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Introduction



Produced by Intellectual Disability Services
Department of Family Services and Aboriginal and Islander Affairs
in conjunction with the Department of Social Work and Social Policy,
University of Queensland

Introduction

to the

Menstrual Preparation and Management Kit for Women who Have High Support Needs

Developed by
the Menstrual Management Research Team,
Department of Social Work and Social Policy,
University of Queensland

in conjunction with

the Department of Family Services and
Aboriginal and Islander Affairs

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ACKNOWLEDGMENTS

Project staff wish to thank:

- The Commonwealth Department of Health, Housing and Community Services, for funding;
- The Queensland Department of Family Services and Aboriginal and Islander Affairs (Division of Intellectual Disability: IDS), for their co-operation, support, and expertise;
- Ann Taylor, for artwork;
- Clerical and administrative staff from the Department of Social Work and Social Policy, The University of Queensland, St Lucia, Brisbane. 4072
- Sancell Pty Ltd and Libra products, for assistance with funding.

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THE HISTORY OF THE MENSTRUAL PREPARATION AND MANAGEMENT KIT

This Kit was developed as part of a two and a half year Menstrual Management Project, funded by the Commonwealth Department of Health, Housing and Community Services. The project objective was to develop resources to promote educational and lifestyle menstrual management approaches for women who have high support needs (that is, women who have severe or profound intellectual disability).

In the past, education and use of non-medical menstrual management approaches have not generally been a first response to menstruation by families and others assisting these women. Historically, menstrual regulation, suppression and elimination have often been the first and only approaches to menstrual management for women who have an intellectual disability.

Since 1988, several cases in the Family Court of Australia have focussed on menstrual elimination through hysterectomy. There has been a social tendency to sanction hysterectomy as a first response to menstrual management for women who have an intellectual disability. Some of the women undergoing hysterectomy have been as young as seven years of age.

Feelings people have about menstruation for a woman who has high support needs can affect choices they are likely to consider in response to her menstruation. Attitudes can reflect the devalued status of women who have an intellectual disability, as well as a societal taboo on menstruation. This taboo inhibits discussion, preparation and planning for menstruation.

While interviewing mothers of thirty young women, Carlson and Wilson (1994) found that for 14 of the young women, menstruation had been surgically eliminated. Menstrual cycles of another three young women were being chemically suppressed. The most common reasons given for these decisions were related to fertility concerns and difficulties with menstrual discomfort, flow, or cyclic emotional changes.

Another issue was ease of care for those providing these women with personal assistance: this included family members, educators, and residential staff. Difficulties were frequently *anticipated*, not actually occurring at the time. Other workers have documented this trend toward menstrual suppression or elimination (Wolf & Zarfes, 1982; Bambrick & Roberts, 1991; Parsons, 1984). It has a strong historical and cultural basis (Abraham, Fraser, Gebiski, Knight, Llewellyn-Jones, Mira, & McNeil, 1985; Paige, 1973;).

The High Court of Australia ruled in 1992, that parents as guardians could not lawfully authorise the "sterilisation" of their daughter (who has an intellectual disability and is under the age of 18 years) without the order of the Family Court of Australia. Before consent for sterilisation is given, the Court may require evidence that approaches, less intrusive than surgery have been thoroughly investigated.

In future, many more women who have high support needs may experience menstrual cycles and periods. Adoption of educative and supportive menstrual management approaches may become a more common initial response to menstruation by families and others assisting these women.

In view of this situation, education and residential staff, families and others who assist these young women may need information e.g.:

- About how to prepare for menstruation;
- About acceptance of menstruation as a natural part of life for women who have an intellectual disability; and
- About how to respond to possible difficulties associated with menstruation.

The Menstrual Preparation and Management Kit is designed to provide information and suggestions about menstrual management for women who have high support needs. It may be used by families, teaching staff, friends, volunteers, residential staff, medical and legal practitioners, health educators and community health workers, and anyone who regularly assists a woman with personal physical and hygiene needs.

For a review of relevant literature and how it relates to the Kit contents, please read section II.

II WHAT THE LITERATURE SAYS: HOW IT RELATES TO CONTENTS OF THE KIT

FEELINGS ABOUT MENSTRUATION

Although menstruation is an almost universal female experience, menarche, or first menstruation, can elicit a wide range of responses from young women and those assisting them. Factors include cultural differences (Taylor, 1988; Scambler & Scambler, 1985), religious background (Paige, 1973; Abraham et al., 1985), and gender (Hays, 1987; Brooks-Gunn & Ruble, 1986). A Victorian advocacy group wrote:

"Other people feel uncomfortable talking about sex and periods to disabled women so they don't. Other people's coyness about periods inhibits women getting clear information." (STAR, 1990, p.3)

In mainstream western society, menstruation is often a taboo subject, hidden from others and discussed only with close friends or female relatives (Abraham et al., 1985; Gray & Jilich, 1990). Menstruation may be regarded as an inconvenient and embarrassing bodily function. One survey suggested that many Australian women would avoid periods if safe, reversible methods of doing so were available (Abraham et al., 1985). Menstruation generally begins between the ages of 9 and 17; this is similar for all young woman, whether with, (Elkins, 1986; Goldstein, 1988) or without an intellectual disability (Woods, Dery, & Most, 1982; Abraham et al., 1985).

Gray (1991) and Hasleton (1989) suggested that attitudes towards menstruation among people assisting women with an intellectual disability will have a strong effect on the young women's responses to menstruation. There may be concern around the time of menarche about sexual and fertility issues e.g. masturbation at inappropriate times and places, and sexual abuse (Carlson & Wilson, 1994).

People's feelings about menstruation were recorded as part of the Menstrual Management Project. Examples included the following:

"What do you think women in general feel about having their periods?"

J: They wish they didn't, and that men did!

A: It's an annoyance.

D: It's just a part of life. I wish men got them!

F: Wish we didn't have to.

C: Pain in the butt.

G: Am always glad to see mine as I'm diabetic. I get very moody. Some women get irritable, moody, and feel "unclean".

N: Most women probably see it as a natural part of life, and accept it.

T: It varies tremendously. Still surrounded by myth, but not as much of a problem as it used to be.

"If a woman has a disability, do you think that people's feelings about her menstruation are different?"

- J: Yes, and different again depending on whether the disability is physical or intellectual. Some people say that they don't need periods if they aren't going to have kids. Some males (staff) object to pad changing. But women with disabilities are entitled to menstruate just like other women.
- A: Yes, different if a woman has an intellectual disability: if she has difficulty understanding, hygiene or behaviour problems, people think hysterectomy is OK.
- D: They might be. Male staff may find it difficult, looking after a woman's menstruation.
- F: Yes. The public may think that these women are unclean because they can't look after themselves.
- C: Yes. We don't know what they're feeling, especially if they're non-vocal.
- G: Yes, they might be different. Bleeding in public could occur - people will look, and the young woman may feel embarrassed.
- N: Yes - it's a big concern for teachers. For some, dealing with menses is distasteful, abhorrent. They wonder how they're going to cope with menstrual flow as well as urine and faeces. Some people may also think that periods are "unnecessary", as these young women will not be having children.
- T: Not in my experience, although some people may regard these women as a "race apart", who will not have periods.

In an American survey, female tertiary students suggested that young women need information, support and reassurance around the time of their first period, or menarche (Rierdan, 1983). Gray & Jilich (1990) and Gray (1991) recommended that menstrual preparation for women who have an intellectual disability should be provided by people who have an awareness of their own attitudes and assumptions about menstruation. Consistency, and positive, supportive attitudes were suggested as important elements of effective preparation for menstruation.

**FEELINGS ABOUT INTELLECTUAL DISABILITY:
THEIR EFFECT ON MENSTRUAL MANAGEMENT FOR WOMEN
WHO HAVE HIGH SUPPORT NEEDS**

Antonak and Livneh (1991) suggest that attitudes towards people who have an intellectual disability are for the most part negative. These attitudes can create or support negative expectations that limit opportunities for independence. Evans and Scotti state:

"Expectations determine the social and environmental conditions that are established for an individual who is profoundly disabled" (1989, p.103)

Examples of the low expectations frequently held for people with high support needs have been well documented. A tendency for parents to foster an extreme and disabling interdependency with their disabled children was noted by Hammar and Barnard (1966). Physical maturity may be seen as a crisis, to which people respond with over-protectiveness, and denial of sexual feelings (Craft, 1985). Wolraich and Siperstein (1986) reported that physicians tended to have particularly low expectations about the self care abilities of people who have high support needs. A significant proportion of people assisting women with high support needs may assume that these women are not capable of responding appropriately to menstruation.

Possible responses to menstruation for women who have high support needs include education and support, and elimination of menstruation by hysterectomy. There seems to be considerable support among parents of people who have an intellectual disabilities, for their sterilisation (Wolf & Zarfes, 1982; Bambrick & Roberts, 1991). In an American study, Wolf and Zarfes (1982) found that approximately 70% of parents surveyed agreed with the principle of sterilisation. Parents whose daughters were older than 15, or had high support needs, were more likely to approve of involuntary sterilisation. Bambrick and Roberts (1991) reported that 14% of British families surveyed listed difficulty with management of periods as a possible reason to choose hysterectomy for their daughters. Thirty-nine percent cent of surveyed parents in an Australian study said they would like their daughters to have hysterectomies so that the "problem" of menstruation wouldn't exist (Parsons, 1982).

Ferrara found that parents were more likely to support normalisation activities for people who had an intellectual disability when discussing a general category, than when discussing their own child.

Many parents may feel reluctant to prepare their daughters who have high support needs for menstruation. Teaching, residential staff and other professionals need to be aware of a number of factors which may contribute to lack of preparation for menstruation:

- a) Constant physical and emotional demands associated with meeting the needs of daughters who are taller and heavier, but still very dependent (Adams, Wilgosh, & Sobsey, 1990);
- b) Sadness or anger with realisation that puberty and menarche may not lead to an adult life similar to that experienced by women who do not have a disability (Davis, 1987; Craft, 1985; Kratochvil & Deveraux, 1988);
- c) Uncertainty about how much these young women can understand;

- d) Relatively low priority given to the young women's independence, (Hammer & Barnard, 1966); and
- e) Lack of information or support for families about how menstrual preparation can occur.

Some families have been able to prepare young women who have an intellectual disability for menstruation. One mother used modelling: she allowed her daughter to watch while she changed her own menstrual pads (Department of Family Services and Aboriginal and Islander Affairs, Division of Intellectual Disability Services, 1993). Another mother reported that her daughter with Down Syndrome was able to change her menstrual pads after an initial phase of instruction and supervision (STAR, 1990). Basic explanations and "practice runs" with wearing of menstrual pads were used successfully by the mother of another young woman who had a moderate intellectual disability (Anonymous parent, 1989).

Included in the Menstrual Preparation and Management Kit are a number of resources to assist with preparation for menstruation. An audio tape repeats basic messages about menstruation over relaxing background music. This can be used to provide young women with information about menstruation. It also provides those assisting the young women with suggestions about appropriate explanations which can be given.

Modelling or demonstration of menstrual self-care is provided on a short (3 minute) videotape. This tape, like the audio tape, can be used either by the young women, or by those assisting them, for ideas.

A series of coloured illustrations provides the sequence of skills required for changing of menstrual pads. It may be suitable for use by women who have functional vision. Basic messages, including use of symbols, may assist with communication of needs, and learning of skills involved.

STUDIES SUPPORTING LEARNING OF MENSTRUAL MANAGEMENT SKILLS BY WOMEN WHO HAVE HIGH SUPPORT NEEDS

Over the last 25 years, researchers have demonstrated convincingly that people who have high support needs *are* able to learn self care skills (McCartney, 1990; Langone & Burton, 1987). While most attention has been focused on toileting (Bensberg et al., 1965; Azrin & Fox, 1971; Heyward, 1988), it is also clear that if approaches are systematic and consistent, people with high support needs can learn self care skills such as dressing (Bensberg, Colwell, Cassel, & Cassel, 1965; Azrin, Schaeffer & Weslowski, 1976), face washing (Bensberg et al., 1965; Teffry, Martin, Samels & Watson, 1970), and tooth-brushing (Snell, Lewis & Houghton, 1989).

The limited research available suggests that women who have high support needs may also be able to be effectively involved in menstrual self care. Hasleton said:

"If a woman can put on a buttonless garment and follow a simple instruction like 'put the red cup on the table', she should be able to learn menstrual self management." (1989, p. 24)

This statement was supported by Brekke (May 1983). She reported a strong correlation among women who had high support needs, between their menstrual care skills and eating, toilet use, cleanliness, and language development.

Reported studies addressing menstrual management for women with high support needs involved small numbers of women, who had differing degrees of intellectual disability (Hamilton, Allen, Stephens & Davall, 1969; Dedrick, 1974; Richman, Reiss, Bauman & Bailey, 1984; Epps, Stern & Horner, 1989; Demetral, Driessen & Goff, 1983). Goals included awareness of menstruation (periods), asking for pads when needed, ability to use and dispose of menstrual pads, and appropriate behaviour such as leaving pads in place, rather than removing, displaying them, or spreading their contents.

Strategies used to achieve these goals included detailed task analysis and simulation of menstrual flow (Dedrick, 1974; Demetral et al., 1983; Richman et al., 1984), familiarisation with wearing of pads (Demetral et al., 1983; Dedrick, 1974), and modelling of appropriate behaviours, either by care givers, or with dolls (Demetral et al., 1983; Richman et al., 1984; Epps et al., 1990). While most of these studies assisted young women already menstruating, some investigated preparation for menarche prior to the event (Demetral et al., 1983; Dedrick, 1974).

Mothers of nine young women who had mild to severe intellectual disability were involved in a menstrual preparation program (Demetral et al., 1983). The young women were provided with basic explanations about periods, and pad management practice. Seven of the young women learned to change their menstrual pads, and four generalised pad management skills from the simulated setting to their own menstruation, with minimal prompting. The authors described the program as a positive experience which had the following benefits for the young women:

- a) Avoidance for the young women of surprise and possible trauma at finding menstrual staining on clothing;

- b) Avoidance of development of inappropriate behaviours such as removal of, or refusal to wear pads;
- c) Allowing the young women the pride and dignity of caring for themselves. They commented:

"The women clearly enjoyed the experience and the mothers/caregivers were delighted that they now had a way to manage this dimension of their daughter's life rather than fear it". (1983, p.44)

Results were encouraging. Women involved in reported studies were generally able to acquire menstrual self-care skills. In several cases generalisation occurred from trained to untrained stimuli: from responding appropriately to a stain on the pants, to responding to staining on both pad *and* pants (Dedrick, 1974; Richman et al., 1984). Maintenance of skills following intervention was reported for between 5-6 months (Richman et al, 1984), and 18 months. Epps et al. (1990) found that menstrual care skills were retained for up to 18 months after initial teaching occurred, when "booster" training sessions were provided. Longer-term reviews of skill maintenance were not reported.

Elkins et al., (1986) described a health clinic for women who had a range of intellectual disabilities. The most common reason for referral was request for hysterectomy. Only eight of the sixteen young women were experiencing menstrual hygiene problems. Goals identified for the young women included learning of menstrual management skills. A number of clinic principles were established:

- a) Decisions were to be in best interests of the young woman;
- b) Each young woman was to be treated as a unique individual;
- c) Problems were to be regarded in the context of total reproductive health concerns: for example, hysterectomy would not eliminate the possibility of sexual abuse;
- d) Decisions should reflect a "least restrictive means" of intervention;
- e) Decisions should reflect a wide range of societal views, and should be open to review by an ethics committee.

A number of programs have been developed in Australia to address menstrual management for young women who have moderate support needs (Gray & Jilich, 1990; Jones, 1989; Telford & Smith, 1992).

In "Guidelines for Menstrual Management", developed for use with young women who have moderate support needs, Gray and Jilich (1990) identified the following goals:

- a) Recognition of sexual body parts, and awareness of their changes with puberty;
- b) Understanding that women menstruate - it is a universal experience;
- c) Knowing when a period is likely to occur;
- d) Knowing how and when to use pads;
- e) Understanding the socially private nature of menstruation; and
- f) Development of appropriate personal hygiene routines.

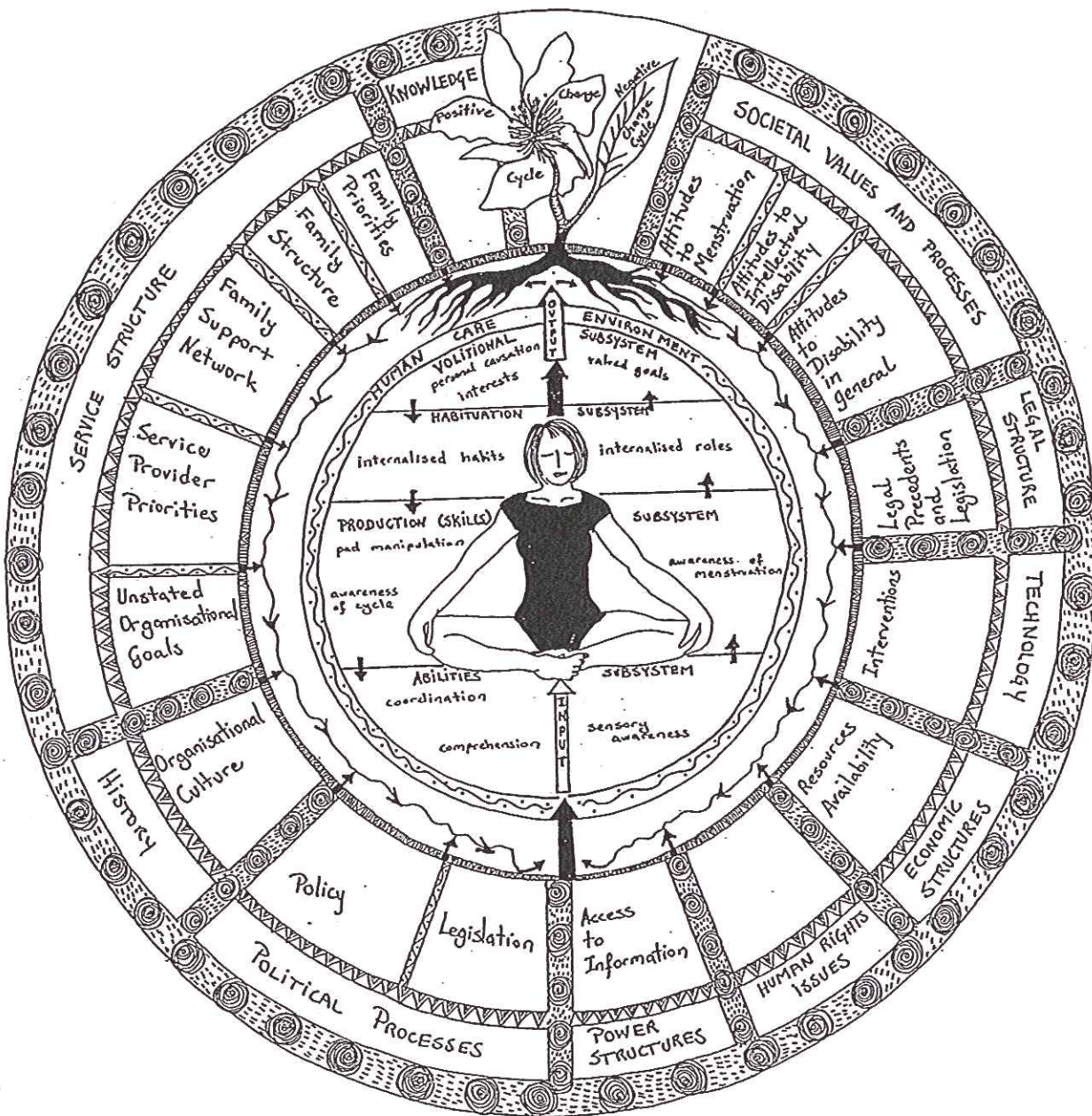
The applicability and relevance of goals and strategies suggested by such programs has not been extensively investigated for women with high support needs. Llewelyn-Scorey (1989), suggested both informal and formal approaches to menstrual management for women with high support needs. These strategies were trialled in an institutional setting with some success.

While there may be some reduction in the relevance and feasibility of such goals for women with very high support needs, their achievement is addressed in the menstrual preparation and management Kit. Acceptance of menstruation for these women by their care providers is of equal importance to skill development. A significant part of Kit content is related to this issue of acceptance of menstruation (see **Learning Guide, Parts 2, 3 and 4**).

MENSTRUAL PREPARATION AND MANAGEMENT: A SUGGESTED MODEL OF INTERVENTION

A model of intervention for menstrual management based on Kielhofner's model of human occupation [Kielhofner, 1980; Kielhofner, 1989 a, b, c] and the work of Jones and May (1992), Dever (1989), and Chapparo and Ranka (1992), is presented in figure 1.

FIGURE 1



Attitudes form an essential component in Kielhofner's model. Emphasis on awareness and influencing of attitudes is continued in the model, which is a dual one: the same processes are at work for both the individual woman, and what is called her "human care environment".

Kielhofner describes each person as "a system", composed of a dynamic network of inseparable relationships. The volitional subsystem is based on personal causation, values and interests. Its role is *choosing*. The habituation sub-system consists of roles and habits. Its function is *patterning*. The performance sub-system is based on three types of skills: perceptual-motor, planning and problem-solving, and communication/interaction. Its role is *producing occupational behaviour* (output of information and action to achieve purposeful ends).

The volitional sub-system sets priorities concerning activities the person engages in. These choices can, however be limited by factors operating in the other sub-systems. For example, in the production sub-system, poor skill mastery may reduce a person's chances of engaging in behaviour which she/he would otherwise have chosen. A situation where a young woman wished to change her own menstrual pad, but is unable to remove the adhesive strip because of poor dexterity, may illustrate this process.

Characteristics of people who have high support needs are incorporated into the model. Women who have high support needs may experience severe limitations in motor and sensory function, as well as seizure disorders, variable states of arousal, and delays in understanding and responding (Bagnato & Campbell, 1992). It is not always clear whether limitations in function are due to reduced *ability* or *lack of opportunity for mastery practice*. Existing skill development may reflect an environment where expectations are unnecessarily pessimistic. For this reason, the team model subdivides the production sub-system into "skill" and "ability" sections.

Kielhofner suggests that for successful intervention, no person can be understood away from their environment, and that the surest way to achieve permanent organised change is via environmental change (1980)(b). The proposed model incorporates a number of global elements into "the environment" e.g. power structure, history, societal values, and knowledge. More direct influences on menstrual management for these women, located more centrally in the model, include organisational policy, family priorities, availability of appropriate resources, and attitudes towards menstruation among people providing the women with personal assistance.

There is interaction between both levels of the team model, with output from the young woman becoming part of feedback to those assisting her. Similarly, alteration of expectations and habits from people assisting each woman may prompt changes within her system. This model suggests that information about attitudes towards menstruation for women who have high support needs should be collected. Provision of information, practical support and resources to people assisting the women, is also indicated.

Examples of approaches which occurred during the course of the menstrual management project, and how they relate to the proposed model of intervention, are outlined below.

Within the framework of the proposed model, menstrual management goals for these women could be categorised into two groups:

- a) "Environmental": related to feelings, values, information and support available to those providing them with assistance; and
- b) "Individual": related to the women's menstrual cycles, behaviour and skills.

Environmental goals included:

- a) Acceptance of menstruation as a normal and natural experience for each woman by those assisting her;
- b) Confidence among staff that menstrual management could be integrated without fuss into daily routines; and
- c) Support from staff for involvement of each woman in her menstrual management.

A woman's involvement might include awareness of her cycle, and where possible, direct participation in pad management.

Individual goals for the women included:

- a) A very basic understanding that menstruation occurs for all women and is a normal bodily function; and
- b) As much awareness as possible of their own menstrual cycles and menstruation; and
- c) Full or partial independence with menstrual pad management.

A number of strategies were chosen to assist with the environmental and individual goals outlined above. Strategies for environmental change included provision of information, provision of materials and processes to increase awareness of feelings about menstruation, and use of an empowering, consultative rather than an "outside expert" approach.

It was agreed that accurate information about the menstrual cycles of the women was needed. Menstrual charting would allow staff to anticipate behavioural changes and to adjust daily routines to suit energy and interest levels. It might also assist with clarification of any premenstrual changes, and of cycle length, regularity, and "heaviness" of menstrual flow. Other positive outcomes might be increased awareness by the women of their bodies and their cycles, and the possibility of integrating menstrual management and communication goals. Charting media developed by the project were trialled by the women and staff.

Some approaches used to teach the women menstrual skills followed those reported in the literature. The first was informal use of behavioural approaches such as task analysis (identifying steps for which the women needed assistance); chaining; and verbal, physical and gestural prompts. Preferred activities and social rewards were used for encouragement, rather than food rewards.

A second strategy was to modify elements of the physical environment to maximise the women's level of independence. Examples included the purchase or improved placement of disposal units or bins, hand-washing facilities, and paper bags; review of pads, pants and clothing with a view to comfort and ease of use; and storage of pads in places accessible to the women, such as in their bedroom cupboards. Whenever possible, menstrual charts were also stored and used where the women could observe and assist.

A third feature of the approach taken was a process of "personalising" for the women. A range of menstrual pads was trialled, and pads were chosen on the basis of each woman's needs and preferences. Women with heavier flow needed more absorbent pads than those with moderate or light flow. Some women preferred tapered pads, others the "ultra-thin" style of pad. Cueing and assistance from staff was also related to the known preferences and learning styles of the women. An example of individualising approaches occurred when choosing prompts for two of the women: because Jenny became very agitated and upset if touched or assisted during other activities, staff decided to use only verbal and gestural prompts while teaching her pad management skills. In contrast, Delia received verbal and physical prompts, as these were considered to be *her* preference.

Reported menstrual management research had incorporated very structured goal-setting and instructional methods (Hamilton et al., 1969; Dedrick, 1974; Richman et al., 1984; Demetral et al., 1983; Dedrick, 1974). While drawing on elements of these studies, this project used a more flexible approach, related very closely to individual abilities, preferences and needs.

IN SUMMARY

A model of intervention concerning menstrual management for women who have high support needs was developed (see FIGURE 1). Of particular significance in this model are attitudes held by people assisting the women. The model is an holistic one which considers the whole person, as well as the context in which she lives. Materials and processes included in the Menstrual Preparation and Management Kit relate to the proposed model. Knowledge, feelings, and awareness of relevant issues are key elements of these resources. Both assessment and teaching strategies are tailored, not standardised. There is support in the literature (Arnadottir, 1990; Smith, 1992) for an individualised framework, particularly when clients have the diversity of abilities and deficits which falls under the blanket term "high support needs".

**EFFECTIVE STRATEGIES:
PROMOTING ACCEPTANCE OF MENSTRUATION AND
EDUCATIONAL APPROACHES AMONG PARENTS AND OTHERS
ASSISTING THESE YOUNG WOMEN**

Project resources and processes incorporated features consistent with recommendations from literature summarised in this section. Literature relating to families and parents may apply to the needs and experiences of staff, for example in teaching and residential settings.

Parents of children who had severe disabilities surveyed by Adams, Wilgosh and Sobsey (1990) demonstrated a very high level of commitment to their children. Their expressed preferences for assistance from professionals included concrete, practical help, explanations about progress their children were making, support, and encouragement. Working within families' systems, rather than trying to change them, was suggested by Donnellan and Mirenda (1984).

The booklet "Managing Menstruation" (Taylor, Carlson, Griffin & Wilson, 1993) included in the Kit, was developed in response to requests for information from parents, teachers and residential staff for relevant information. It was intended to provide such information in an acceptable form. Contents include summaries of educational, lifestyle and medical approaches to menstrual management. Teaching strategies, planning guidelines, details of menstrual and incontinence products, suggestions for management of discomfort and premenstrual changes, and charting ideas, are also included. There are also sections detailing common myths about menstruation, facts for older women, legal and sexual issues, and readings and resources.

Other parental requests included that professionals:

- a) Be interested in their child;
- b) Be professionally committed, careful and accurate in assessments and giving advice;
- c) Treat parents with consideration and respect; and
- d) Provide a personalised approach, where the child's personality, and parents' ideas and information were considered (Baxter, 1989).

Involvement by families in determining students' priority needs was suggested in the New South Wales Department of Education curriculum statement (1989) as a way of gaining their commitment to, and active participation in students' education. The document gave strong support to partial participation by students in all activities:

"Students should not be excluded from activities simply because they lack the full range of skills normally required for participation . . . Maximising participation fosters self-esteem on the part of the student, and positive attitudes on the part of those involved with the student." (1989, p 56)

Suggested strategies for involving those assisting these students included use of interviews, questionnaires, meetings, parent involvement in data collection, and workshops.

Use of menstrual pads was included in a comprehensive curriculum management system for students with severe mental impairments by England and Langton (1983), who also supported partial participation by these students.

Knowledge, attitudes and policy awareness were targeted by Manikam and Hensarling (1990) when educating parents about issues related to sexuality for young people with an intellectual disabilities. Instruction tailored to meet the needs of each family, inclusion of siblings (for example with role modelling), and involvement of both parents, were strategies suggested by Harris et al.(1991) for facilitation of learning by families. An audio-visual resource included in the Kit is an extract from the video "Janet's Got Her Period". Please read *Resources in Managing Menstruation* for details.

Assessment of menstrual management skills seems to have been largely overlooked in service provision literature. Only two inclusions of items relevant to menstrual care were found in published assessment protocols (Schoening, Anderegg, Bergstrom, Fonda, Steinke, & Ulrich, 1965; Cone, 1984). The suitability of standardised assessments for use among people who have high support needs has been questioned (Arnadottir, 1990; Smith, 1992; Shapiro & Browder, 1990; Duncan, 1987; Sigafoos, 1987). Shapiro and Browder (1990) and Klein-Parris, Clermont-Michel, and O'Neill (1986) suggested interview of care providers as an appropriate alternative for collection of baseline information, when working with people who have high support needs.

Two planners, one for young women not yet menstruating (premenarchal), the other for women already having periods (postmenarchal) are included in the Kit. Their aim is to facilitate involvement of parents and others in deciding menstrual management priorities, and strategies for achieving them. Items are related to the proposed model of intervention. They include attitudes and expectations of those assisting the women concerning menstruation, self care skills identified by Brekke (1983) as being correlated with success in menstrual care, activity and learning preferences, sensory awareness, mobility, use of technology, behavioural difficulties, and information about relevant health factors. Continence, and details of incontinence products used, is clarified: it is anticipated that goals for young women who use incontinence products will differ significantly from goals for those who are even partially toilet regulated. Information about difficulties during menstrual cycles or menstruation is recorded for women already menstruating.

The Planners facilitate an individualised approach, based on information concerning both the women's abilities and deficits in function. They link information obtained with specific "action plans" which are summarised onto a single sheet for ease of recording and use.

Ducharme and Feldman (1992) recommended the use of "general case training", where teaching examples were chosen to sample the "instructional universe" of the skill to be trained. This multiple case study approach was suggested as an effective staff education strategy for promotion of generalised effects across clients, settings, and client programs.

Written instructional methods were found to be less effective than performance-based approaches.

A Learning Guide included in the Kit incorporates tailoring to individual needs, role play, and a general case approach of multiple case studies. It may be used in either an individual, "self paced" way, or as a basis for small group workshops.

Most Kit materials are print based. This allows items to be photocopiable, to help reduce costs for users. It is hoped that the flexibility and low cost of Kit use will balance the disadvantage of working with print based materials, whose effectiveness has been questioned (Ducharme & Feldman, 1992).

III A CONTENTS LIST, AND HOW TO USE EACH ITEM OF THE MENSTRUAL PREPARATION AND MANAGEMENT KIT

The Menstrual Preparation and Management Kit is an integrated package. Some resources in the kit can be used without reference to others. However, it is advised that individual items should be used in the recommended way.

RESOURCE	CONTENTS	SUGGESTIONS FOR USE
"MANAGING MENSTRUATION"	<p>This booklet provides information on all available approaches to preparation for menstruation and management of menstruation. Topics include:</p> <ul style="list-style-type: none"> • Menstruation • Fertility • Sexual Feelings • Cultural Influences & Feelings • Management Practicalities • Managing Menstrual Difficulties • Older Women • Legalities • Medical Approaches • Planning Guidelines • Readings • Resources • Product Details • Menstrual Charts • Myths about Menstruation • Drug Interactions with the Pill • Tranquillisers and menstruation • Avoiding Infections • Exercises to Relieve Discomfort 	<p>The booklet is a basic source of information and practical ideas about menstruation for all people who assist young women with high support needs, including:</p> <ul style="list-style-type: none"> • Parents • Family members • Educators • Care workers • Social workers • Medical practitioners • Health workers • Volunteer workers • Legal practitioners • Counsellors • Other agencies which provide a service to women who have intellectual disability. <p>This resource should be used in conjunction with the other items in the KIT.</p>
LEARNING GUIDE	<p>Part 1: Quiz The aim of this quiz is to provide a lighthearted introduction to some facts about menstruation.</p> <p>Part 2: Feelings about Menstruation This part helps identify feelings and attitudes towards menstruation, and towards menstruation for women with high support needs. Notes from research and literature demonstrate how feelings differ. These feelings can affect approaches to menstrual management.</p> <p>Part 3: Examining Expectations This part assists users to be aware of possible approaches to preparation for menstruation. Expectations about the capabilities of these women will also be a focus.</p> <p>Part 4: Examining Priorities Here users listen to a tape about a young woman with high support needs. A number of different viewpoints are presented.</p> <p>Part 5: "Trouble Shooting" This part identifies some common concerns about menstrual management for women with high support needs. Issues and possible strategies are presented.</p>	<p>It is suggested that this comprehensive guide should be used:</p> <ul style="list-style-type: none"> • In correct sequence • Gradually (in sections over several weeks) • Either as self-paced (in situations where group work is not possible such as in isolated areas, night shifts, sensitive relationships) • Or within a group format (see below for guidelines)

RESOURCE	CONTENTS	SUGGESTIONS FOR USE
GUIDE TO FACILITATING GROUP WORK with families and others who assist women with high support needs	This Guide assists facilitators to work through the five parts of "The Learning Guide" with groups of people. There are suggestions for different approaches which can be used with groups and within each session.	This can be used in conjunction with the above "Learning Guide" when working with groups of 16 people or less. Guidelines are given to assist facilitators.
PLANNERS	<p>These planners use existing knowledge about each woman to assist with her menstrual preparation or management. They help to identify menstrual management goals and ways of achieving them.</p> <p>The Premenarchal Planner includes information about:</p> <ul style="list-style-type: none"> • Support for those assisting the woman; • Giving explanations about menstruation; • Anticipatory possible difficulties; • Summary <p>The Postmenarchal Planner includes additional information about:</p> <ul style="list-style-type: none"> • Current difficulties with menstrual cycles; • Thinking ahead about management; • Providing supportive environments; • Behavioural difficulties; • Relevant Health Information; • Summary 	<p>Ideally, the planners are completed in a co-operative way by all the people who assist the woman in different settings. These settings include home, school, residential centre, respite centre, and volunteer friend's home.</p> <p>The premenarchal planner is used for young women not yet menstruating.</p> <p>The postmenarchal planner is used for women who have started to menstruate.</p>
MENSTRUAL CYCLE CHARTS	<p>♣ Calendar - A small paper yearly calendar with illustrations for each month and large daily boxes for recording cycle information.</p> <p>♣ Fabric Wall Chart - A pattern for this chart is provided. It is designed for women who have preferences for visual, tactile or auditory stimulation.</p>	<p>♣ This calendar should be used in conjunction with the self-inking stamps.</p> <p>♣ Details for this pattern are provided in the booklet, "Managing Menstruation", page 27.</p>
SELF-INKING SYMBOL STAMPS	These four stamps have symbols for positive and negative cyclic changes, for pad changing and pad disposal. The stamps will help to involve the woman in charting her own cycles.	<p>These four stamps are designed to be used in conjunction with the enclosed calendar.</p> <p>Order Form enclosed.</p>
MENSTRUAL MESSAGES AUDIO TAPE	<p>This tape repeats messages and information about menstruation over a background of relaxing music.</p> <p>Messages include:</p> <ul style="list-style-type: none"> • Most girls menstruate • It's part of growing up and becoming a woman • It's good to menstruate. It means you have a healthy body • When you menstruate, you will need to use a pad • Women change their pads in a private place. 	<p>The tape can be used with the woman as part of a daily program, for example, in conjunction with switch operation.</p> <p>The messages provide basic explanations and reassurance about menstruation for women who are not yet menstruating or who are menstruating and encountering difficulties. The tape may also serve as a model for people who might otherwise find it difficult to discuss or explain menstruation.</p>

RESOURCE	CONTENTS	SUGGESTIONS FOR USE
ILLUSTRATIONS	<p>These 22 laminated illustrations provide images and symbols for:</p> <ul style="list-style-type: none"> • Pad changing • Menstrual messages (from audio tape). <p>Each illustration includes symbols for women who use non-verbal forms of communication.</p>	<p>These illustrations provide women with:</p> <ul style="list-style-type: none"> • images of the steps involved in changing and disposing of menstrual pads. • images which complement the messages provided in the above Menstrual Messages Audio Tape.
VIDEO: An edited version of "Janet's Got Her Periods"	<p>This video is an edited version of "Janet's Got Her Periods", produced by the Centre for Social Health in Melbourne. The video features a woman who has intellectual disability and her sister who models menstrual self-care. The edited video repeats a pad changing sequence several times.</p>	<p>This video can be used with women who have a preference for watching television. The video provides positive images of modelling menstrual self-care.</p>
POLICY ANALYSIS: "Menstrual and fertility management for women who have an intellectual disability and high support needs: An analysis of Australian policy" Second Edition 1993	<p>This document analyses Australian and international policy, legislation and legal precedents on issues related to menstrual management for women who have intellectual disability.</p>	<p>This document provides an easily read introduction to issues about past and current menstrual and fertility elimination practices in Australia and overseas.</p>

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