participation in the task force to the Client Advisory Committee and the Provider Advisory Committee. Additionally, ACRC will send the same solicitation to those signed up to receive email updates on the altaregional.org website. The goal will be to have two members of each stakeholder group participate along with up to four regional center employees. This small group size is in line with research regarding the optimal size of meetings in order promote engagement and performance (Allen et al., 2020). Advocate involvement may require targeted recruitment. ACRC will engage both The State Council on Developmental Disabilities and Disability Rights California for participation.

The CFP Task Force is modeled on the Developmental Services (DS) Task Force, which provides guidance to the California Health and Human Services Agency and the California Department of Developmental Services on service delivery for individuals with I/DD. In 2019, there were 157 Californians appointed to the DS Task Force and its corresponding workgroups (Department of Developmental Services, 2020). The CFP Invitation Letter closely mirrors materials developed for the application to the DS Task Force (Regional Center of Orange County, 2019). It is desired, by using similar application procedures and documents, that it will be easier for applicants to complete a familiar application. An Invitation Letter (Figure 4) describes Task Force involvement, time commitment, and serves as an application for participation.

Communication Strategy and Products

The communication strategy for CFP will enhance the project in several ways. First by increasing awareness of both the social and practice problem. Second, by engaging stakeholder

groups to contribute their time to develop and conduct training. Finally, by encouraging utilization of the training materials in planning team meetings for the development of annual Individual Program Plans for regional center clients. Alta California Regional Center will host a page on its website containing the marketing materials for CFP.

The products created for the campaign will include short form videos that can be shared on the Twitter, YouTube, Instagram, and Facebook pages for the agency. The campaign will disseminate fliers that specifically encourage clients, families, and advocates to volunteer to assist in the development and delivery of training materials to regional center service coordinators. The Prototype document highlights the user experience for the service coordinator, family, and client both before and after they participate in CFP. Another type of infographic (Figure 5), will display the necessity for immediate implementation of CFP due to the staggering increase of individuals living with aging caregivers. Just as advertising campaigns use short statements to describe their product, these same types of statements will be created for service coordinators to describe what CFP is and the benefits to the client, the planning team members and themselves. These statements or taglines, such as, “plan for the future, so no adult with disabilities has to needlessly face homelessness” or “proper planning may prevent homelessness” are short, impactful and easily translated into the native languages of clients and families. Finally, there will be a flyer promoting the training material to service coordinators that explains the CFP initiative from problem identification through the expected change that will result from implementation. This material will also highlight the time-savings and stress reduction for service coordinators when they engage in extensive planning, as opposed to trying to react to client homelessness typically in an emergency.

Communication products will not focus on one type of developmental disability and its corresponding attributes, for example, clients with severe cerebral palsy in wheelchairs. Instead images and descriptions will include several types of developmental disabilities along with a range of severity of disability. Cialdini (2009) describes the liking principle and discusses the power of similarity when individuals make decisions. Having a campaign that uses images and examples of a range of disabilities will increase the audience members engagement. Further, in considering one sought after demographic, aged caregivers, internet-based communication may not sufficiently reach caregivers over age 70, a direct mailing of a flyer regarding the initiative will be sent prior to service coordinators implementing the required change to the IPP process.

CFP will use clients, family members, advocates, and service providers to supplement the information provided by regional center staff. Specifically, in disseminating the information after the pilot at ACRC, these stakeholder groups will be vital in providing testimonials as to the efficacy of the initiative. These individuals are easily accessible, and research discusses building credibility using testimonials (Sperber et al., 2010).

Addressing the Practice Problem

CFP addresses the practice problem that service coordinators facilitating supports for adults with I/DD and their family are not assessing risk to homelessness or offering opportunities for independent living to adults with I/DD and their families, adversely limiting housing options. As opposed to other interventions, described previously, that aim to prevent homelessness in adults with I/DD, CFP creates a comprehensive approach that seeks to change the behavior of those holding the practice problem in place. The well-defined implementation steps are in line with research into both the causes of the problem, as well as the development of an effective solution.

Ethical Concerns and Unintended Consequences

CFP modifies already exiting processes to enhance the competencies of service coordinators and change the behavior of planning teams for adults with I/DD. As described in the Problem Space section above, CFP is rooted in supported decision making, person-centered planning, the social model of disability and inclusion. Each of these espouse the importance of creating opportunities for those with disabilities to experience their life as they desire it. While not necessarily an "unintended consequence" it is likely that CFP will bring to light the need for more access to affordable housing and qualified staff to support individuals to live in homes of their own. Research conducted by the State Council on Developmental Disabilities (2018) showed a significant need for more funding to develop and maintain housing options for California's growing population of adults with I/DD residing with aging caregivers. It is an aim of this project to accurately quantify the housing needs. The data can be both disseminated to government developmental services personnel as well as legislative staffers involved in health and human services funding.

Conclusions, Actions, and Implications

Informing Future Decisions and Actions

The implementation of CFP seeks to inform future decisions and actions by beneficiaries and stakeholders on multiple levels. First, planning teams will decide to develop caregiver succession plans and consider all future living options, including adults with I/DD living in homes of their own with necessary supports in place. Service Coordinators will use the skills learned in their training to assist in the development of these plans and engage the team about the supports needed for the client to reach their stated goal. Second, with the successful implementation at Alta California Regional Center, it is desired that the other 20 regional centers

in California will similarly decide to adopt their own CFP programs. The key stakeholders at this level include California regional center executive management staff and advocacy groups. Third, with the data obtained by implementation of CFP across the State of California the regional centers can quantify numbers of individuals at risk of homelessness due to living with a primary caregiver age 70 or older. Regional centers can present this data to inform key decisionmakers such as State Department of Developmental Services management staff, legislators, and their staff about the need for more affordable housing options for this population.

The Social Work Field of Developmental Disability Services

Prior discussion focused on the ways in which CFP aligns with current practices in the field of development disabilities, including aspects of Supported Decision Making, Self-Determination, Person-Centered Planning, and Inclusion. Additionally, the National Association of Social Workers (NASW) Code of Ethics (2017) provides guidelines for the conduct of professional social workers, such as those coordinating services for adults with I/DD. Two of the values contained in the Code of Ethics align closely with the necessity for and wide implementation of CFP. The first value, service, speaks to the need to address social problems such as homelessness in adults with I/DD. The second value, competence, is the ongoing increase of both skills and knowledge of social workers, as well as the expectation that they incorporate what they have learned into practice.

Implications for Practice

Developmental disability professionals can use the innovative aspects of a successful CFP pilot as a model to ameliorate other social problems facing children and adults with I/DD. Three components of the project highlight its usefulness in further opportunities for action. First, an analysis of the social norms present amongst individuals (Leitner, 2018) involved in future

planning for adults with I/DD led to the decision to require a discussion of caregiver succession and opportunities for independent living at every annual planning meeting for those at risk of homelessness due to caregiver incapacity. Second, CFP uses evidenced-based implementation strategies such as involving clients and family members in project development and implementation, making implementation and subsequent documentation mandatory, and receiving feedback from beneficiaries (Powell et al., 2012). Third, CFP materials including the logic model, storyboard prototype, implementation budget and short form video have influenced decision makers to implement the pilot fully at Alta California Regional Center. Similarly, other social problems such as social isolation for adults with I/DD (Bigby, 2009; Milner & Kelly, 2009) or a lack of experienced direct support professionals to support independent living (Crane & Havercamp, 2020) may also be addressed by following a similar framework.

Limitations

CFP was envisioned to impact the developmental disability service system in California. This system affords service coordinators the opportunity for at least annual contact with planning teams for the purposes of implementing CFP. It also requires the development of an Individual Program Plan outlining the goals of the individual with I/DD and the corresponding services and supports that the government will fund to meet those goals. The regional centers are unique in California as being non-profit agencies that are written into California law for the purposes of determining an individual meets the definition of having a developmental disability and coordinating government funded services. If a service is requested by a client, regional centers are required to fund the service, locate a service funded by another means, or issue a notice of action which may include a hearing in front of a judge (Department of Developmental Services, 2001). Whereas many states have lengthy waitlists for services, California remains the only state

where individuals with I/DD living in the least restrictive community environment is considered a civil right and there is an entitlement to receive services to reach that goal (Vogel et al., 2019).

Others outside of California can benefit from adopting the tenets of CFP. Developmental disability professionals seeking to replicate CFP should modify implementation based on both their ability to regularly access clients or the responsibility the social worker or service coordinator carries in assuring service provision. However, like-minded developmental disability professionals should retain the evidenced-based implementation strategies that are foundational to CFP. Additionally, agencies without the robust government revenue to support operations, as ACRC has, should be mindful of their ability to dedicate staff time in project implementation. Finally, ACRC has significant stakeholder involvement in agency decision making, as required by California law. Those seeking to implement CFP should make sure they have access to stakeholders – clients, families, advocates, and service providers that can partner in development, implementation, and assessment of the intervention.

Capstone/ Prototype Dissemination

As described previously, the Prototype describes CFP in the form of a storyboard of the current user experience and the sought-after change, from a third-person omniscient viewpoint of the client, family, and service coordinator. This Prototype displays proof of concept that the activities promoted by CFP will lead to a behavioral change that will prevent adults with I/DD from needlessly falling into homelessness. Further proof of concept will be the pilot implementation that can immediately begin at ACRC. CFP communication materials, purposefully, require no expertise in the developmental disability field to understand. As an example, housing developers and legislative staff both may have significant interest in this project, especially as it relates to quantifying housing needs. There are numerous opportunities to

share about CFP to encourage replication. Conferences held by advocacy groups, developmental disability service provider trade associations, University Centers for Excellence in Developmental Disabilities as well as those related to the field of aging and developmental disabilities would all be ideal in reaching the intended audience of like-minded disability professionals that want to address this problem in their local communities.

Next Steps

Piloting of CFP is set to begin at ACRC in January 2021. As the Executive Management Team at ACRC already supports implementation, the next step will be an internal meeting with the ACRC staff that will be primarily involved in development, implementation, and assessment. These individuals are outlined in the CFP budget (Figure 3). This meeting will seek to educate staff on CFP as well as outline specific duties and responsibilities. A public notice will be issued via ACRC mailing list targeting clients, families, advocates, and service providers. This notice will solicit interested stakeholders to participate in an introductory meeting which ACRC will hold remotely via video conferencing.

The introductory meeting, much like the earlier internal meeting, will describe the program, introduce the regional center staff that will support the program and call for attendees to apply to participate in the CFP Task Force. We will explain to participants that a short biographical set of questions (Figure 4), will be used by ACRC staff to determine who will be selected as participants. The questionnaire also includes an acknowledgement of the respondent's commitment to participate in meetings at least quarterly through the first two years of development and implementation. As mentioned previously, this process mirrors the application process the State of California Department of Developmental Services utilized in 2019 in reconstituting their Developmental Services Task Force (The Arc California, 2019). ACRC

employs an individual with developmental disabilities that serves as a client advocate as well as a member of the Executive Management Team. This individual's work schedule does not permit their full participation in the CFP Task Force; however, they will be involved in reviewing applications of prospective task force members. It should take no longer than six weeks to go from the initial internal meeting to announcing the members of the task force. Thus, will begin the pilot at ACRC as described in the Implementation Gantt Chart (Figure 6).

In closing, the time to address this problem is now. We need to find out what the preferred future is for adults with I/DD. We need to document it in Individual Program Plans. If a client desires it, we need to prioritize offering service and supports that lead toward independent living. We must get a handle on who is likely to need housing in the next five years or the next ten years. We need to move beyond just offering care home placements and offer individualized settings that offer opportunities for adults with I/DD to live in a manner where they will be treated with dignity and respect in their community. We need to do this before they are faced with the devastation of homelessness. It is necessary to implement CFP and ensure no one suffers from homelessness because effective planning was not done.

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Figure 1

Logic Model

Logic Model - Coordinated Future Planning					John W. Decker
Grand Challenge: End Homelessness **Social Problem:** Homelessness and risk for homelessness among adults with Intellectual/Developmental Disability (I/DD). **Practice Problem:** Service coordinators facilitating supports for adults with I/DD and their family are not assessing risk to homelessness or offering opportunities for independent living to adults with I/DD and their families. **Implementation Site:** Alta California Regional Center – Sacramento, CA - 26,000 clients & 515 employees					
Internal Processes			External Results/Outcomes		
Inputs	Activities	Outputs	Short-Term	Intermediate	Long-Term
Agency staff Stakeholders – adults with I/DD, families, advocates, service providers Policies and procedures Existing needs assessment tool Modifiable Individual Program Plan (IPP) templates	Housing needs assessment for those living with 70+ caregivers with no succession plan. Training service coordinators about discussing independent living and affordable housing with planning teams. **Sustaining Innovation** Requiring discussion about caregiver succession planning and independent living at IPP.	500 adults with I/DD and 70+ caregivers assessed for risk to homelessness. 100 service coordinators trained. 500+ adults with I/DD offered opportunities for independent living.	Adults with I/DD - Increased access to affordable housing resources. Adults with I/DD and families - Increased knowledge about options for independent living. Adults with I/DD and families - Improved development of caregiver succession plans for those adults with I/DD remaining in the family home. Service Coordinators - Increased competency discussing independent living, referring to affordable housing resources and assessing for risk of homelessness due to caregiver incapacity. Families and Service Coordinators – Increased acceptance of independent living as viable option for adults with I/DD	Adults with I/DD - Increased utilization of independent and supported living services in homes of their own. Agency - Increased understanding of the number of adults with I/DD in need of housing options. Service Coordinators - Reduced crisis/ emergency placements needed. Adults with I/DD - Reduced incidences of unsheltered homelessness. Agency - Data on the need for affordable housing used to seek additional government funding.	*Adults with I/DD live the most included way possible in a community of their choosing.* Adults with I/DD - Care home placements only used for those that choose to live in them. Developmental Disability System – Activities scaled and replicated at the other 20 regional centers in California.

Figure 2

Prototype

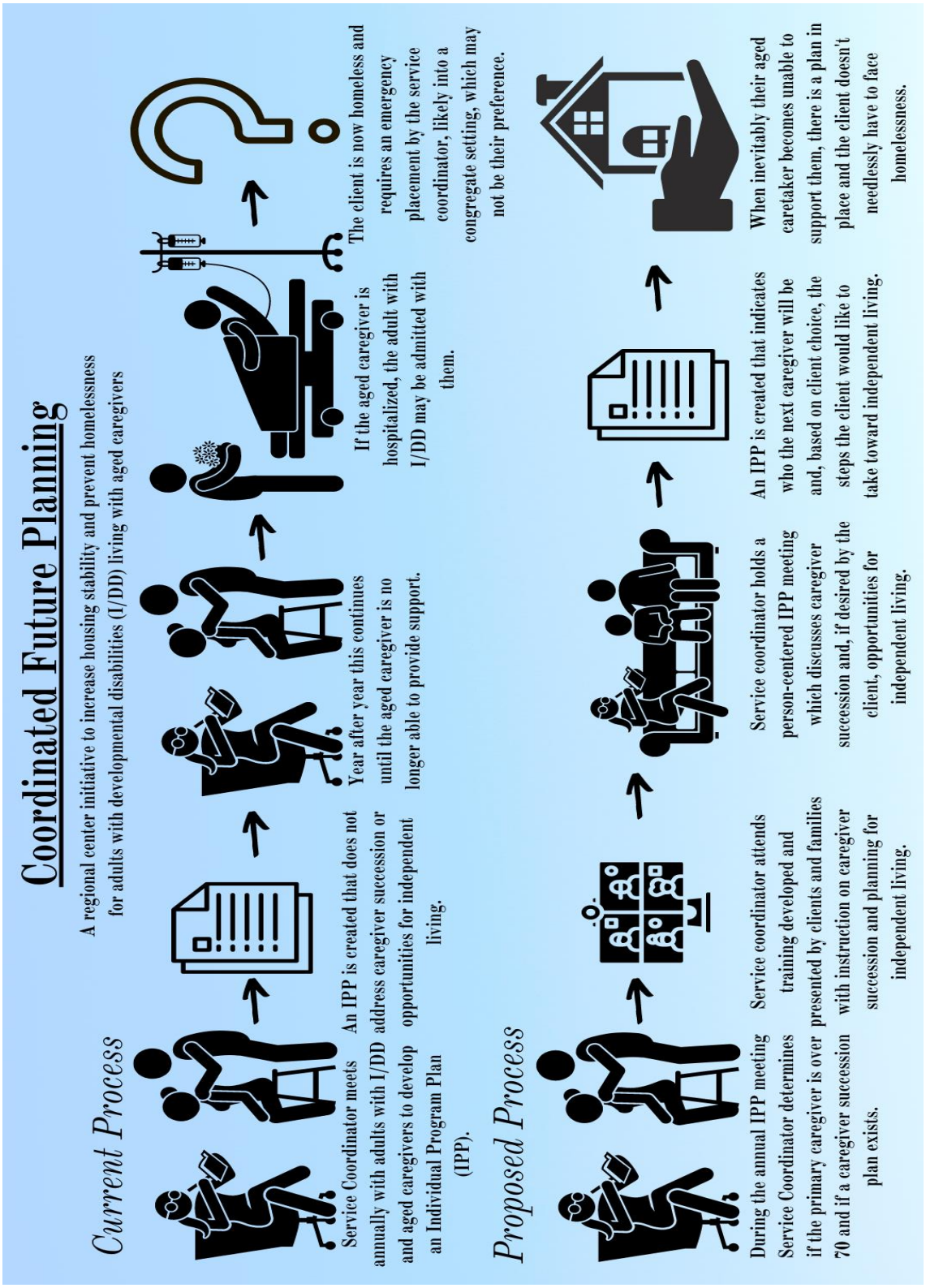


Figure 3

Budget

Coordinated Future Planning (Startup Phase) Startup Phase - **12 months**		
	Startup (12 mos.)	Startup Justification
Revenue		
Government Contracts	$76,370	Amount of total operations funding used by CFP funded fully from $49,804,000 total annual agency revenue from State of California contract.
Total Revenue	$76,370	
Expenses		
Personnel Expenses		
Regional Center Staff Costs	$54,900	Five staff positions will spend up to 10% of their time in the first year on developing this project. Director CSS $181,000 X 10% - $18,100 Associate CSD $126,000 X 10% - $12,600 Training Manager $96,000 X 10% - $9,600 Training Specialist $73,000 X 10% - $7,300 HCBS Specialist $73,000 X 10% - $7,300
Benefits	$16,470	30%
Total Personnel Expenses	$71,370	All salary information retrieved from: https://www.altaregional.org/post/w-i-code-46395-reports
Operating Expenses		
Training Materials	$3,000	Cost to develop including holding meetings and creating training materials.
Video Recording	$2,000	Recording training session (one-time expense)
Total Operating Expenses	$5,000	
Total Expenses	$76,370	

Figure 3

Budget (Continued)

Coordinated Future Planning First Full Year of Operation - **Fiscal Year July 1, 2021 to June 30, 2022**		
	On-Going (Annual Costs)	On-Going Justification
Revenue		
Government Contracts	$36,685	Amount of total operations funding used by CFP funded fully from $49,804,000 total annual agency revenue from State of California contract.
Total Revenue	$36,685	
Expenses		
Personnel Expenses		
Regional Center Staff Costs	$27,450	Five staff positions will spend up to 5% of their time on the ongoing implementation of this project Director CSS $181,000 X 5% - $9,050 Associate CSD $126,000 X 5% - $6,300 Training Manager $96,000 X 5% - $4,800 Training Specialist $73,000 X 5% - $3,650 HCBS Specialist $73,000 X 5% - $3,650
Benefits	$8,235	30%
Total Personnel Expenses	$35,685	All salary information retrieved from: https://www.altaregional.org/post/w-i-code-46395-reports
Operating Expenses		
Training Materials	$800	Cost for ongoing items like photocopying, food for training meetings.
Client and Family Surveys	$200	
Total Operating Expenses	$1,000	
Total Expenses	$36,685	

Figure 4

CFP Task Force Invitation Letter

January 2020

Alta California
Regional Center

Coordinated Future Planning Task Force

Alta California Regional Center (ACRC) wants a diverse group of stakeholders to be on the Coordinated Future Planning (CFP) Task Force. Members will include clients, families, advocates, service providers, and regional center staff. Regional center staff will choose the task force participants.

Those not chosen for participation will still be able to provide public comment on the initiative.

The CFP Task Force will develop, implement, and evaluate Coordinated Future Planning, a new regional center initiative to prevent homelessness in adults living with aged caregivers.

For additional information please visit altaregional.org/CoordinatedFuturePlanning.

CFP Task Force Member Roles, Expectations, and Responsibilities

Time commitment:

1) CFP Task Force members can expect at minimum 6 meetings a year. Each meeting will last at least 2 hours.
2) Meetings will be held both in-person and via video conferencing.
3) Applicants are expected to participate for a minimum 2 year period.

Selection Process for Members

To apply for the CFP Task Force, please submit an application via email to: CFPTaskForce@altaregional.org.

The number of CFP Task Force members will be limited. Not all applicants will be appointed. Applicants not chosen may be considered if any vacancies occur. There is no monetary compensation for participation on the CFP Task Force.

Figure 4

CFP Task Force Invitation Letter (continued)

Application for the CFP Task Force

If you need help with this application, or have any questions, please email CFPTaskForce@altaregional.org or call 916-978-6400.

First & Last Name: _____ **Today's Date:** _____

Your Address: _____ **Zip Code:** _____

Preferred Phone #: _____ **Email Address:** _____

Gender Pronouns: ☐He/His ☐She/Her ☐They/Their ☐ Other:_____

Occupation/employer (if applicable): _____

Work Address (if applicable): _____ **Zip Code:** _____

Which categories describe you? Select all boxes that apply:

☐American Indian or Alaska Native

☐Asian

☐Black or African-American

☐Pacific Islander

☐White

☐Hispanic/Latino

☐Other Not Listed:_____

☐Don't Know

☐Prefer Not to Answer

My preferred language is: _____

Relationship to the Developmental Service System? Please check all that apply:

☐Self-Advocate/Client

☐Service Provider

☐Parent

☐Advocacy Organization

☐Sibling

☐Other Family Member

☐Conservator

☐Other :_____

Figure 4

CFP Task Force Invitation Letter (continued)

If you are a Service Provider, what type of services does your organization provide?:

☐Day Programming
☐Employment
☐Residential – ARFPSHN
☐Residential EBSH
☐Residential – CCH
☐Residential SRF
☐Residential Other _____
☐Respite
☐Transportation
☐SLS/ILS
☐Early Start
☐Crisis Services
☐Financial Management Services (FMS)

Please share a few sentences on any life, career, volunteer, or training experiences/expertise you have that would help the CFP Task Force: (100 word limit)

Please share the names and contact information for two people who can be references for your application:

1) Name: Phone: Email:_____
2) Name: Phone: Email:_____

Please attach one or more of the following (check which one(s) are attached):
☐Biography ☐Resume ☐Curriculum Vitae ☐I don't have one of these

Do you need any accommodations to participate in meetings? (Examples: Communication: sign language, communication device, voice amplifier, someone familiar with your communication style, interpreter/translations; Accessibility: transportation, space considerations) **Please explain the accommodations or arrangements you need**:

_____

_____

Figure 5

Why CFP Infographic

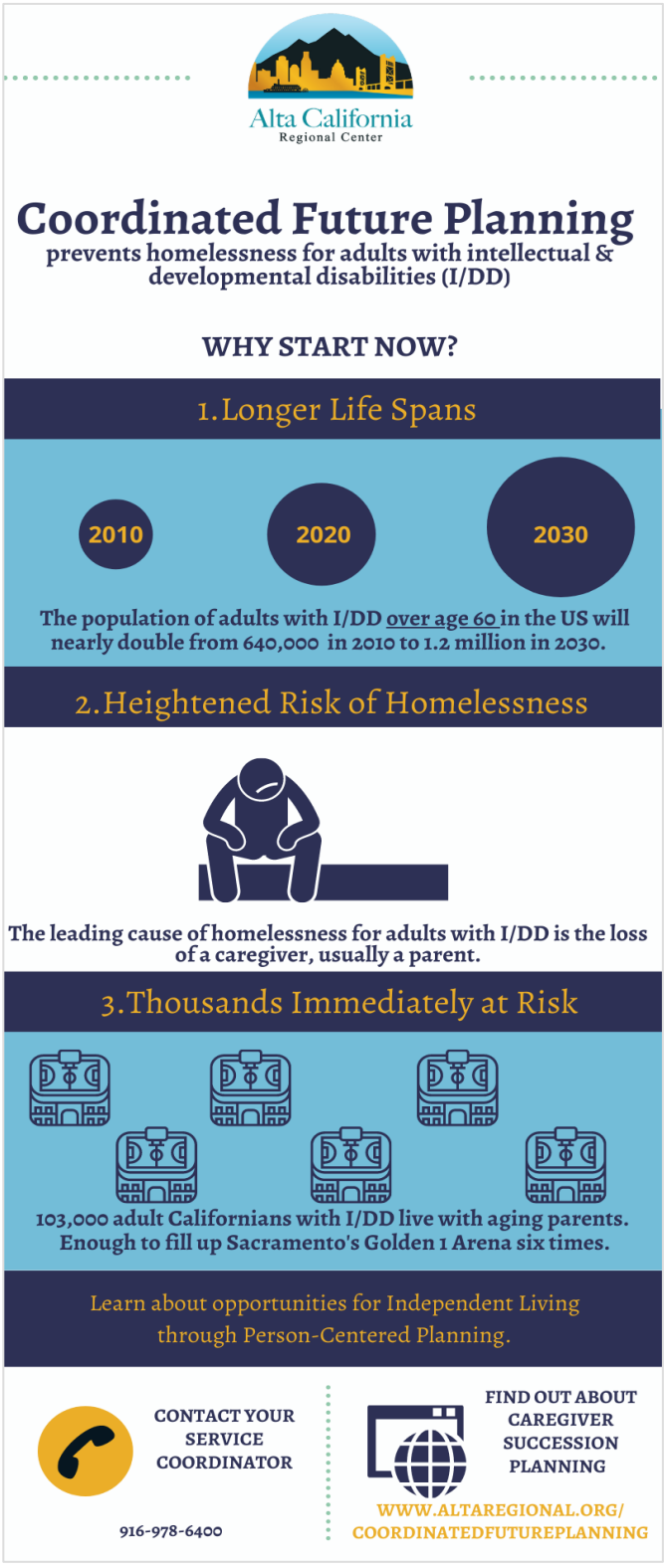
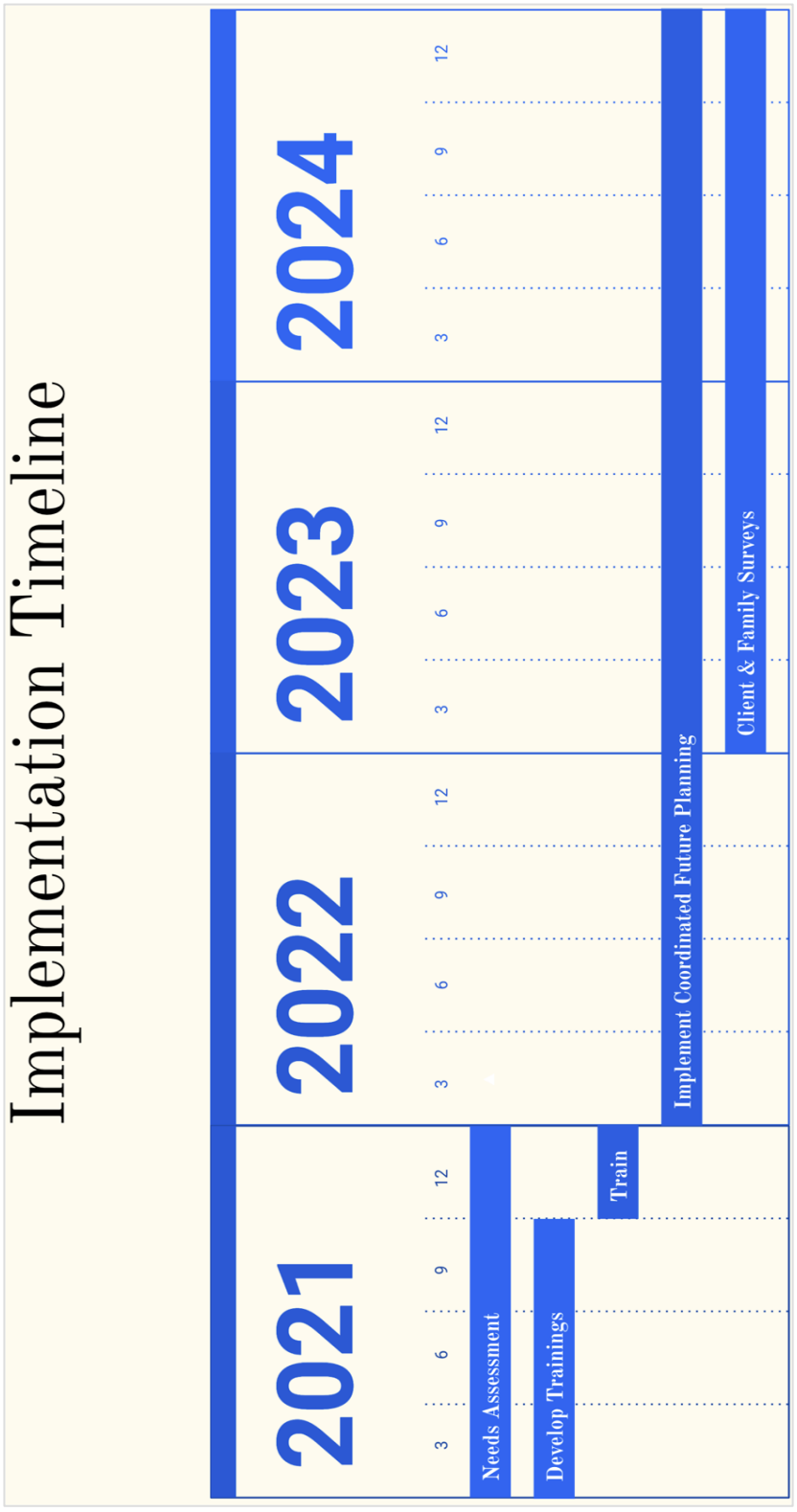


Figure 6

Implementation Gantt Chart