Mothers Raising Daughters with Cognitive Delay: 
Reflections on Menarche & Menstruation

Britta Saltonstall
University of Washington

KEY WORDS: DISABILITY, MENSTRUATION, CAREGIVER EXPERIENCES, TRANSITION EVENTS

This small qualitative study was undertaken to explore the experiences of mothers and daughters in the unique contexts of moderate to severe cognitive delays and the transition to menstruation. Cognitive delay is also referred to internationally as mental retardation, cognitive disability, learning disability, or mental disability. This investigation was an initial step on a research path towards enhancing awareness and support for issues faced by early adolescent girls with disability, their caregivers, and their service providers in the United States. Purposeful sampling strategies were used to recruit four participants raising daughters with moderate to severe cognitive delays. The data collection method was semi-structured individual interviews. A co-authored approach to data analysis was used to code and create categories for description and interpretation. Themes emerged around the mothering challenges of preparation for menarche, teaching menstrual care, and negotiating fertility concerns. Implications for resource and support provision for caregivers facing a socially stigmatized female transition event in a unique disability context were identified.

In representing the experiences of parents who are raising a child with disability, current literature in the fields of disability studies often follows a theoretical model based on resilience, family life-cycle, and family systems theories. This model emphasizes the concept of adaptability in both individuals and families facing situations that may involve adversity or stress. Resilience theory includes a strengths-based focus on the impact of developmental transitions on individuals and family units (Hawley & DeHaan, 1996). Family systems theory highlights the reciprocal impact that developmental transitions have on the relationships within a family (Bubolz & Whiren, 1984; Foster, Berger & McLean, 1981). Researchers in the fields of child development, family studies, and disability studies have pinpointed certain events and stages in a child’s life as key developmental transitions (Foster et al., 1981; Hanline, 1991; Turnbull, Summers & Brotherson, 1986) which can be viewed in the context of their impact on other members of a family system. These developmental transitions include critical time periods and events such as birth of a child, entry into school, birthdays, and puberty.

Recognition of transition periods and events in the family life cycle is particularly important for systems serving families impacted by disability. Grief and reflection around a child’s disability status may be evoked during developmental transitions which are often celebratory for

1 Address all correspondence to: Britta Saltonstall, Box 357925, University of Washington, Seattle, WA, U.S.A. (e-mail: saltob@u.washington.edu)
parents of a child without disability (Beavers et al., 1986; Hanline, 1991; Schell, 1981; Turnbull, Summers & Brotherson, 1986). Evidence exists that parents caring for a child with special needs may experience heightened stress during transition periods. Research has also demonstrated that with perceived supports and resources, such families can respond with resilience and adaptive functioning to their child’s developmental transitions (Dyson, 1991; Fine & Simpson, 2000). Menarche is a significant and impacting event in every female’s development (Havens & Swenson, 1986; Beausang & Razor, 2000), and can be explored in the context of both individual and family resilience. Following resilience theories, families impacted by disability are strong, adaptable, and have valuable experiences to share regarding their coping with transition events.

As primary caregivers, mothers are key members of family systems. In Western culture, despite a variety of family constellations, mothers are often integrally involved in the developmental transitions of their family as a whole. The developmental event of a daughter’s menarche (first menstrual period) is an early adolescent transition that is most commonly addressed by mothers in families where mothers are present (Carlson & Wilson, 1994; Costos, Ackerman & Paradis, 2002; Kalman, 2003). While research has examined the impact of certain developmental transitions on parents and family systems (such as the birth of a child with a disability: Schell, 1981; Trute & Hauch, 1988), the distinctly female transition to menstruation has received much less recognition. While a variety of investigations across social and physical sciences have considered the experiences of adolescent girls, their families, and menarche/menstruation, these have primarily reflected the experiences of people not impacted by cognitive disability (Beausang & Razor, 2000; Costos et al., 2002; Cumming, Cumming & Kieren, 1991; Havens & Swenson, 1986; Kalman, 2003; Koff & Rierdan, 1995; Swenson & Havens, 1987). Much less is known about the perspectives and experiences of primary caregivers during a daughter’s development through early menstruation in the context of disability (Carlson & Wilson, 1994).

Influenced by feminist standpoint theories, this investigation is located in women’s unique standpoints or experiences. I embrace the caring work of mothers as a valid and valuable topic of inquiry, and am influenced by developments in feminist methodology (Harding, 1987, 2004; Naples, 2003). The feminist research tradition, much like larger, male formulated research traditions, has been criticized for leaving out the multiple voices and statuses of women with developmental disabilities (Olesen, 1994). Recent work detailing the content and context of feminist disability studies reveals a purpose to “unsettle tired stereotypes of people with disabilities” and “aspire to retrieve dismissed voices and misrepresented experiences” (p.1557, Garland-Thomas, 2005). Investigating the experiences and voices of women impacted by disability in shared female contexts such as mothering or female
sexuality is an important mission for twenty-first century women’s advocates. An exploration of the dissonance between feminist perspectives and disability advocacy perspectives on ‘caring’ is one example of developing a common cause for women with and without disabilities (Hughes et al., 2005). This approach to inquiry challenges a historical tendency to focus on the experiences of women with disability that identify them as different from mainstream women (Olesen, 1994).

This study was undertaken to explore and document mothering experiences with a daughter’s transition to menstruation in context of moderate to severe cognitive delay without physical limitations. Moderate to severe cognitive delay can be a main characteristic of a variety of developmental disabilities, including autism spectrum disorders and chromosomal syndromes. Moderate to severe cognitive delay is often linked with social and communication delays; all three deficit areas can pose significant challenges in the development of socio-sexual knowledge and self-care. These levels of cognitive delay exist in low incidence both in terms of the general population and the population of children with special needs.

The developmental transitions of puberty and menarche are viewed and valued differently across cultures and family systems (Beausang & Razor, 2000). Cultural context should be considered in examining transition events, family resilience, and socially private topics (Carlson & Wilson, 1994; Costos et al., 2002; Hawley & DeHaan, 1996). A discussion of menarche in mainstream U.S. culture involves topics of medical health, self-care, socio-emotional development, and sexuality. In discussing menstruation, fertility emerges as a related topic (Carlson & Wilson, 1996). Menarche and menstruation have often been seen as topics cloaked in secrecy and taboo in Western culture (Beausang & Razor, 2000; Costos et al., 2002).

In a unique line of research on mother and caregiver decision making processes around menstruation, Australian researchers Carlson and Wilson (1994) explored these topics in the context of learning disability and high daily support needs. Unlike fertility management, topics of menstrual care and decision making had not been previously investigated in detail for this population (Carlson & Wilson, 1994, 1996; Griffin et al., 1994). In a 2002 literature review, Stinson, Christian, & Dotson point out a historic lack of attention to women’s sexuality issues in the context of disability, and highlight the potential impact this may have on negative views and self-views of females with developmental disabilities. Disability advocates are currently engaged in discussions of the ethics of ‘others’ making decisions regarding people’s access to knowledge about their body, access to sex education and self-care information, and access to social and sexual relationships (Carlson & Wilson, 1994; Lumley & Scotti, 2001). The following study was designed to gain in-depth information on the experiences of certain ‘others’ in their roles as mothers. The following research questions were of focus in the
design, analysis, and discussion of the findings in this inquiry.

1. What thoughts, feelings and actions about menarche do mothers of daughters with cognitive disability share in an interview context?
2. If and how do mothers perceive their experiences with a daughter’s menarche and menstruation to be impacted by her disability status?
3. What systems of support did the mothers have access to during the transition to menarche, and what type of supports are preferred?

METHOD

The purpose, design, and methods of this inquiry reflect a case study application (Merriam, 1998). Case study application was selected to facilitate recognition of the unique experience of an individual unit of analysis while allowing for cross-case analysis. An interpretive approach to constructing knowledge (Coffey & Atkinson, 1996) was followed across the purpose, design, analysis, and discussion of the results of this project. Grounded theory matches the exploratory nature of this study and influenced data analysis as an inductive process in which theory develops out of the data (Glaser & Strauss, 1967). The purpose of my research lay in exploring a key caregiver’s experiences with menstruation and disability for future application to improving support services for this developmental transition. The units of analysis were the specific individuals and their perceptions of experiences in context of their mother/daughter care-giving relationship. The main data source came from semi-structured individual interviews (Patton, 1980).

Participants & Settings

The primary participants in this study were four mothers, each raising an adolescent daughter with moderate to severe cognitive delays. Purposive sampling was the chosen sampling procedure due to its prior use and purpose in discovering in-depth information about certain individuals. The four participants were all connected with a variety of special services and disability related supports. These mothers were between 40 to 50 years of age, married, and raising more than one child. Participants lived in a major metropolitan area in the Northwestern United States. These mothers’ primary job involved child-raising and caring for their daughter’s special needs in the family home.

The daughters were currently between 14 and 15 years of age. All had experienced menarche and subsequent menstrual cycles within the last five years.

The one-on-one interviews were conducted in the mothers’ homes following their preference. A portion of one interview took place in a public coffee shop at the mother’s request.
Procedures

In-depth interviews with each participant lasted between 2-3 hours. Interview sessions occurred in April of 2004. The sessions followed a semi-structured, guided interview protocol (Patton, 1980). A semi-structured interview format is particularly suitable for exploring culturally sensitive and relatively unexplored topics such as puberty and menstruation (Carlson & Wilson, 1994, 1996; Costos et al., 2002). The interview procedure included a regular reminder to the interviewees of their right to pass on answering a question or to end the interview at any time. This procedure was chosen given that the topics of discussion are considered by many in Western culture to be personal and private (Costos et al., 2002).

Each interview session was audio taped (Patton, 1980) and transcribed verbatim. Researcher notes were taken during (a) introductory phone calls, (b) interviews and (c) immediately after each interview session for use in corroborating and cross-checking researcher observational and reflective data with interview text (Carlson & Wilson, 1996).

Data Analysis

Analysis included repeatedly listening to and reading the entire data corpus on tape and in text (Glesne, 1999). Following my quest to explore the meaning of target experiences in these mothers’ lives, I chose to approach data collection and analysis as a co-authored process. A “co-authorship” approach (Kvale 1996) is applicable to the study’s exploratory analysis process in which I stayed close to the participants’ own categories and themes after asking my own previously formed conceptual questions of the data (Coffey & Atkinson, 1996).

Co-authorship began during data collection. The semi-structured interview format allowed participants to introduce issues and themes that were important to their experience but not specifically addressed by the pre-written protocol. As formal analysis of the corpus of interview text began, coding by thought unit (Merriam, 1998) was completed. Codes stemmed from the following sources: a) the original research purpose and supporting literature, b) the disability context of the study’s conceptual framework, and c) the mothers’ shared ideas during the interview. The plausibility of the selected codes in relation to the data was confirmed by three colleagues who were not involved in the study procedures through independent coding of portions of the interview texts.

Grouping the codes into category construction was largely directed by participant themes (Coffey & Atkinson, 1996). This interpretive approach was influenced by Stringer (2004), and involved recognizing pre-existing themes and ‘illuminative moments’ in the language of the respondents and their described experiences. The coding to category constructing process included both within and cross-case analysis (Merriam, 1998). Following methods suggested by Merriam
(1998), a simple visual display was used to check whether the constructed categories made sense together and reflected the original purpose of this research study. In a final step of co-authorship analysis, participants were invited to review the final selected categories and give input on the validity of these themes in reflecting and interpreting their experiences.

**FINDINGS**

The experiences of mothers raising daughters with disabilities are vast and varied. The current study provides only a porthole of insight into the experiences of some mothers raising daughters with cognitive delays in context of early menstruation. Data analysis revealed that being a mother in this special context seemed synonymous with being a teacher of a topic for which there was no guidebook. Being a mother was accompanied by a strong sense of aloneness and responsibility. Being a mother in this context also afforded opportunities for pride and love. Two main themes emerged from the mothers’ overarching stories about their daughter’s menarche in relation to family systems, resilience, and lifecycle theory. These categories were *Preparation* and *Fertility*. The first category outlines the stories of these mothers’ experiences with the event of menarche; the second category reflects related mothering challenges that were highlighted by this particular developmental transition.

*Preparation*

Preparation can be conceptualized as consisting of anticipation, communication, and action-related planning for an event. Exploring the roles of anticipation and communication in preparation is supported by current dialogue around opportunities for individuals with disabilities to access pertinent information about their sexual development and their bodies (Bambara & Brantlinger, 2002; Thompson, 2002). Research from typically developing populations also supports a focus on communication and anticipation as components of preparation. Results from this literature reveal that women and girls who report some of the most negative experiences with menarche and menstruation were those who describe having received insufficient or negative preparation for the transition (Beausang & Razor, 2000; Swenson & Havens, 1987).

*Anticipation of menarche:* Two of the four mothers related having thought about their daughter’s menarche prior to occurrence. The first of these two mothers referred to menstrual knowledge, past experience, and observation of physical development as reasons for anticipation. Inger had unique experiences in her past that related to atypicality and menstruation. She described her daughter receiving specialized medical services to address signs of precocious puberty. Despite much discussion on medically delaying early menarche, Inger had not received any information from the doctor about how to prepare for or support
menstruation for her daughter when it did occur. When asked if she thought she would have anticipated menarche if her daughter had not been receiving services for precocious puberty, Inger replied “I think so. I’d worked in the group home [for women with disability] when I was in school, and that [menstruation] was a real issue.” Her interaction with a physician around early puberty and her past work experience with women with disabilities influenced her anticipation. Both of these experiences can be considered out of the norm for most mothers raising girls with disability.

The second mother emphasized that she had thought a lot about her daughter’s menarche, and this anticipation led her through a series of steps in preparation for the event. “Oh, definitely I thought about her having a period. Absolutely…. I knew that Hailey’s body was entering puberty, by seeing the changes, and knew that that meant her period would be coming soon” (Petrina). The two additional mothers contrasted dramatically with Inger and Petrina in their described lack of anticipation for menarche. Both of these mothers appeared surprised by their daughter’s first period, primarily due to a perception that their daughter was young for menarche.

Well, since she was only 10, I had not thought about it. I really hadn’t even brought my mind to it…You know, when you have a child with disabilities, it’s like the physical parts you figure you just deal with when they happen. (Anna K.)

From a family systems perspective, preparation is impacted by communication between parties involved in the reciprocal impact of a transition event. The four mothers each identified themselves as being the person responsible for all aspects of their daughter’s menstrual support. Sole responsibility was accepted and embraced by the mothers, but also led them on different paths in terms of communicating about and preparing for their daughter’s menarche. Petrina’s anticipation of her daughter’s menarche paved the way for a number of preparatory actions. Petrina stated that she had always known that she would communicate with future daughters about menarche in ways that she herself did not feel prepared as a child. The fact that her daughter had cognitive delays did not change this determination for preparation. Petrina did describe some of her preparatory actions as “not working” for her daughter due to her delays.

I took Hailey—I took her to Center’s Hospital. They offer a class for girls. She might have been 12. It was in an auditorium setting, and you go with your parent…It was a two-part thing, and we didn’t go to the second part, because the first one she couldn’t sit still and attend, and it didn’t work out for her. And that’s how it goes. (Petrina)
Inger’s anticipation of her daughter’s menarche led her to prepare materials and initiate discussion of the impending event with both her husband and the array of service providers involved in her daughter’s development. Neither Anna K. nor Kristin described taking preparatory action for menstruation. When directly asked if they had spoken to anyone (including family members) about menarche prior to its occurrence, both mothers replied that they had not. At the time of menarche, Anna K. had menstrual supplies in the house as she had an older daughter who used them. Kristin related not having supplies available when menarche occurred.

Communication about menarche: Data revealed that only one of the mothers recalled communicating with her daughter about menstruation or related topics prior to menarche. Petrina emphasized and described her attempts to communicate with her daughter about what her period would look and feel like. Inger described wondering if and how to communicate with her daughter about menarche. Anna K. and Kristin described not taking any actions around communicating with their daughters. Interestingly, the same rationale (relating to the daughter’s cognitive delays) was used by Inger for thinking about communicating with her daughter and by Kristin for not thinking about communicating with her daughter about menarche.

*I wondered how I was going to do that, because you really wonder how much of that information she can absorb.* (Inger)

*No, because I don’t think she would understand. So I’m sure I didn’t think about doing that.* (Kristin)

Both the mothers’ general perceptions of daughters’ comprehension abilities and the daughters’ reactions to the actual event of menarche were used to explain the limited communication about menstruation. The mothers varied in how much they attempted to explain menstruation to their daughters. The mothers gave rationale for their communication approach in the following ways after menarche had come and gone.

*Um, I probably did. Not really having to do with the period, but like, ‘Oh, Kelley, I’m really sorry you’re scared’ Dealing with her emotions more than dealing with the facts of the period. I probably didn’t talk a lot about facts, because I knew those were all gonna be foreign words to her.* (Anna K.)

*Well, as far as talking to her, when she started, I would say, ‘Well, you started your period. We gotta use a pad now.’ But that’s as far as I went. If I tell her the birds and the bees, she wouldn’t know what’s what, so I don’t talk to her about that.* (Kristin)
I wanted to present it as a positive experience: ‘This is great.’ ‘You got your period.’ …I knew that it would be challenging and messy, and that I just needed to talk to her about it as much as I could. (Petrina)

Menarche in action. Reflecting on the event of menarche evoked a variety of thoughts and feelings in these mothers. Early menstrual cycles were primarily described as times of aloneness and uncertainty around how to best support their daughter. The two mothers that cited having anticipated and actively prepared for their daughters’ menarche also related fewer memories of isolation than those who did not. All the mothers also recalled feeling that they had not been adequately prepared for their own menarche as maturing girls.

Key thoughts expressed by these mothers in their interview responses focused on a) menstrual self-care, b) a daughter’s abilities, and c) the significance of menarche and early menstrual cycles in their daily caregiving relationship. Dominant feelings associated with the daughter’s transition to menstruation included responsibility, uncertainty, and worry. Feelings less often cited but of importance to note in the context of family life cycle and resilience theories were pride, commitment, and acceptance. These dominant thoughts and feelings were well reflected in the mothers’ descriptions of their daughter’s very first menstrual experience.

I remember she was upstairs...And it was the weirdest thing because she was so scared... She climbed in my bed. It was like, 3 o’clock in the afternoon. She’s never gone into my bed. Kind of a scared cry...She was real clingy... It was really bizarre. I really just couldn’t figure out what I could say to her. So I just kind of let her be as clingy as she wanted to be....There are few emotions with Kelley. I mean, she fell about a month ago and fractured two of her little toes and didn’t cry. Like no emotion at all shown. So for her to be so obviously scared was really bizarre. (Anna K.)

Your reaction at the time? (Saltonstall)
‘Poor Kelley.’ ‘How in the world is this going to get successful?’ ‘How can I make her not scared?’...‘How can I help her get calm?’... I don’t know how to put it into words. I would just say I was nervous of what my responsibility was. It is completely, completely your responsibility. ‘How am I going to teach her’... ‘What do I have to learn?’ ... So the responsibility is huge. I just was overwhelmed. (Anna K.)

While Anna K’s recollection of the menarche was dominated by descriptions of her daughter’s extreme behavioral and emotional reaction, Inger’s memories reflected a practical approach to the event.
This different approach may be related to Inger’s preparation for menarche as well as her daughter’s differing behavior and reaction during the event itself.

Well, it actually happened while Kevin [brother] and I were at baseball practice. You know, nothing goes according to plan. (Inger)

What was your reaction upon hearing of Cindy’s first period? (Saltonstall)

Well, part of it was, “Oh, crud, I’m not home.” But, you know, everything seemed to be pretty much under control. (Inger)

Unlike Anna K. and Inger, Kristin did not describe details of her daughter’s menarche beyond the fact that it had occurred when she was out of town and her children were under the care of a female relative. She and the relative talked on the telephone about what to do, and about the fact that her daughter “did not even seem to notice the period at first”. When asked about her own emotional reaction to the event, Kristin simply replied “Um, worried.”

Love and support were underlying emotions demonstrated by all of these mothers in discussing their daughter’s development. Success in teaching their daughters aspects of menstrual self-care was a topic in which certain mothers showed feelings of pride. Since menarche, Inger, Petrina, and Anna K. had been teaching their daughters to participate in using menstrual supplies. Despite lengthy and variable acquisition processes with these skills, the mothers expressed their daughters’ progress in terms of accomplishment. “She’s doing really well...She’s not independent, but maybe semi-independent. So she’s doing a great job.” (Inger). In contrast to the other three mothers, Kristin has always done full care for her daughter with the use of menstrual supplies. Over the course of the interview, Kristin did spontaneously express the following new thoughts around menstrual care.

I’m not sure she’s ever going be able to do that… Then again, maybe she will. I don’t know. I guess I have to teach her. Which I haven’t done yet. She is a bright girl. She might, she would probably get it. (Kristin)

In addition to pride around her daughter’s self-care accomplishments, Petrina was unique in her direct expression of additional excitement that her daughter had reached “womanhood”. “I feel proud of her. It’s exciting. It’s exciting for me. It was a relief, you know, because I didn’t know what would happen. Um, and then, then it’s worrisome.” Petrina was the only mother who recalled having talked to others in personal relationship systems about her daughter’s menarche. These confidantes included her husband, female friends, and female
family members. After much deliberation with these significant others as to how to honor her daughter’s transition to womanhood, Petrina decided on a private mother-daughter celebration. “I took her out to dinner and gave her this necklace. And, you know, for me it was something really special, and she was kind of like, “Yeah”. She was more interested in the French fries, you know.” (Petrina). Despite her daughter having low engagement in the celebratory event, Petrina recalled the activity with fondness and appeared to associate it with positive adjustment to the transition.

Fertility

Fertility was a challenge brought about by menarche that involved a conflicting constellation of thoughts, feelings, and actions in these mothers’ caregiving role. Despite clear differences across the mothers in frequency, detail, and emotional tone when discussing fertility, the topic was introduced and explored during each interview. This exploration was due to the reality that any support the mothers had received about the transition to menstruation was primarily related to medical interventions for menstrual regulation or suppression. Actions and decision making around fertility varied across the mothers’ stories. Inger sought medical advice at the time of menarche, and since then her daughter has received monthly hormone shots to lighten her periods and protect her from pregnancy. Petrina and her husband had recently made the decision for her daughter to take birth control pills on a continuous active cycle for the primary purpose of lightening and regulating the timing of periods. Anna K. simply responded “No” when directly questioned whether she or anyone else had considered medical intervention for her daughter. “It’s personal. I couldn’t, um, I couldn’t imagine giving her something, or giving her a shot.”

Kristin’s response to interview questions about fertility focused on a view of innocence in relation to her daughter’s cognitive and social functioning. This view of innocence about sexuality had dissonance with concern raised by her daughter’s recent fertility status.

I’ve thought about it [fertility management], but I haven’t taken any steps...It’s kind of like, how can she have bad dreams when nothing bad ever happens to her and she’s so happy- and I think she only thinks of happy things?...But we know bad things can go on, and we see it...So it’s kind of the saying about what she doesn’t know hopefully won’t hurt her. (Kristin)

Fertility status was directly paired with safety concerns in these mothers’ stories. When the mothers talked about fertility, they consistently used terms representing sexual assault such as “take advantage of” (Inger), and “bad things” (Kristin). Anna K. did not initiate
any mention of fertility during the interview, and generally gave one word answers to direct questions about her daughter having reached fertility status. Upon delicate probing, Anna K. did expand on her answers and related this story of deep worry around her daughter’s sexual vulnerability.

_The year I got my period, actually, I was in 6th grade. And there was a girl that was retarded in my sister’s school... And when we moved the next year, we’d heard that somebody had gotten her pregnant. So, you know, it’s been years, but that memory was right there—it always is—to know that there are people that will do that, and take all of the things that you’re used to as a mom, and Kelley’s used to as a kid, totally take it away in one action._ (Anna K.)

The findings in the two categories of preparation and fertility reflect similarities to the small body of existing published literature on menstruation in developing girls. These similarities include a) a potential relationship between lack of preparation for menarche and negative experiences with menstruation, b) the indication that through systematic intervention girls with cognitive disability can learn some level of independence in menstrual self-care, c) mothers may face unanticipated challenges during this developmental transition, and d) mothers identify a lack of resources and outside supports for buffering stresses related to the transition. The findings involving conflicts around sexual maturation and fertility reflect themes across prior literature in Western culture concerning a general lack of recognition and positive support for female sexual development, particularly in context of disability (Carlson & Wilson, 1994; Hingsburger & Tough, 2002; Stinson, Christian & Dotson, 2002).

The mothers were directly asked if they had sought out or been offered any educational resources, social supports, or special services prior to, during, or after menarche. Their responses indicated that they had not been able to access resources that they felt were appropriate to their unique mothering context. Two of the mothers individually used the same powerful metaphor to describe their experiences. “I was looking for any information. And I just got none. Which is amazing. Okay, this is like I’m reinventing the wheel. Nobody knows anything.” (Anna K.)

_It would have been great to have something, because I think a lot of us feel like we’re reinventing the wheel, but we just have to wing it...There’s just not a lot out there...Most of what’s around is geared either for kids with typical development, or maybe kids with mild to moderate disabilities._ (Inger)
If a mother indicated that she had desired more supports and resources about disability and early menstruation, she was then asked where and from whom she would most like to have accessed support. “A school nurse I think would be kind of a logical first person”. (Inger) “I think the teachers and the doctors. I don’t think my doctors had anything…I think definitely at the school because they’re dealing with it too. They need to learn too.” (Kristin)

School. School. Or pediatricians... I think the school district should make it a point of it being an important thing...Because, um, you can’t get much more important. (Anna K.)
This could be done through a parent support group...it would have been really useful for me... Otherwise, it could be through the schools, I would think, because you have a natural network there of parents - middle schoolers, high schoolers, and special education. That should be something they should take on. (Petrina)

The results of this study suggest that schools and medical offices may be strongly preferred settings for accessing social and educational support about menstruation. These service systems could offer resources about a) anticipation and preparation for menarche, b) strategies for supporting self-care during menstruation, c) opportunities for parents of maturing students with disability to connect with one another, and d) issues related to fertility and safety.

**DISCUSSION**

Did you feel excited when your daughter got her first menstrual period? (Saltonstall)
No, not really, because I was more like ‘Okay, here we go’...Well, I was happy that she was growing up. I think when your child is different, and experiences a lot of these milestones—you know, be it graduation, kindergarten, whatever—it’s a very bittersweet thing. It’s sort of a sense of grieving, you know, about what it could have been like if things were different. (Inger)

The findings in this study reflect previous literature on the potential impact of transition periods in the life-cycle of families affected by disability (Beavers et al., 1986; Foster et al., 1981; Hanline, 1991; Schell, 1981; Trute & Hauch, 1988; Turnbull, Summers & brotherson, 1986). These transition periods are marked by key events which may present reciprocal stressors in family relationships. Despite being a predictable female transition with identified social and psychological implications, menarche has not previously been studied in context of mothering and
cognitive disability in the United States. The results of the current investigation indicate that menarche is an event perceived by a key family member to mark transition to new responsibilities and potential stressors. As expressed by Inger in the previous quotation, the transition to menstruation may evoke grief and reflection over a child’s disability status. A perceived lack of systematic supports for this transition may leave mothers in special contexts questioning why they must “reinvent the wheel” of how to support their daughters.

The mothers in this study primarily associated their experience of a daughter’s menarche with challenge and worry. These challenges were related to the desire for specialized resources and supports which were not perceived to be available at the time of the event. These desired supports were cited as primarily social (connecting with other mothers in similar contexts to share experiences), and educational (accessing specialized instructional strategies for teaching menstrual self-care and management). The worry associated with menarche and early menstruation had roots in the challenges of introducing menstrual supply use and monitoring of their daughter’s sexual safety. The transition raised new challenges for old concerns about their daughters being stigmatized or excluded from activities and opportunities due to her delayed adaptive functioning.

Of equal interest to the challenge of menarche was the described impact that regular menstrual cycles have in the lives of these mothers and their daughters. One danger in identifying transition events is a loss of awareness of the regular occurrences that impact the lives of families and primary caregivers in context of disability. I had not anticipated the depth of ongoing concerns and stressors these mothers described around menstruation. Menarche is an event. A daughter’s menstrual cycles are monthly occurrences. The mothers’ stories reflect that both the practicalities of their daughter’s menstrual self-care, and the related fertility associations, have kept menstruation on their minds and in their direct caregiving responsibilities far beyond the event of menarche.

The mothers interviewed could be described as having a strong history of specialized services, social, and family support. All four daughters received private disability services beyond the public education system that were funded through the family’s private medical insurance or personal funds. These services included individual therapies (speech, occupational, physical), behavior or psychological support services, medical services, and social activities. In addition, all four mothers described some ongoing level of involvement in parent advocacy groups related to their child’s disability.

I am struck by these mothers’ perceived aloneness around anticipating, preparing for, and supporting their daughters’ transition to menstruation. The presence of support networks has been shown to be a mediating factor in how parents respond and adjust to the potential stressors involved in raising a child with a disability (Hanline, 1991; Trute
Despite having access to public and private disability services, menarche and menstruation were topics about which the mothers were tentative to inquire and received little outside support. If these mothers experienced isolation and stress around this transition event, then what are the experiences of mothers who do not report having access to extensive special services? For example, mothers living in isolated areas of their community, served by failing school districts, and living in poverty? What about the experiences of mothers with low family support who balance raising a daughter with disability and full-time employment outside the home?

Much more study of primary caregivers’ experiences with menarche and menstruation in the context of daughters with cognitive disability should be undertaken to gain insight around these questions. In the meantime, service providers and policy makers should be aware that even a mother who has access to both public and private special services may not be receiving the information she desires around topics that are socially silenced. Despite social stigma, these topics reflect real learning and daily care issues in her daughter’s life.

In relation to their experiences, the mothers in the study had a wealth of ideas about what type of resources and supports would be useful in supporting the transition to menstruation. Of paramount importance to all of these mothers was the inclusion of caregiver stories and experiences in any type of resources for parents or professionals. “I think, it seems to me, that it just feels more valid when there’s actually some voice in there that comes from people who’ve been through it.” (Inger) The mothers varied in their preferred support and resource modality (book, pamphlets, video, workshop, website, parent support group), but all of them cited public school and medical offices as preferred settings through which to receive such support.

The results of this investigation reflect a need for the development and dissemination of systematic menstrual support and resources for caregivers of girls with moderate to severe cognitive disability. Despite past empirical evidence demonstrating successful intervention strategies and environmental supports for teaching menstrual self-care to this population (Demetral, Driessen & Goff, 1983; Hamilton et al., 1969; Richman et al., 1986; Richman et al., 1984), caregiver access to these specialized educational strategies in the twenty-first century appears limited and desired.

The mothers’ stories reflect the position that historical stigmas about menstruation, disability, and female sexuality may continue to play a role in (a) limited research attention to the topics, (b) a lack of systematic support structures for transition services, c) a potential paucity of educational curricula and resources developed for these topics, and (c) a lack of training and distribution for these curricula and resources (Bambara & Brantlinger, 2002; Carlson & Wilson, 1994; Lumley & Scotti, 2001; Stinson et al., 2002).
POLICY IMPLICATIONS & STUDY LIMITATIONS

The privatized nature of healthcare and a largely state-run system of social services in the United States leaves the federally funded public education system as the most consistent and comprehensive disability service provider for children age 3-21 across the United States. Access to social and health services such as in-home and supplemental care for children with disabilities lacks consistency across communities and appears highly dependent on fluctuations in state funding. The mothers in this study all referred to school as their daughter’s primary special service system, and gave little mention of other public support systems outside of their own privately paid medical or supplementary services.

U.S. federal legislation and state regulations in education govern the design and implementation of special services and protect the civil rights of each child with a disability to receive a free and appropriate public education (FAPE). A special education planning team may involve a variety of service providers whose responsibility includes communicating and coordinating with non-school based providers (i.e., private medical doctors) in designing and implementing a service plan. Parents are legally recognized as equal partners on these special education planning teams (IDEA 1997, Public Law 105-17). The voices of mothers in this study give a loud call to policy makers across team, school, district, and state levels that support for menstruation be recognized as a parent priority equal to professional priorities in planning their child’s special education services.

Throughout the interviews, each mother consistently discussed support for menarche and menstruation as a care and self-management priority rather than a sexual education topic.

The whole thing around her being disabled and having her period is a big, a big thing, because of all the implications, you know, related to babies… and then just the management of it. A big issue… the big difference is how Merriam can manage her period, compared to normally developing girls. And probably also some of her understanding. But that’s not as relevant as the management. (Petrina)

The mothers in this study revealed that support for menstrual self-care was currently lacking in their daughter’s public special education, despite having received years of services from this system for other self-care and personal management skills (such as toilet training, teeth-brushing, and nose-wiping). Increasing recognition of menstruation as a component of parent-professional partnership in educational planning during late childhood and early adolescence is one step towards impacting policy concerning what all girls in the United States have access to learning about their unique development. These mothers’ stories also reflect a clear need for education policy makers to give special
consideration to the personal safety of maturing girls with disability in school settings. Including mothers and other caregivers in system-wide planning for student safety in the public schools is a recommended action.

The primary limitation in this study was a small, localized participant sample. The voices of additional participants need to be heard to build a sufficient knowledge base on this under-explored topic. Due in part to this sampling detail, as well as recognition of variability in experiences of any mothers raising daughters, I do not make claims that the results of this study are representative of any populations as a whole. I believe that the participants’ contributions offer insight into the experience of mothering a daughter with moderate to severe cognitive delays, and expand understanding of a uniquely female physiological and social transition.
REFERENCES


Saltonstall: MOTHERS RAISING DAUGHTERS WITH COGNITIVE DELAY 58


