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## **Access to Breast Prostheses via a Government-Funded Service in Victoria, Australia: Experience of Women and Service Providers**

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# ACCESS TO BREAST PROSTHESES VIA A GOVERNMENT-FUNDED SERVICE IN VICTORIA, AUSTRALIA

## Experience of Women and Service Providers

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*For many women, the only alternative to breast reconstruction following a mastectomy is to use external prostheses, which need replacing regularly at a cost of up to \$395 per prosthesis. Commonwealth and state governments across Australia have responded to this need by providing subsidies to assist in the purchase of breast prostheses. However, current arrangements have been highly variable and sometimes difficult to access. As part of a larger review of breast prosthesis services in Victoria, Australia, the aim of this research was to evaluate client satisfaction among Victorian women who accessed funds through the State Government's Aids and Equipment Program, compare the responses of the program service providers with the experiences of clients accessing funding, and identify opportunities to improve service provision.*

**Keywords:** *breast cancer; mastectomy; external breast prosthesis; breast prosthesis services; government-funded programs*

Breast cancer is a major public health issue. Despite a relatively stable mortality rate over the past 20 years, the incidence of breast cancer in

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Australia continues to increase at a rate of 1.5% per year (Kricker and Jelfs 1996), with approximately 10,000 new cases diagnosed in 1997 (Australian Institute of Health and Welfare [AIHW] 2000). Approximately 40% of women diagnosed with breast cancer in 1995 had a mastectomy as their primary surgical treatment (Hill et al. 1999). Most, if not all women will experience some degree of psychological morbidity following a breast cancer diagnosis (Harrison and Maguire 1994) and subsequent surgery (Shimozuma et al. 1999; Tjemsland et al. 1999), with many women facing considerable disruption to their physical, emotional, and psychosocial well-being (Fallowfield 1997; Ganz et al. 1996, 1998; Lamb 1995). The loss of one or both breasts can lead to an impaired feminine self-image (Reaby 1998) and sexual dysfunction through loss of body image, embarrassment, and a loss of libido (Maguire et al. 1978; Reaby 1998).

The use of an external breast prosthesis may help to improve body image and quality of life and reduce emotional distress (Fallowfield et al. 1990; Parker 1996). A breast prosthesis is worn inside the bra to closely simulate the natural contours of the breast, which outwardly restores feminine shape. It is normally made of molded silicone gel and differs in size and shape. Breast prostheses can be fitted from approximately 6 to 8 weeks after surgery and generally need replacing every 2 to 5 years. Up to 90% of women who have had a mastectomy at some stage use breast prostheses (Rowland et al. 1993). Currently in Australia, prostheses range in cost from \$AUD150 to \$AUD395 (all future reference is in Australian dollars). For many women, this may present as a significant financial burden.

In Australia, the Commonwealth and state governments responded to this potential financial burden by providing financial assistance toward the cost associated with a breast prosthesis. However, anecdotal evidence suggests that significant deficits exist in the provision of breast prosthesis services for women.

In Victoria, Australia's second largest state (population approximately five million people), a major source of funding for the purchase of breast prostheses is through the Victorian state government's Aids and Equipment Program (AEP). Women who are treated in the public hospital system receive funding for their initial prosthesis from the treating hospital. By contrast, women who have their surgery in the private hospital system and do not have appropriate private health insurance (i.e., ancillary cover that encompasses other health services such as dental, chiropractic or podiatry services) can apply for a funding subsidy of up to \$300 for their initial prosthesis. For replacement prostheses, all women can apply to the AEP for a subsidy up to \$300.

Women who seek financial assistance from the AEP face several potential problems. First, the scheme is based on the premise that individuals are “disabled.” Women must indicate on the application form that they are disabled and obtain a letter from their doctor certifying their disability. Second, financial assistance is priority-based in that a person is assessed on the basis of perceived “functional need, safety and prevention of injury” and breast prostheses are only one of many categories (i.e., oxygen, wheelchairs) considered for assistance. As a consequence, women may experience a delay of up to 12 months between application and receipt of financial support due to the competition for funds with other applicants. Women cannot purchase a breast prosthesis and later receive the subsidy as a reimbursement. Third, anecdotal evidence suggests that the attitudes and perceptions of the individual AEP service providers determine the actual level of funding women receive after applying for the subsidy. Hence, some women may receive less than the designated funding level of \$300 from the AEP. Such funding limitations may restrict the choice of a prosthesis to one that may be inappropriate for the individual.

As part of a state government program to investigate the impact of funding on prosthesis services for women, a telephone survey of AEP providers and women who accessed funds through the AEP was conducted. Client satisfaction surveys are often conducted in the evaluation of medical services to determine whether the service is meeting its objectives, to monitor or improve the service or to meet accountability requirements (Rossi and Freeman 1993). Telephone surveys are a popular tool because of the improved response rates found using telephone surveys compared with mail-out methods (Burroughs et al. 2001).

The aim of this research was to ascertain client satisfaction among women accessing funding through AEP and to compare the responses of the program service providers with the experiences of women applying for funding. The results would be used to inform policy makers on the redevelopment of a breast prosthesis policy to enhance Victorian women’s access to quality prosthesis services.

## METHOD

A telephone interview was conducted with women who had approached the AEP for financial assistance for the purchase of an initial or replacement prosthesis in the preceding 12 months. The AEP service providers were also

interviewed to derive their experiences and perceptions associated with providing funds from the AEP.

Prior to the AEP quantitative study, preliminary investigations were undertaken, including focus groups with 5 AEP service providers and 10 women in the target group to identify the issues, optimal wording, and possible response categories. The questionnaires were pilot-tested on a group of 5 women in the target age group and 1 AEP service provider (reference group member). Internal consistency checks were included in the Computer Assisted Telephone Interview (CATI) program.

#### **SAMPLE IDENTIFICATION, RECRUITMENT STRATEGIES, AND CONSENT PROCEDURES**

A total of 20 of the 29 Victorian AEP service providers agreed to participate in the recruitment of women who had accessed the AEP for an initial or replacement prosthesis in the previous 12 months. The service providers were issued information sheets and consent forms, which they distributed to the last 8 women who had applied for funding for a breast prosthesis through their center within the previous 12 months. Service providers excluded women with documented psychiatric conditions and women who had difficulties speaking or understanding English, due to financial constraints associated with utilizing interpreters. Women who agreed to participate returned the consent form and information sheet to the study's project coordinator for subsequent contact by telephone.

#### **COMPUTER-ASSISTED TELEPHONE INTERVIEWS (CATI)**

The survey of clients, conducted using CATI, took an average of 30 minutes and comprised 34 questions with open-ended and forced-choice responses. Participants were asked their date and country of birth, marital and employment status, and use of private health insurance, followed by questions about their experiences accessing the AEP, including the administrative procedures required to obtain funding for a prosthesis, waiting periods, funding levels and their use of, and satisfaction with, their prosthesis.

Interviews were also conducted with a sample of AEP service providers. This survey comprised 21 questions with open-ended and forced-choice responses and included questions on the administrative processes required for clients to obtain funding, waiting periods, and priorities for funding levels. The questionnaires were pilot-tested with a group of 5 service providers and 10 women who had a mastectomy, prior to implementation.

## STATISTICAL ANALYSES

Data collected were analyzed using SPSS<sup>®</sup> and STATA<sup>®</sup>. Descriptive statistics were used to characterize the sample. Statistical tests for univariate analyses included chi-square test for comparing groups and *t* test for comparing means. A logistic regression model was constructed to identify the relationship between waiting periods and funding levels and satisfaction. Women were categorized into three age groups for analysis—59 years or younger, 60 to 69 years, and 70 years and older.

As women were recruited through AEP centers, the sample was less efficient than a simple random sample of the same size. Thus, if this design effect was not accounted for in analyses, standard errors for proportions would be underestimated. Procedures within the statistical package STATA<sup>®</sup> accommodate complex sample designs within analytic procedures by adjusting for the clustering of observations. Therefore, STATA<sup>®</sup> was used for analyses comparing proportions and mean scores between groups, and the clustering of women within each AEP center was adjusted for by using the cluster option available within this statistical package. The results of the analyses were considered statistically significant when  $p < .05$ .

## RESULTS

### PARTICIPATION

Recruitment documents were distributed to 165 eligible women, of which 94 (57%) women agreed to participate. Of these, 2 women were ineligible due to limited English, 2 women could not be contacted, and 1 woman subsequently died. The data collected for two of the interviews were corrupted, resulting in 87 (53%) complete interviews. Of the AEP issuing centers, 11 were metropolitan-based and the remaining 9 were rural-based.

The demographic characteristics of the AEP participants are shown (see Table 1). A total of 55 (63%) women had applied for breast prostheses through AEP on more than one occasion. Of the 32 women who had applied for AEP funding only once, 20 (62%) were applying for funding for their first prosthesis and 12 (38%) were applying for funding for a replacement prosthesis. Women who had applied to AEP once ( $n = 32$ ) were compared with women who had applied multiple times ( $n = 55$ ). There were no significant differences between the two groups on any of the demographic variables.

**TABLE 1: Demographic Characteristics of Women Who Participated in the Survey**

<i>Demographic Characteristic</i>	<i>% of AEP Sample (N = 87)</i>
Age	
Less than 59 years	36
60 to 69 years	31
70 and older	33
Marital status	
Married	71
Separated/divorced	11
Widowed	15
Never married	2
Country of birth	
Australia	77
Employment status	
Full-time/part-time employed	16
Unemployed	1
Home duties	16
Retired/pension	67
Private health insurance	
Yes	55
AEP issuing center	
Metropolitan	68

NOTE: AEP = Aids and Equipment Program.

Of the 13 (45%) AEP service providers who were interviewed, 8 (61%) were metropolitan based; 10 (77%) were female; average length of employment with AEP was 9 years (2-20 years). The number of breast prostheses funded in the financial year (July 1999 to June 2000) ranged from 9 to 100. The average across the centers was 44 prostheses, and approximately 43% were first prostheses. The percentage of funding allocated to breast prostheses in the past financial year ranged from 1.4% to 10%, with an average across centers of 2% to 3%.

#### ACCESS TO INFORMATION

Of AEP service providers, 23% reported that the information received by women about obtaining funding for prostheses through AEP was either "excellent" or "very good," with 39% indicating the information provided was "fair" or "poor." According to the service providers, access to information was mainly from breast care nurses (BCNs) (85%) or fitters (85%). Although the majority (77%) of service providers provided information about how to apply for funding and the level of funding available, other

information about breast prostheses was limited. For example, only three (23%) service providers reported providing women with information about suppliers for prostheses.

Table 2 shows access to information about AEP funding for women who had applied once compared to those who had applied on more than one occasion, confirming service provider perceptions that BCNs and fitters were the most common source of information for first-time applicants. Compared to women who had applied on more than one occasion, women who had applied to AEP once were more likely to have found out about AEP through BCNs (34% cf 13%) or through fitters/retailers (28% cf 9%) ( $p < .05$ ). Significantly more women who had applied to AEP on more than one occasion found out about the funding through a GP (16% cf 6%) compared to women who had applied to AEP on one occasion only ( $p < .05$ ).

#### ADMINISTRATIVE PROCESSES

The administration procedures involved in providing breast prostheses were reported by service providers to be either "extremely easy" or "easy" (84%). Providers thought this because there is no direct contact with women because they are not required to obtain quotes to be eligible for funding. According to the service providers, the only complication was following up the doctor's referral letter that was necessary before funding was approved.

The majority of women also reported that the administrative procedures were either "extremely easy" or "easy" (82%) to complete through AEP, with 78% completing the AEP application forms without assistance.

#### WAITING PERIODS FOR FUNDING

The time taken to process an application for a breast prosthesis, from when an application was submitted until funding was available for the woman to go for her fitting, varied across AEP centers. Three centers (23%) reported no waiting periods in the past financial year (July 1999 to June 2000), one center reported a 2.5-week waiting period, whereas nine reported an average wait of 4 to 6 months.

Service providers were also asked what they considered the longest wait would have been for a breast prosthesis in the past financial year: 54% indicated 6 to 10 months. More than two thirds of service providers (69%) reported that breast prostheses were categorized as a "low priority" in terms of funding. Two service providers reported that because breast prostheses were such an inexpensive item, they processed them as they were received.



**TABLE 2: Women's Access to AEP Information**

	<i>First AEP Application</i>		<i>Multiple AEP Applications</i>	
	n	%	n	%
Breast care nurse	11	34	7	13
Fitter or retailer	9	28	5	9
Surgeon/hospital	6	18	12	22
Family/friends	2	6	9	16
Cancer Council Victoria/booklet	4	21	4	8
Mastectomy Association of Breast Cancer				
Support group/community center	4	12	1	2
GP	1	3	9	16
Other	5	15	7	13

NOTE: Percentages do not equal 100 due to multiple response.

Table 3 shows the proportion of women in the survey who indicated that they had to wait for funding or not. A total of 45% of women reported that they received funding immediately after their application was submitted. Of women who applied for the first time, 41% were able to get funding immediately, whereas 27% of the women who had applied through the AEP previously did not have to wait. However, this difference was not significant. Of those who had to wait for funding, waiting time ranged from 5 days to 6 months (average: 10 weeks).

The average length of time women had to wait for funding is shown in Table 4 for first-time applicants compared to all applicants. First-time applicants and women applying to nonmetropolitan issuing centers reported shorter waiting periods. Women who were applying for funding for their first prosthesis reported waiting times between 5 days and 3 months (average: 47 days).

#### SATISFACTION WITH WAITING PERIODS FOR FUNDING

According to service providers, perceived satisfaction with waiting periods among applicants varied according to length of waiting period. In centers where women had to wait for 6 months, service providers reported that applicants were generally dissatisfied, whereas service providers at centers with a 0- to 2-month wait reported applicants were extremely satisfied with waiting periods.

Women were asked how satisfied they were with the length of time they had to wait for the funding for their prosthesis. Logistic regression analyses

**TABLE 3: Access to Funding Experienced by Women Who Applied for a Prosthesis**

	<i>All Women</i>		<i>First Prosthesis (subset of first application)</i>		<i>First Application</i>		<i>Multiple Applications</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Able to get funding immediately	28	32	9	45	13	41	15	27
Had to wait	58	67	11	55	19	59	39	71
Do not know/remember	1	1	—	—	—	—	1	2

**TABLE 4: Waiting Periods Experienced by Women Who Applied for a Prosthesis for the First Time Compared to All Applications**

	<i>Minimum Wait (days)</i>	<i>Average Wait</i>	<i>Maximum Wait</i>
First prosthesis (55%)	5	47	90
All women (67%)	5	72	180

revealed significant reductions in level of satisfaction as waiting time increased. In the first analysis, satisfaction was measured as either “extremely satisfied” or “less than extremely satisfied.” There was a significant association between shorter waiting periods and extreme satisfaction ( $\chi^2 = 25.35$ ;  $p < .001$ ). Women were significantly less likely to say they were “extremely satisfied” with the waiting period if they had to wait longer than one week for their funding.

In the second analysis, satisfaction was measured as either “satisfied” or “not satisfied.” There was a significant association between satisfaction and shorter waiting periods ( $\chi^2 = 13.60$ ;  $p < .001$ ). Satisfaction levels did not vary significantly for waiting periods up to 30 days. However, beyond one month, women were significantly more likely to say they were not satisfied with the time they had to wait for financial assistance.

The majority of women (81%) who had to wait for funding were given an explanation as to the reason for the delay. The main reasons provided were “lack of funding and need to wait for further funding to be approved” (74%) and “there is a waiting list” (11%). Women reported being “satisfied” (57%) or “extremely satisfied” (23%) with the explanation provided.

Being satisfied with the explanation given for funding delays was significantly associated with higher levels of satisfaction with the length of time a woman had to wait ( $r = 0.58$ ;  $p < .01$ ), as well as with greater satisfaction with

the amount of funding provided ( $r = 0.31$ ;  $p < .05$ ). That is, the more satisfied a woman was with the explanation given as to why she had to wait, the less likely it was that she would become dissatisfied with the waiting period or with the amount of funding provided.

#### SATISFACTION WITH FUNDING AMOUNT

All the AEP service providers interviewed were "satisfied" or "extremely satisfied" with the funding ceiling of \$300. Women reported similar levels of satisfaction with the amount of funding provided for their prostheses. The majority of women reported being either "extremely satisfied" or "satisfied" (92%) with the amount of funding provided.

Funding varied across and within centers, with 55% of centers providing inconsistent funding amounts. In the past 12 months, seven centers provided the full subsidy to 61% of women but provided \$20 to \$170 less than the amount for which 39% of women were eligible.

There were no significant differences in satisfaction levels between women who had applied to AEP once and women who had applied more than once. However, older women (70+ years) reported significantly higher levels of satisfaction with the funding provided ( $F = 8.05$ ;  $p < .001$ ) compared with younger women.

AEP funding ranged from \$130 to \$395, with an average of \$258 (median \$252). Prostheses purchased ranged from \$130 to \$395, with an average price of \$283 (median price \$300). Overall, 33% of women had to provide extra money for their prosthesis over and above the funding provided by AEP, with 72% of these women reporting that this was acceptable. Extra contributions made by women ranged from \$20 to \$200 (average \$66). Women who had applied to AEP on one occasion were significantly more likely to have contributed their own money to pay for their prosthesis and to feel that this was acceptable than women who had applied on more than one occasion ( $\chi^2 = 3.58$ ;  $p < .06$  and  $\chi^2 = 6.74$ ;  $p < .01$ ).

There was a significant association between the amount of money a woman had to contribute from her own funds and satisfaction with the amount of funding provided ( $\chi^2 = 7.01$ ;  $p < .01$ ). The more money a woman had to contribute, the less satisfied she was.

#### CHOICE OF PROSTHESIS OUTLETS

All the service providers reported that women were given a choice as to where they could purchase their prosthesis.

By contrast, 31% of women interviewed indicated that they were not given a choice. A total of 50% of women who accessed AEP funding for their first prosthesis reported they were not given a choice of fitter compared with 26% of those who applied for a replacement prosthesis ( $\chi^2 = 3.50; p < .05$ ). Women who applied to AEP for the first time (whether it was for their first or subsequent prosthesis) were more likely to report not being given a choice (38%) compared to women who had applied on more than one occasion (27%). However, this difference was not statistically significant. Whether women were given a choice did not differ significantly between metropolitan and nonmetropolitan issuing centers. The most common reason given by AEP for recommending a particular outlet was that it was close to the woman's home (44%), whereas 22% of women who received a recommendation were given no reason.

#### DISABILITY QUESTION

Both service providers and women were asked their response to the disability question on the AEP application form. More than one third of service providers (38%) reported having experienced problems with the question on the woman's eligibility due to her disability, with women not completing the question, or indicating that they were not disabled.

Almost half of the women interviewed (49%) reported that it did not bother them answering this question, whereas 35% indicated that it was not appropriate. More than one third of the women (36%) said that they did not think they had a disability, whereas 11% did consider that having had a mastectomy meant they were physically disabled.

#### REPLACEMENT PROSTHESIS

The majority of service providers (77%) believed that a woman should be eligible for a replacement prosthesis when it was worn out or in need of repair, rather than every 2 years. Women reported that the average time since they purchased their last prosthesis was 5 years ago (range 2 to 20 years). All women were asked (without prompts) why they needed a replacement prosthesis. The majority (75%) reported that their old one was worn out, 15% said that their weight had changed such that their old prosthesis was now the wrong size, and 4% indicated that their 2 years were up.

### SUGGESTIONS FOR IMPROVEMENT

Women were asked their suggestions for improvement in accessing AEP. Overall, 65% of those who responded mentioned difficulty finding out about AEP funding and 17% mentioned the inappropriateness of the requirement for a doctor's referral letter, as women would not be applying for funds for a prosthesis unless they had had a mastectomy.

### DISCUSSION

This survey was undertaken to determine the level of satisfaction among clients who accessed funding through AEP services for breast prostheses and to explore opportunities to improve service provision in this area.

Before discussing the results, it is important to acknowledge the study's limitations. The results of this survey need to be considered in the context of participation. Although AEP service providers have kept some client records for at least the past 6 years, the level of detail makes it difficult to assess the representativeness of the sample. It is also not possible to assess nonresponse bias. Based on reports from AEP providers, 43% of first-time applicants accessed funds for their initial breast prostheses. In our study, there was an underrepresentation of first-time applicants with 23% of the sample who had applied to AEP for funds for their initial prosthesis. We assume our sample is an underrepresentation of this group of women. Our response rate was much higher than other studies involving a once-only mail-out (Picavet 2001) and the issues raised by the participants in this survey reflected similar issues raised in the focus groups that were undertaken on commencement of this study. We consider the concerns raised by women to be a fair indication of issues that are relevant to all clients of AEP who are accessing funds for breast prostheses. Similarly, although 45% of service providers participated in the survey, we cannot assume that the perceptions and issues raised by the service providers in the survey reflect all AEP service providers. However, this response rate is similar to other response rates achieved in other studies. In addition, the perceptions and issues raised by the service providers in preliminary discussions during focus group consultations were again similar to the results presented.

We believe this study highlighted interesting differences of opinion between AEP providers and clients. The survey found similarities and discrepancies between service providers and client perceptions in the provision of breast prostheses. AEP providers and clients reported satisfaction with the administrative processes, the level of funding available (\$300) and waiting

periods less than one month postapplication. The results also found that both AEP providers and women thought that information on how to access AEP was limited and that there was inequity in distribution of funds and inconsistency in the application of guidelines both within and across the AEP service providers. Providers rightly acknowledged the importance of BCNs and fitters in providing information to first-time applicants of AEP.

Service providers did not appear to have a clear view of the role of a breast prosthesis, which was generally given a lower priority compared to other aids and equipment, hence the waiting periods imposed on clients for their breast prosthesis. Although service providers indicated that clients were extremely satisfied with waiting periods up to 2 months, clients responded differently, with satisfaction decreasing significantly after 30 days. Providers also indicated that women were given a choice of outlets. However, women reported discrepancies in the choice of outlets offered.

The study proposes a number of recommendations, many of which have already been implemented. Educational strategies may also be introduced to reinforce new and existing policy guidelines.

The survey highlighted a level of complexity and variability across AEP service providers regarding waiting periods. This in turn influenced women's satisfaction with service provision and prosthesis use. For example, consistent and shorter waiting periods should apply across AEP issuing centers—ideally within one week for a first prosthesis, or within one month of application for replacement prostheses, rather than current waiting periods. This change would aim to reduce the potential impact of the loss of one or both breasts that has been shown to lead to an impaired feminine self-image (Reaby 1998). The initiative would require a significant challenge because waiting periods for all aids and equipment are based on demand, which varies from center to center and on the time of the year. However, improved assessment, priority-setting processes among prosthesis applications and provision of explanations for any potential delay in funding may improve the current situation. Second, a uniform subsidy of \$300 should be offered to all women who apply for funding through AEP to ensure equity to all applicants. Third, the results also highlighted the lack of information about AEP and availability of funding to potential clients. Provision of information has been found to be associated with higher levels of satisfaction (Tanner, Abraham, and Llewellyn-Jones 1983). An important avenue for accessing information about AEP could be through hospital clinics and doctors' surgeries. To improve client access to information, the results suggest that the availability of AEP funding be advertised through the distribution of brochures and/or posters to all clinicians' rooms, GPs, hospitals, Royal District Nursing Service branches, radiology clinics, and prosthesis retailers. Advertisements

should also be regularly placed in newsletters, such as those distributed by manufacturers of prostheses and consumer activist groups. Breast cancer support groups were also considered to be an important resource for women for accessing information about AEP.

In addition, many women questioned the requirement that a doctor's referral accompany every application and resisted the labeling implicit in the "disability question." However, following completion of this study, this issue had been addressed as part of a wider review of AEP, and women applying for prosthesis funding no longer need to complete the disability question.

Finally, women should be given a choice of prosthesis supplier. This provides women with the opportunity of being participants in decision-making processes, which in turn has an impact on their self-esteem. Allowing women to participate in decisions is beneficial to their adjustment to their cancer diagnosis (Butow et al. 1993; Manfredi et al. 1993).

The results of this research will form part of an overall review of breast prosthesis services, designed to improve women's access to quality prosthesis services. Revised policy initiatives are central to addressing the gaps to ensure equitable access to quality breast prosthesis services for all women.

## NOTE

1. Business name of the Anti-Cancer Council of Victoria.

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