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Economics

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

1999

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Wijk, P. V. D. (1999). *Economics: charon of medicine?*. s.n.

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Chapter 7 Economic evaluation of alternative ways of delivering care to people with a mental handicap

Summary

The traditional care for people with a mental handicap in the Netherlands consisted of an 'all-in' package of services: people with a mental handicap were almost without exception admitted into a residential home. Large institutions accommodated several dozens of people with a mental handicap.

Institutionalization was considered to have large advantages. However, there was growing documentation that institutional care had negative aspects. Ever since, a variety of innovative services has emerged in the care for people with a mental handicap. During the eighties, there has been a desire to deliver effective treatment in the least restrictive environment possible. Many non-economic reasons have been mentioned for this deinstitutionalisation. However, the cost side adds an important dimension to policy considerations regarding deinstitutionalisation.

In this pilot-study, a cost analysis was conducted, based on a longitudinal pretest-posttest design, to gain insight in the cost consequences of moving individuals from institutions to a small-scale setting. For this purpose, a model was constructed based on data from annual reports and a survey amongst parents and caregivers, including data about the costs before the transition (costs of intermediate care facilities) and after the transition (costs in small-scale settings).

The results show that there were no significant cost differences between clients in community-based small-scale facilities and residential care facilities. However, when costs of informal care are included, these results change dramatically. Depending on the assessment procedure used to value informal care, small-scale settings become 10%-25% more expensive.

*The present chapter is partly based on the following paper:
Wijk, P. van der; Groothoff, J.W.; Post, D.; Koopmans, L. (submitted).
Economic evaluation of alternatives for care in residential homes: Is deinstitutionalisation more expensive?*

7.1 Introduction

In the fifties large institutions were built to protect persons with mental retardation from society and to allow them to live in a safe, protective environment far from population centers. In these institutions hundreds of mentally handicapped people were admitted and received care for 24 hours a day. Moreover, they received a complete range of services including housing, food, paramedical services, etc. The Declaration on the Rights of Mentally Retarded Persons in 1971 can be seen as a turning point in the delivery of care for people with a mental handicap people. This Declaration states that *"whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life"* (General Assembly of the United Nations, 1971). Since then the terms normalization, integration and deinstitutionalisation have frequently been heard in the mental health care sector. Attitudes in the mental health care sector have changed, mainly as a result of several experiments which demonstrated that people with a mental handicap can live successfully in local communities provided that they are given appropriate support. Several non-economic reasons have been mentioned for deinstitutionalisation, for example adaptive behavior improvement, quality improvement and normalization. Although, the driving forces behind normalization and deinstitutionalisation are not economic, financial aspects play an important role in the diffusion of such experiments to a more national level. When community-based service models were implicitly mandated to provide the mechanism that would enable retarded people to experience independence, autonomy, freedom of choice, and respect - dimensions that are considered to be important items of an individuals quality of life (Emerson, 1985)- the government explicitly asked for more details about cost consequences.

One of the most important economic incentives to deinstitutionalisation in the Netherlands was the fact that more and more innovative forms of care were included in the Exceptional Medical Expenses Act (AWBZ). This strong tendency towards independent living arrangements for people with a mental handicap (and elderly people), led to a big increase in expenditure for housing within the AWBZ. The question rose whether the costs of housing should remain part of the budget of the health care sector, and in particular of that of the Exceptional Medical Expenses Act. A distinction between the costs of

housing and care was proposed. The most important motivation underlying this concept was that other people in society must pay their own rent too (normalization).

The financial consequences will play a major role in the decision making on the continuation of small-scale settings. In this light, it seems strange that so little information is available to support policy decisions on care for people with a mental handicap. This is not only the case with regard to care for people with a mental handicap, but also with regard to other care activities. In the Netherlands, economic research in this sector is still in its infancy. In the international literature, the attention paid to this aspect is fairly recent (Dockrell, 1995; Hatton et al., 1995; Knobbe et al., 1995; Beecham et al., 1997).

The aim of this paper is to explore the economic impact of deinstitutionalisation of care for people with a mental handicap in a broad sense: What will be the financial implications of introducing this policy of transitioning retarded people to small-scale settings on a societal base.

7.2 Material and methods

Subjects

32 subjects were included in this pilot-study, all of whom were enjoying intermediate care facilities. Participation of staff was necessary for selecting patients suitable for care arrangements outside the institution. Therefore, a random design did not reflect the daily decision making situation. Because the government wanted to be informed about the cost consequences for a large range of clients, participants were taken from different classes of people with a mental handicap, but all of them were expected to succeed in the small-scale environment. The characteristics of residents are presented in table 1.

Table 1: Client characteristics of all participants

	Age	Sex	Level of mental retardation	no.	Physical handicaps	Visual handicaps	Challenging behavior
Intermediate care facility (N=32)	23	44% M 56% F	Light:	9	22 %	11%	11%
			Moderate:	11	18 %	18 %	18%
			Severe:	7	43%	43%	29%
			Very severe:	5	80%	60%	20%

The assessment of impairments and level of mental retardation were derived from the judgment of clinical, educational and care staff in each facility. As can

be seen, the majority of participants were judged to suffer from moderate mental retardation, as well as some sort of visual, hearing and physical impairments more mixed. The ratio of male to female participants was almost equal. The average age was 23 years. Additional problems of a physical nature (for instance dependence on a wheelchair), visual problems and major challenging behavior (aggression, self-injury) were scored extensively, but only the general figures are shown here. Despite the high percentage of subjects with additional problems, all subjects were expected to be fit to live in a small-scale institution.

Settings

The costs of two different service modes were compared: a traditional (an intermediate care facility) and the new concept of delivering more tailor-made care in small-scale settings. Both services basically provide 24-hour staff support for residents.

People in the intermediate care facility live in small units, with usually no more than 24 residents. Generally, these facilities have a central kitchen and cleaning staff. The day program is carried out at a special educational or habilitative center in the neighborhood.

Small-scale settings differ in nature and size. Facilities with two to six people were included in this research project. In these houses, domestic and cooking tasks are performed out by care staff and residents.

Costs

The examination of community-based small-scale settings and institutional costs was based on principles widely applied in health economics, described by Knapp (1995) and Gold et al., (1996). Costs were measured integrally, and from a societal perspective, in order to include all cost components.

Furthermore, cost comparisons were made on a like-with-like basis, comparing individuals that move from one setting to another.

As information about the costs of small-scale settings was scarce, the costs calculation was based on a survey amongst parents and personnel. Nature, frequency, and duration of all health and welfare services provided to participants during the 3 months prior to their relocation to a small-scale setting were included. Direct care costs were measured in the month before the patient's relocation to a small-scale setting. During one week all staff activities were registered. Included were: all direct contacts with clients, indirect client-related activities, and not assignable time of caregivers (like time spent on

group care, staff meetings and supervision). These data were gathered on a day-to-day basis by interviews with members of staff. Care time was registered on several care items: time for support in instrumental activities (cleaning, doing the dishes, etc.); care time necessary for daily life activities (washing, getting dressed, eating, etc.); nursing care (providing medication, tending to patients with an epileptic attack, etc.); and time for support with respect to psychological functioning and challenging behavior. The one-year outcome of the evaluation of the two groups was analyzed by applying the Wilcoxon Matched-Pairs Signed Rank Test. In all statistical tests a significance level of .05 was chosen. Furthermore, 95%- confidence intervals were computed for all groups of care activities.

Further direct costs include: time costs of primary caregivers, medical consumption in complementary facilities (hospital admission, visits to general practitioner, visits to paramedics), care appliances, transportation, housing (rent, depreciation, equipment, maintenance) and food provision (e.g. Meals-on-Wheels). Such a detailed analysis was necessary because the budgetary system in the Netherlands includes part of them in the institution's budget, while in small-scale settings they are excluded and therefore at the cost of the individual. A cost analysis at the societal level should include all these cost components.

Another important reason for individual costing is the fact that in small-scale settings the support from informal caregivers is in general much higher. To identify these costs additional questionnaires were used to obtain details about informal care (*direct non-medical costs*), and to try and find out if lost wages and productivity losses (*indirect costs*) by relatives play a role. Measurement of these informal care hours was simply done in minutes per day. The interpretation of these figures and the valuation of them are very difficult. We used two methods to assess informal care. First, the opportunity-cost method, which proposes to value time spent on informal care as the cost of the best alternative use of resources for that time. When the time spent on informal care would otherwise have been spent on working for a wage, that time should be valued as being equal to that wage (Busschbach et al., 1998). Second, the shadow-price method, which simply uses the cost that would have occurred when the informal care was performed by professional caregivers. To value the activities performed by informal caregivers, the same list of activities was used to establish the care intensity of individuals. For instance, helping to take a bath took professional caregivers 15 minutes. The assistance with bathing, which took informal caregivers one hour, was valued at 15 minutes.

Three-months cost estimations of individuals were compared to the situation before the transition using the Wilcoxon Matched-Pairs Signed Rank Test. Overhead costs were divided over clients on an average basis, because these types of costs can hardly be assigned to individual clients.

7.3 Results

Direct care-related costs

Table 2 provides data about the individual care intensity of all clients in the different settings.

Table 2 Care intensity for individual activities of caregivers and costs in different setting for all groups of people with a mental handicap (in minutes per client per week)

	Intermediate care	Small-scale
<i>Individually assignable tasks</i>	<i>N=32</i>	<i>N=32</i>
Instrumental activities	105	85
Activities of daily life	24	12
Nursing care	7	7
Psychological functioning	112	114
Total	248	218
95%-confidence interval	225-271	201-235
Wilcoxon Matched-Pairs Signed Rank Test:		*
<i>Not face to face, but individually assignable</i>	180	172
95%-confidence interval	174-187	164-181
Wilcoxon Matched-Pairs Signed Rank Test		NS
Other (including sickness, etc)	725	610
95%-confidence interval	600-850	540-680 ¹
Informal care – opportunity time	160	200
95%-confidence interval	90-230	110-290
Wilcoxon Matched-Pairs Signed Rank Test		NS
Informal care – shadow time	70	90
95%-confidence interval	30-110	45-135
Wilcoxon Matched-Pairs Signed Rank Test		NS

* p < 0,05

¹ Not individually assignable, so no difference tests possible

The resident-staff ratio in the intermediate care facilities was 1:0.53. Therefore, an average of 19.1 hours per week per resident was available¹. More

¹ 0,53 * 36 hours, which is the average amount of hours a professional worker is available in the Dutch care sector.

than 4 hours were directly assignable to individual clients. Another 3 hours of care were used for indirect client-related activities (such as administrative work, group consultation for certain clients, etc.). Approximately 12 hours could be attributed to group-related activities, group care activities, or at least to helping different individuals at the same time.

On average, per resident in small-scale settings, 0,43 full-time equivalent per week is available for professional caring in small-scale facilities, i.e. means 16.6² hours. Only 22% (3.5 hours) of these care hours can be attributed to individual care of residents. 2.5 hours are indirect client-related activities. A little over 10 hours is left for group activities, etc.

As can be deduced from the table, in small-scale settings less care is needed for instrumental and daily life activities. This development can be partly accounted for by the fact that the inhabitants perform more tasks themselves, especially when it comes to cooking, doing the dishes, cleaning, etc. Savings on personnel in these small-scale settings may very well be possible. However, there will always be need for a supervisor.

In Table 3 the averages of individual costs for direct care are presented, based on three different levels of specialized personnel. Overall, no significant differences in costs as a result of differences in care intensity could be detected, not even when informal care minutes were added. Indirect costs (productivity gains or losses) were not taken into account. None of the participants said to have started or quit their job during the research period.

²0,43 * 36 hours.

Table 3 Individual costs of care time in Dutch guilders

	Intermediate care facility N = 32	Small-scale setting N = 32
Wage of caregivers per hour (gross) ¹		
-Nurse	36.-	36.-
-Coach/caregivers	33.-	33.-
-Household	27.-	27.-
-Informal caregivers	20,-	20,-
Total weighted individually assignable time per client per day ³	21.3	18.7
Not face to face	14.6	13.8
Not individually assignable	57.0	47.9
<i>Total</i>	92.9	80.4
95%-Confidence interval	71.5-114.3	73.8-97
<i>Informal care</i>		
Opportunity cost method	7.5	9.6
Shadow-price method	5	6.5

¹ Including costs for the employer and income taxes.

² Many of the informal caregivers do not have a paid job. That is why the average wage rate of informal caregivers is below that of the professional caregivers, although the care sector is not famous for its high salaries.

³ Based on the division of activities: housekeeping activities were mostly provided by a less specialized worker than the other activities. Nursing care was only done by qualified nurses.

Total costs

In Table 4 the averages of individual costs for the different care facilities are presented. Average societal costs for an intermediate care facility are Dfl. 175.5, and for a small-scale setting Dfl. 171. In all settings, costs of personnel account for more than 50% of total costs. There seem to be considerable differences between various settings in the staff time not spent on performing primary tasks. Especially in the small-scale settings administrative activities are often performed by the executive staff during their working hours. Average costs for day care activities are added for both settings, because they are not included in the all-comprehensive package of services provided in these facilities. This amount of Dfl. 37.- is the weighted average cost for people attending special schools, working in a sheltered workshop or spending time in a day care facility, two days a week. Although the pattern of activities does not change, people in small-scale settings tend to attend more activities outside their own home. This volume effect causes an increase in the costs of day care activities, as shown in Table 4. Additionally, the cost of transportation rises and

client bounded expenses increase. In general, the average societal costs of care delivery do not change significantly, not even when we take the amount of informal care into consideration.

Table 4: Average of individual costs (in guilders) per day, divided in eight cost categories

	Intermediate care facility		Small-scale setting	
	Absolute	in %	Absolute	in %
Personnel not executing primary tasks	7.-	4.0%	4.0	2.3%
Personnel executing primary tasks	93.0	53.0%	81.0	47.4%
Food	7.5	4.3%	9.0	5.3%
Cleaning, etc.	1.0	0.6%	n.a. ¹	
Client bounded	1.0	0.6%	4.0	2.3%
Transport	1.0	0.6%	4.0	2.3%
Overhead	8.5	4.8%	3.5	2.0%
Housing	19.5	11.1%	20.0	11.7%
Daycare	37.- ²	21.1%	45.5- ²	26.6%
Total	175.5	100 %	171.-	100 %
95%-confidence interval	160-191		144-206	
one-way ANOVA			NS ³	
Informal care	5-7.5		6.5-9.6	

¹ Mostly included in the personnel executing primary tasks.

² The average costs for day care activities, two days a week.

³ No significant differences were found in cost patterns between facilities.

7.4 Discussion

At present, literature on costs of deinstitutionalisation which particularly focuses on people with a mental handicap is still scarce, although there are some studies from the UK and the USA. The results are diverse. The correlation between size of the facility and cost is not clear. Heal (1987) concludes that larger facilities are more expensive. However, this conclusion is confounded by the fact that the larger facilities are owned by the state. Public facilities are found to be more costly than private facilities (Heal, 1987). On the other hand, the results of Nerney et al. (1990) contradict this outcomes. They concluded that smaller facilities with fewer than six residents appeared to be more expensive. Campbell and Heal (1995) suggested a U-shape relation with facility size, with intermediate-sized facilities being the least costly. Knobbe et al. (1995) found some public savings for community-based alternatives when compared to state institutions. Hatton et al. (1995) compared four different

service models at a single point in time. Comparing specialized institution-based units, a specialized campus-style education service, specialized community-based group homes, and ordinary community-based group homes (which probably reflects best the small-scale settings included in this study), they found that the specialized group-home model was to be preferred, since this model was not associated with considerable high costs. This conclusion seems to be supported by the results of our study. Dockrell et al. (1995) describe how closure of long-stay mental handicap hospitals leads to a range of new resettlement initiatives for clients with learning disabilities, which were on average 25% more expensive, while improving the quality of life of individuals on attributes like personal privacy, choice/autonomy, participation in domestic activities, access to the neighborhood and the use of community facilities. Beecham et al. (1997) conclude that, at mean, community care was less expensive than long-stay in-patient care. Ashbaugh and Nerney (1990) find that variety in costs between community care settings and larger scale facilities mainly depend on staff-to-resident ratios. The results of our study seem to support these findings. Furthermore, our analysis suggests that from a societal perspective, small-scale settings are not significantly more expensive intermediate care facilities, while participation in domestic activities and use of community facilities seemed to increase. A subgroup analysis, considering the relation between the severity of the mental handicap and individual costs, could not yet be performed, due to the small number of clients in each class of mental handicap.

The most important potential shortcoming of most cost comparative studies on the care for people with a mental handicap is the selection bias resulting from the confounding of resident characteristics between different settings. Type and level of disabilities vary systematically between different care arrangements. This points directly to the necessity for an individualistic costing procedure, which can only be researched in a matched group comparison or a longitudinal design. In this pilot-study we used a longitudinal design, following people who first lived in an institution or in an intermediate care facility and then moved into a small-scale setting. These people, as such, serve as their own controls.

Due to the intensive method of observations, the number of individuals included in the study was small, thereby reducing the degree to which findings can be generalized to other settings.

In this study a first trend can be seen that individuals in small-scale settings tend to make more use of public facilities, like public transport and day care

facilities. In general, no significant cost increase could be found from the transition of people with a mental handicap from intermediate care facilities to small-scale settings.

A special problem in economic evaluations in the care sector is the identification, measurement and valuation of non-care-related and indirect costs. In this study we measured total informal care time using interview data. Although the concept of informal may be clear, the measurement and valuation of care minutes remains problematic. What items have to be included (which activities are regular and which are specifically related to the mental handicap), how much time do we account for them (is 24-hours surveillance counted for 24-hours or just for a fraction of that, because it is possible to do something else during that time), and what is the monetary value of an hour invested in caregiving. For the valuation of this informal care time we used two different methods: the opportunity-cost method and the shadow-price method. Both seem to have their pros and cons (Busschbach, 1998). In this study, the amount of informal care and the value of it did not dramatically change the results. When, however, a pure home-care alternative is evaluated, informal care is likely to have a large influence on total costs. A discussion about measurement and valuation of these costs in economic evaluation, especially in the care sector, seems necessary.

Acknowledgement

This study was supported by the Dutch Ministry of Welfare, Health and Sports

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