



DULCE
An initiative
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The DULCE Approach to Setting Goals with Families of Infants

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Charlyn Harper Browne

Deneisha Watson

Krystine Fuster

Danielle Patrick



**Center for the
Study of
Social Policy**
Ideas into Action

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INTRODUCTION

The Center for the Study of Social Policy (CSSP) engaged in a 12-month (November 1, 2021–October 31, 2022) planning and implementation project which focused on developing and pilot testing a collaborative goal setting process for families of infants that is derived from goal concordant care—a health care approach for seriously ill patients. The purpose of this paper is to describe the initial success of this endeavor, including a description of and guidelines for the collaborative goal setting process, initial findings from pilot testing of the process, examples of parents’ and practitioners’ reflections about their experience of the goal setting process, and a list of draft training and technical assistance tools.

ABOUT DULCE

The target population for this small-scale project was families participating in a CSSP initiative called DULCE (Developmental Understanding and Legal Collaboration for Everyone). Developed at the Boston Medical Center, DULCE is an innovative strengths-based approach implemented in the pediatric primary care setting with families of infants, birth to six-months-old. DULCE was developed to promote the healthy development of infants and address the family’s immediate needs during the critical first six months of life. Although many families who choose to participate in DULCE are those who are faced with social and economic challenges, all families who seek services at a primary care setting which implements DULCE are invited to participate. This universal approach minimizes stigma and recognizes that all families need support during this first phase of their infant’s life.¹ Currently, DULCE is being implemented in 17 communities in nine states.

The work of DULCE is carried out by a collaborative Interdisciplinary Team comprised of a Family Specialist, medical provider, mental health representative, legal partner, and early childhood system representative. Vital to the success of the Interdisciplinary Team is the Family Specialist, a community health worker who is trained in the principles of child growth and development, as well as practices that forge healthy, trusting parent-infant relationships and parent-practitioner relationships. Family Specialists attend well-child visits with families; help parents strengthen their parenting skills; provide peer support; engage with families to identify their concerns and unmet needs; and problem solve collectively with other Interdisciplinary Team members to identify and connect families to relevant resources and services.² In addition, the work of DULCE is supported by a National Team of individuals with expertise in pediatric primary care, public interest law, mental health, early childhood system building, child development and relational health, public health, and quality improvement.

DULCE was one of four research and demonstration projects selected by CSSP to participate in the National Quality Improvement Center on Early Childhood—funded through a cooperative agreement with the Children’s Bureau (2008-2013)—to test its approach for improving outcomes of infants and their families.³ In this context, a randomized controlled trial was conducted with over 300 families. Results showed that the DULCE approach significantly increased access to needed concrete supports for intervention families, and intervention infants were more likely to have completed routine well-child visits and immunizations and less likely to have visited the emergency department by age six months.⁴



A key component of the DULCE approach is screening for and addressing a family’s immediate health-related social needs that could negatively impact infant and family health outcomes. Family Specialists screen families for nine health-related social needs, specifically: (a) food security, (b) housing stability, (c) housing and health safety, (d) transportation, (e) employment security, (f) financial supports, (g) utilities, (h) mental health/caregiver depression, and (i) intimate partner violence. DULCE practitioners are keenly aware that parents may feel embarrassed, judged, or fearful of potentially negative consequences when asked about their current circumstances. Thus, to reduce these possibilities, Family Specialists actively work to build a trusting relationship with families that fosters a willingness to be vulnerable and share personal information with the Family Specialist; help families feel valued and respected; and inquire about the family’s strengths, resources, and protective factors, in addition to assessing their immediate needs and risk factors. With this approach, families can see themselves as more than their “needs” and have confidence in their ability to exert control over what happens to them.⁵

THE IMPORTANCE OF COLLABORATIVE GOAL SETTING WITH FAMILIES

Goal setting with families is regarded as essential to achieving positive outcomes for infants and their families. If a practitioner attempts to impose goals and services upon a family that are incongruent with the family’s values and priorities, the probability of successful goal attainment is limited.⁶ A successful approach to avoiding this incongruence is through collaborative goal setting; that is, the process of families and practitioners jointly determining meaningful goals and how they will be achieved. The increasing emphasis in health care and other fields on collaborative goal setting with families grows out of an awareness that “a shared understanding of the individual’s goals directly impacts the outcomes and experience of the person receiving care.”⁷ For example, a growing trend in patient-centered care—also called person-centered care—is to ask patients “What matters to you?”⁸ and not singularly “What’s the matter with you?” Proponents suggest that determining what matters most to patients is an essential component of high-quality service delivery, can be the foundation for a stronger partnership with patients in improving health, and can increase a family’s motivation to work to reach a goal.^{9,10,11}

GOAL CONCORDANT CARE

Goal concordant care is a type of collaborative goal setting. Goal concordant care is a health care approach typically used in palliative and end-of-life care. It refers to medical care that:^{12,13,14}

1. Is based in a foundation of trust and clear, open communication between the patient and health care professional.
2. Elicits, respects, and honors a patient's values, hopes, priorities, goals, and treatment preferences and limitations—that is, what matters most to the patient—in addition to explaining the diagnosis, prognosis, and treatment recommendations.
3. Is informed by a negotiated agreement about the patient's goals of care if the health care professional's recommendations are not aligned with the patient's priorities.
4. Encourages ongoing conversations with patients because priorities may shift, and circumstances may change.

These principles of goal concordant care contributed to the development of a goal setting process for the DULCE approach. While goal concordant care primarily focuses on goals related to the health care of patients, applying these principles in the context of families with infants also would focus on goals related to addressing factors that both promote healthy development and well-being (e.g., forming secure parent-infant relationships) and threaten it (e.g., housing instability).

INTEGRATING COLLABORATIVE GOAL SETTING INTO DULCE PRACTICE

Although DULCE already included some of the principles of goal concordant care (e.g., building trust with families; encouraging families to identify the services they want and need) and screened for a family's health-related social needs, the practice of intentionally asking families about their goals and assessing progress toward goal attainment, had been informal. Thus, the CSSP DULCE team viewed the integration of collaborative goal setting into DULCE practice as involving adapting some existing practices, creating some new practices and tools, and being more systematic in documenting practices and outcomes.

As a foundation for developing a DULCE goal setting process, the literature about best practices related to goal concordant care and patient/person-centered goal setting was reviewed and synthesized, and the ways in which DULCE already honors family goals were explored in discussions with Family Specialists. These efforts resulted in the delineation of a collaborative goal setting pathway for DULCE families that includes seven key activities (see Figure 1) and guidelines for Family Specialists to implement each activity. Generally, the goal setting activities build on the components of goal concordant care and patient/person-centered care models and are grounded in DULCE principles and practice. The DULCE pilot communities and members of the DULCE National Team reviewed the activities and guidelines and provided feedback. While these activities build on each other, Family Specialists do not implement them strictly in a stepwise fashion. For example, documentation and keeping accurate records should take place within each activity to ensure data integrity.

Figure 1. Key Activities in the Goal Setting Pathway for DULCE Families



GUIDELINES FOR IMPLEMENTING GOAL SETTING ACTIVITIES



Eliciting Goals and Priorities

1. Use established training in the strengths-based approach and relational practices to: (a) prepare to meet a family for the first time; (b) build a trusting relationship; and (c) acknowledge the family as being knowledgeable about their child.
2. Include the following statement in your typical introductory conversation with a family: *“Our whole team is here for your whole family. We want to make sure that your family feels supported and has access to whatever matters most to you—your priorities, hopes, concerns, and needs—to adjust to the birth of your baby.”*
3. Inquire about what matters most to families to put them at ease so they do not feel judged but feel invited to share their story.
4. Employ different strategies to elicit what matters most to families. Use: (a) open-ended conversation prompts, (b) information from the screenings of health-related social needs, and (c) the new DULCE tool called “What Matters Most Inventory.”
5. Follow DULCE procedures for using a strengths-based approach to conduct screenings to identify health-related social needs.



Engaging in Shared Decision-Making

1. Accept the family’s initial goals and action steps without judgment.
2. Share the family’s goals and desired action steps with the Interdisciplinary Team during the weekly case review. Discuss goals of care and possible next steps that support what matters most to the family.
3. Share the Interdisciplinary Team’s views with the family about the goals of care, action steps, and resources and supports. Explore areas of agreement and difference, and assure the family that it is okay to question, challenge, or disagree with the Interdisciplinary Team’s recommendations.
4. Work toward consensus when there are areas of disagreement. This involves considering: (a) what’s most important for the well-being of the infant, adult(s), and/or family; (b) what can be accomplished within their time of participation in DULCE; (c) personal, interpersonal, and community strengths, resources, and supports; (d) barriers to achieving goals and if they can be overcome; and (e) indicators of progress or goal attainment.
5. If the family’s preferences conflict with the Team’s recommendations, discuss any conflicts with the child health provider and other members of the Interdisciplinary Team. Make sure the family is aware of all options, benefits, risks, and consequences of their choices. Encourage the family to reflect on the impact of different options on their family.

If there is conflict, discuss the nature of the conflict with the family and Interdisciplinary Team. Both entities may need to reevaluate their perspectives and possibly find alternatives. For example, see if the differing options can occur in a related sequence rather than discarding one altogether.



Documenting Decisions

1. Have a recorded understanding of what is important to the family, the steps toward meeting their goals, and progress made.
2. Use the family's own words as much as possible.
3. Record key information using the site-specific mechanism for tracking data and information, including: (a) specific goals to be addressed, (b) action steps to be taken during participation in DULCE, (c) barriers to goal achievement and how they will be addressed, (d) indicators of progress and goal attainment, (e) circumstances that facilitated and/or interfered with progress, and (f) goals and action steps that will be a part of the transition plan.



Implementing Action Steps

1. Leverage the Interdisciplinary Team's knowledge, resources, and supports to address a family's goals, priorities, needs, and concerns.
2. Implement the designated action steps to be taken by the family and members of the Interdisciplinary Team.
3. Identify and address barriers or circumstances that may be impeding progress toward goal attainment.



Monitoring Goals & Action Steps

1. Engage in ongoing conversations about goals/what matters most, as priorities may change.
2. Monitor progress; that is: (a) confirm what steps were taken since the last meeting/ conversation, (b) ask about what may be getting in the way of taking steps to achieve goals, (c) check to see if goals need to be changed, (d) offer encouragement and moral support, and (e) identify and celebrate progress.



Assessing Progress and Experiences

1. Review action steps taken to progress toward goals. Identify circumstances that both facilitated and interfered with progress.
2. Solicit feedback from the family about the goal setting experience and progress made.
3. Reflect on one's own goal setting experience and progress made.
4. Solicit feedback from the Interdisciplinary Team about the goal setting experience and progress made.



Transitioning Families

1. Use established practices for transitioning families out of DULCE and incorporate a conversation about the goal setting process.
2. Identify continuation goals or new goals that should be addressed in the family's relationship with their child health provider and/or a community partner who will continue to work closely with the family.
3. Remind the family that, upon graduating from DULCE, follow-up by the Interdisciplinary Team is available as needed.



INITIAL SMALL-SCALE TESTING OF THE GOAL SETTING APPROACH

Following training on the collaborative goal setting activities, the DULCE pilot communities conducted a series of Plan-Do-Study-Act (PDSA) cycles to test the activities with families, observe the results, share what is learned, and act on relevant lessons in subsequent cycles. Table 1 provides a summary of the nature of the PDSA cycles.

Table 1. Instructions for Conducting the Goal Setting PDSA Cycles

	INSTRUCTIONS
CYCLE 1	<ul style="list-style-type: none"> • Ask a parent in one or two families, “What matters most to you?” (verbatim) • Record parents’ responses to the question verbatim. • Ask parents how they feel about the “what matters most” question. • Reflect on parents’ own perception of the question and its importance. • Discuss the results with their respective DULCE team.
CYCLE 2	<ul style="list-style-type: none"> • Ask a larger group of parents “What matters most to you?” or another version of the question. Record verbatim the different question asked. • Record parents’ responses verbatim.
CYCLE 3	<ul style="list-style-type: none"> • Discuss the goal setting PDSA cycles and findings with the Interdisciplinary Team during case review. • Record concerns and recommendations shared by the Interdisciplinary Team verbatim.



KEY FINDINGS

Several important findings grew out of the pilot communities' PDSA cycles and Family Specialists' subsequent discussions with their respective Interdisciplinary Teams, as well as with the CSSP DULCE team. The quotes that support each finding are statements made by Family Specialists from the pilot communities during individual interviews with them. Family Specialists responded to questions designed to understand the meaning parents and Family Specialists attribute to the DULCE collaborative goal setting process.

Findings about Parents' Experiences

1. Overall, parents responded positively to the goal setting process as an important addition to DULCE practice.

"They know that they have goals in life and their goals are being heard. And not only are they being heard, but we're providing resources for them to meet those goals."

•

"I would say they feel empowered. . . . (They affirm) 'I can learn to speak English. I can get immigration assistance. I can get daycare for my child.' So, it's almost like a weight being lifted off their shoulders because this is one less thing they have to worry about now."

2. Parents responded positively and seemed to benefit from being asked "What matters most to you?", or some version of the question, because the question made them feel that someone cared about them since, after the birth of their child, so much focus had been on their infant or the family as a whole. Thus, for some parents, asking "What matters most to you?" made them feel that they actually mattered.

"I feel like it opens a new conversation and it's more focused on the parent. . . . They felt heard, they felt cared for. One mom said, 'I'm answering on behalf of myself. Finally, someone is not asking about this kid; someone is not asking about my husband.'"

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"They didn't think that (what mattered for them) was something we could help with because when you think of DULCE, you think of baby needs. One mom said she eventually wanted to learn English. And I said, 'Oh you know, we give vouchers for English classes, so we can actually pay for that for you'. . . . So, in my mind, if I would have never asked this question, she would have probably gone by years without even knowing the county offers English classes."

3. Describing goal setting as a shared decision-making process and assuring parents that it is okay to question, challenge, disagree with, or not abide by the Interdisciplinary Team's recommendations affirmed parents as the primary decision-maker and strengthened their sense of agency. Even though parents may not follow the Interdisciplinary Team's recommendation, they are more informed about their options, benefits, risks, and consequences of their choices.

"Education is key. . . . I feel all we can do at that point is educate them and then provide them with the resources so when they are ready, they have everything at hand. I feel like I shouldn't be the one to tell someone what should be a priority for them or not."

•

"A dad wanted to not have rights to a baby at all and the mom was on board about it. So, I mentioned it in case review and our legal partner said, 'There are so many disadvantages of that happening. Share my contact information with her so we'll have a conversation about it'; and they did. But the mom still doesn't agree with the legal partner's advice and she's still on the fence about what she's going to do."

Findings about Family Specialists' Experiences

1. Overall, the Family Specialists responded positively to the goal setting process as an important addition to DULCE practice. When asked about the importance of asking families about their goals and if they intended to maintain this practice, Family Specialists stated:

"We've made it a part of our intake questions."

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"I am sharing resources that maybe I wouldn't have."

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"When we ask them about their goals, we also include dad. We take care of the household. So, it's always nice to kind of extend that to dad and kind of include him and make him feel seen and heard like the same way mom is seen and heard."

•

"The screener is just over basic concerns and problems we need to know about. But the goal setting question is more about their needs and their future, and what they want versus the screeners where it's just questions being answered as a part of our assessment. The goal setting question is for their benefit."

•

"I feel like I'm learning more about family needs. . . . I feel like they're asking for more and they're not being so timid about it. Based off this question, I feel like it's opening more ideas and more questions and more, 'What can you offer me?'"

2. When asked if integrating goal setting into DULCE practice increases their workload, a Family Specialist stated:

“I don’t feel that it is because I used it as a conversation, I didn’t use it as an assessment or as a tool or as something extra. To me it’s just having another conversation with the family. I feel like when you make it feel like it’s an assessment question, they think about it more (in a negative way) than when it’s a conversation. . . So, I make it be a conversation to where I’ll throw in things that I already know versus things that I want to know to make it feel more personal.”

3. The Family Specialists saw value in asking “What matters most to you?” for several reasons. That is, eliciting “what matters most”:
 - a. Occasionally revealed goals, priorities, concerns, or needs that would not be revealed through the standard DULCE screenings for health-related social needs.

“(The question) is like a mirror. . . . It’s an opportunity that no one has ever given them to speak about themselves, and that’s big.”

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“This question has led us to learn about mom a little bit more. We’re using this question to get to know mom’s past. For instance, we’re asking about their (current) partner relationship, but no one has been brave enough to say, ‘What about before?’ It would be nice to help her work on those pasts that affect today.”

- b. Tended to lead to conversations that may not otherwise occur.

“I had no idea that one mom had applied for (the state’s welfare program). . . . There was another mom who was really struggling with postpartum depression and her goal was ‘I just really need some time to myself.’ And so, I helped her brainstorm who could be with the baby while she did that.”

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“One of the things that is changing so much is the time that we’re giving to this question. All the questions on the (screening) checklist are sometimes (closed) ended. . . . But this is a full conversation that leads to something else. Because we’re asking that question, we’re getting to know them more because they’re talking more and now we’re doing the motivational interviewing and we’re listening more.”

- c. Enabled Family Specialists and other members of the Interdisciplinary Team to learn about parents' goals, priorities, and needs sooner than they may have if they had only conducted screenings. Consequently, identifying and discussing parents' goals, priorities, and needs earlier led to more immediate recommendations for and implementation of action steps—if the recommendations were accepted by the family—and, therefore, progress toward goal attainment.

“We have to deal with information quickly. One day, one of our moms was awfully quiet. Today she just texted me ‘Help.’ So, I called (a member of the Interdisciplinary Team) to help her process (what she was experiencing).”

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“From the first day we asked that question we’ve generated seven referrals from the first three families.”

- d. Has led to considerations about the Family Specialists' own professional needs.

“(My colleague) and I are now thinking we’re going to need more reflective supervision because we can’t possibly think that we don’t ‘collect’ these things. . . . Asking how we’re affected became a part of our supervision.”

- 4. Although some parents seemed to resonate with the question “What matters most to you?”, Family Specialists thought it was valuable to have several different questions in their toolbox to elicit what matters most to a parent. Variations include:

“What do you see yourself doing before the baby starts walking?”

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“What are your hopes for your baby? For yourself? For your family?”

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“What are the most important things for your family right now? What are the most important things for your family in the future?”

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“We all have a crystal ball, and we get to pick one wish today. Make one wish today. What would that one wish be?”

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“Around this time/at this visit I like to ask families what matters most to your family right now. . . .I think that younger moms are more hesitant to say anything. It’s almost like they’re caught off guard or they’re not sure if they’re going to say the right thing, or the wrong thing. And then that’s when I’ll be like, ‘Absolutely anything! There’s no right or wrong answer. I’m just trying to get to know you better.’”

5. Family Specialists noted that the collaborative goal setting process seemed to reinforce the importance of and support and strengthen the parent-practitioner relationship.

“It had an impact on my relationship with them. It made me think about what else I can do or maybe that I’m not doing. It made me wonder what else can I do to help bridge the gap between either their homes and maybe resources in the community or just the way I deal with them.”

6. Family Specialists noted that parents tended to identify immediate goals and/or future goals that pertained to the infant, themselves, or the well-being of the family as a whole.

“Parents identified needs and goals like baby supplies, daycare, transportation, housing, rent, learning how to drive, getting a job, learning English, and immigration issues.”

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“Some parents focused on getting themselves together. And then you have others who said, ‘My children are what’s most important to me right now.’ Once again, the majority of responses led back to family concerns.”

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“Parents say things like, ‘I wish this program would go longer. I wish I could get some help with my MLP paperwork. And I wish transportation would be consistent for me and my family.’”

7. The goal setting process had a positive effect on the case review process with the Interdisciplinary Team. The case review process is enhanced in that:

“We’re bringing more information, and we’re kind of all discussing the information together.”

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“The approach that we were using before—we’d regroup again based on everyone’s expertise to figure out what we need to do for mom right now. Now with this new approach, we’re already coming into the Team with an idea; so that’s the big difference. We’re not regrouping again. I’m telling you what mom is saying to me right now and this is what we’re going to do. So, we’re already coming in knowing what mom prefers, knowing what MLP is about to do for her. So, we’re doing the legwork and then coming together and bringing it to the group; we’re laying it out. No one from MLP is saying ‘I’ll touch base with her on Tuesday;’ MLP already touched base with her. . . . So, with this approach we’re coming in with actions already.”



DRAFT DULCE COLLABORATIVE GOAL SETTING TOOLS AND MATERIALS

Draft goal setting tools were developed for use in training and technical assistance with DULCE communities which were informed by Family Specialists’ discussions with the CSSP DULCE team and feedback from the DULCE National Team. Table 2 provides a list and brief description of the draft tools.

Table 2. List of Draft Tools for Collaborative Goal Setting Practice

TITLE	PURPOSE
DULCE “What Matters Most” Inventory	<ul style="list-style-type: none"> To provide examples of what may matter about the infant, parent(s), and/or family
Conversation Prompts	<ul style="list-style-type: none"> To encourage an exploration of family strengths, priorities, and goals
Key Activities in Goal Setting with DULCE Families	<ul style="list-style-type: none"> To illustrate the activities involved in collaborative goal setting with DULCE families
Pathway to Identifying Goals of Care in the DULCE Approach	<ul style="list-style-type: none"> To provide a summary of the activities involved in goal setting with DULCE families
DULCE Goal Setting Progress Scale	<ul style="list-style-type: none"> To have parents rate their progress toward goal attainment
Examples of Goals of Care, Objectives, and Action Steps for DULCE Families	<ul style="list-style-type: none"> To provide an organized illustration of the relationship between goals, objectives, and action steps
Workflow: Integrating Goal Setting into DULCE Practice	<ul style="list-style-type: none"> To provide organized information to be used in training sessions with DULCE communities
Case Review Template (Enhanced)	<ul style="list-style-type: none"> To highlight a family’s most relevant points to discuss, inclusive of goals and priorities
PowerPoint Slide Decks about Collaborative Goal Setting	<ul style="list-style-type: none"> To provide organized information to be used in training sessions with DULCE communities

CONCLUSION

“The constructive goal of research and evaluation is not simply to prove whether a program worked by some distal outcomes. . . but rather to add to the knowledge of how programs and systems need to be implemented to maximize the impact of well-known active ingredients and identify the program-specific pathways that allow the active ingredients to transform both individual and settings in an enduring way.”¹⁵

Junlei Li, PhD—Harvard University Graduate School of Education &

Megan Julian, PhD—University of Michigan Medical School, Department of Psychiatry

The 12-month planning and implementation project focused on developing and pilot testing a goal setting process for DULCE families was successful in that it yielded a well-informed collaborative goal setting pathway which includes seven key activities, draft training and technical assistance tools, positive findings from pilot testing the process, and important qualitative data from interviews with Family Specialists. In the coming year, all DULCE communities will receive training on collaborative goal setting based on what has been learned thus far. More testing and evaluation is needed to ensure that this enhanced component of the DULCE approach is robust and adds to the knowledge of how the DULCE approach should be implemented to maximize its impact. For example, additional study is necessary: (a) to further understand how integrating collaborative goal setting into DULCE practice strengthens its interdisciplinary approach to addressing families’ goals, priorities, and needs during the first six months of their infant’s life; (b) to further illuminate the value of integrating collaborative goal setting into DULCE practice with respect to families and the interdisciplinary providers who work with DULCE families; and (c) to refine newly developed tools, update existing tools, and identify and create any needed additional tools. Through the collective work of the CSSP DULCE team, the DULCE National Team, and Family Specialists and other staff in the pilot communities, the DULCE approach is better positioned to identify what matters most to families and to help families achieve their goals during their engagement with DULCE.



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