



Ruj.Kami : ISM.600-5/4/44 (73)
Tarikh : z Mei 2023

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Pensyarah Kanan
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Kulkiyyah Kejururawatan
Universiti Islam Antarabangsa Malaysia
Kampus Bandar Indera Mahkota
25200 Kuantan
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YBrs. Dr.,

**LANTIKAN SEBAGAI PEMBENTANG PROGRAM KOLOKIUUM PENYELIDIKAN
SOSIAL INSTITUT SOSIAL MALAYSIA (ISM) SIRI 5/2023**

Dengan hormatnya saya merujuk kepada perkara di atas.

2. Sukacita dimaklumkan bahawa Institut Sosial Malaysia (ISM) melalui Kluster Penyelidikan dan Pembangunan akan menganjurkan Program Kolokium Penyelidikan Sosial ISM tahun 2023. Program ini dirancang setiap bulan bermula bulan Januari sehingga Oktober 2023. Program ini bertujuan untuk mengetengahkan hasil dan dapatan penyelidikan/kajian yang telah dilaksanakan oleh pegawai-pegawai agensi, pakar-pakar akademik serta pakar bidang dalam isu-isu sosial.

3. Sehubungan itu, ISM dengan sukacitanya ingin melantik YBrs. Dr. sebagai pembentang Program Kolokium Penyelidikan Sosial ISM Siri 5/2023 ini dengan tema 'Orang Kurang Upaya (OKU)' seperti ketetapan berikut:

Tarikh : 30 Mei 2023 (Selasa)

Masa : 9.00 pagi – 11.30 tengahari

Kaedah Pelaksanaan : Dalam Talian (Zoom Meeting)

4. Pembentang yang dilantik akan dibayar sagu hati berdasarkan Pekeliling Perbendaharaan Bil. 2 Tahun 2005. Bersama-sama ini disertakan borang tuntutan untuk tindakan YBrs. Dr. selanjutnya. **Dimohon jua agar YBrs. Dr. dapat mengemukakan sesalinan kad pengenalan, penyata gaji terkini, salinan buku bank, sijil akademik yang berkaitan untuk proses pembayaran tuntutan.**

5. Untuk makluman YBrs. Dr., kertas kerja yang dibentangkan dalam kolokium akan diterbitkan dalam buku Prosiding Kolokium. Mohon kerjasama YBrs. Dr. untuk menghantar manuskrip pada atau selewat-lewatnya **14 hari selepas tarikh program**.

6. Sebarang maklumat lanjut berhubung perkara ini boleh hubungi **Encik Lee Cheng Kiik di talian 017-6636166** atau **cklee@ism.gov.my**. Segala perhatian dan kerjasama pihak YBrs. Dr. mengenai perkara ini amatlah dihargai dan diucapkan terima kasih.

Sekian.

“MALAYSIA MADANI”

“BERKHIDMAT UNTUK NEGARA”

“ILMU • SEJAHTERAKAN • MASYARAKAT”

Saya yang menjalankan amanah,



(ROHEMI BINTI HAJI RUSLI)

b.p Pengarah

Institut Sosial Malaysia



الجامعة الإسلامية العالمية ماليزيا
INTERNATIONAL ISLAMIC UNIVERSITY MALAYSIA

Kajian Bebanan Ekonomi Ibubapa dan Penjaga Kanak-Kanak Kurang Upaya yang Mengikuti Program Pemulihan Dalam Komuniti (PDK) di Negeri- Negeri Pantai Timur Malaysia.

A study on economic burden of parents and caregivers for Children with Disabilities that Participate in Community-Based Rehabilitation (CBR) Programmes in the East Coast States of Malaysia

Anjuran:
Institut Sosial Malaysia

INTRODUCTION

Statistic Global

- 16% of global population (7.999 billion in 2022)

Statistic Malaysia

- 586,558 PWDs registered in 2021
- 633,653 PWDs registered in 2022

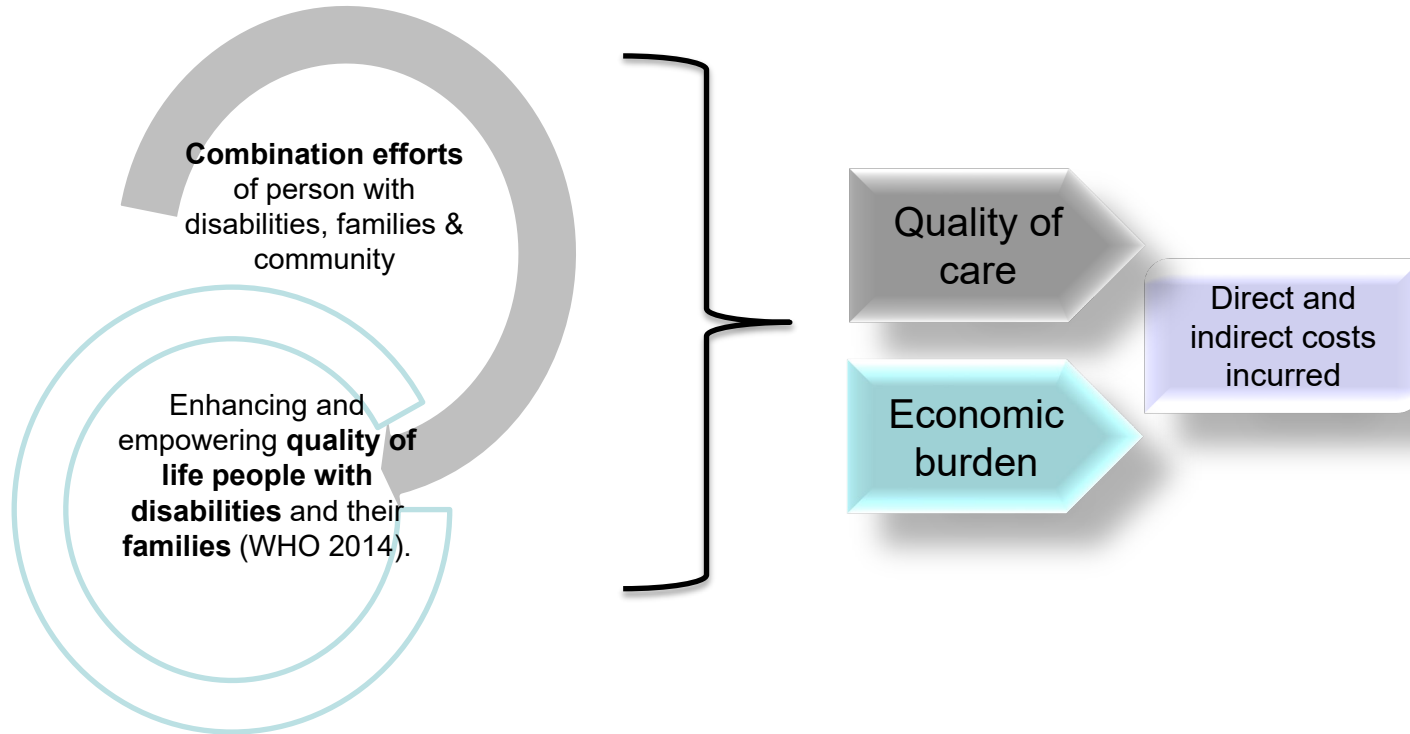
Long-term care

- Economic burden
- Physical burden

CBR (PDK)

- Since 1970s
- Centre-based care & home-based care
- More than 90 countries including Malaysia

CBR (PDK) PROGRAMME



OBJECTIVES

General objective:

To estimate the cost incurred by parents and caregivers of children with disabilities participating in Community-Based Rehabilitation (CBR) in East Coast of region of Malaysia.

Specific objectives:

1. To determine the direct and indirect costs of centre-based and home-based care in Community-Based Rehabilitation (CBR) programmes.
2. To compare the direct and indirect costs between centre-based care and home-based care in Community-Based Rehabilitation (CBR) programmes.

METHODOLOGY

Design

- Cross-sectional study design

Setting

- Pahang, Terengganu & Kelantan
- 30 CBR

Sample

- 297 children with disabilities
- 297 parents and caregivers of children with disabilities

Sampling

- Multi-stage sampling methods

Study tool

- Activity-Based Costing (activity diary)

Analysis

- SPSS 23.0
- Independent T-test, Chi-square test, Mann-Whitney test
- Mean (SD) , Median (IQR) value
- P-value

RESULTS

Table 1: Socio-demographic of children with disabilities

Variables	Centre-based care (N= 160) Mean±SD or Frequency (%)	Home-based care (N= 137) Mean±SD or Frequency (%)	t-test or Chi-square test	P - value
Type of CBR	160(53.9)	137(46.1)		
Gender			$\chi^2 = 1.834, df = 1$	0.176
Female	60 (37.5)	62 (45.3)		
Male	100 (62.5)	75 (54.7)		
Age, years	8.64±3.75	11.85±4.37	$t = -6.723$	< 0.001*
0-12 years	131 (82)	72 (52.6)		
13-18 years	29 (18.2)	65 (47.4)		
Type of disability			$\chi^2 = 8.170, df = 4$	0.086
Hearing	1 (0.6)	1 (0.7)		
Visual	3 (1.9)	2 (1.5)		
Physical	26 (16.3)	47 (34.3)		
Learning	35 (21.9)	20 (14.6)		
Multiple	95 (59.4)	67 (48.9)		

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Table 2: Socio-demographic of parents and caregivers

Variables	Centre-based care (N = 160) Mean±SD or Frequency (%)	Home-based care (N = 137) Mean±SD or Frequency (%)	t-test or Chi-square test	P- value
States			$\chi^2 = 9.542,$ df = 2	0.008*
Pahang	51 (31.9)	23 (16.8)		
Terengganu	50 (31.3)	58 (42.3)		
Kelantan	59 (36.9)	56 (40.9)		
Age, years	41.08±8.91	43.11±9.89	$t = -1.864$	0.063
20 – 30 years	23 (14.4)	11 (8.1)		
31 – 40 years	50 (31.4)	48 (35.0)		
41 – 50 years	64 (40.2)	49 (35.6)		
51 – 60 years	22 (13.7)	17 (12.4)		
> 60 years	1 (0.6)	12 (8.7)		
Ethnic			Fisher's Exact test = 1.397	0.378
Malay	156 (97.5)	136 (99.3)		
Others	4 (2.5)	1 (0.7)		
Education levels			$\chi^2 = 17.775,$ df = 2	0.002*
Not attend school	0	7 (5.1)		
Primary school	20 (12.5)	17 (12.4)		
Secondary school	121 (75.6)	83 (60.6)		
College or university	19 (11.9)	30 (21.9)		

Variables	Centre-based care	Home-based care	Test	P-value
Education levels			$\chi^2 = 17.775,$ df = 2	0.002*
Not attend school	0	7 (5.1)		
Primary school	20 (12.5)	17 (12.4)		
Secondary school	121 (75.6)	83 (60.6)		
College or university	19 (11.9)	30 (21.9)		
Occupation fields			$\chi^2 = 28.471,$ df = 6	< 0.001*
Professional	16 (10.0)	16 (11.7)		
Managerial	4 (2.5)	3 (2.2)		
Support	16 (10.0)	33 (24.1)		
Own business	23 (14.4)	11 (8.0)		
Unemployed	6 (3.8)	13 (9.5)		
Housewife	95 (59.4)	56 (40.9)		
Pension	0	5 (3.6)		
Monthly household income, RM			$\chi^2 = 82.04,$ df = 47	0.001*
< 5,000	152 (95.0)	131 (95.5)		
5,001 – 10,000	6 (4.0)	5 (3.6)		
> 10,0001	2 (1.0)	1 (0.7)		
Source of income			$\chi^2 = 20.973,$ df = 5	0.001*
Salary	128 (80.0)	106 (77.4)		
Pension	3 (1.9)	8 (5.8)		
Children	6 (3.8)	3 (2.2)		
Social welfare services	2 (1.3)	10 (7.3)		
NGO/religious bodies	0	3 (2.2)		
Others	21 (13.1)	7 (5.1)		

*Significant level at p – value < 0.05, df = degree of freedom.

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Table 3: Direct and indirect costs of caregivers per year

Type of Cost	CBR Programme		Mann Whitney test, Z	P-value
	Centre-based care	Home-based care		
	Median (IQR)			
Direct cost (RM)	535.00 (706.00)	55.00(816.00)	-10.578	< 0.001*
Indirect cost (RM)	72.73(51.66)	1,927.27 (11,933.18)	-10.346	< 0.001*
Total CBR cost per year (RM)	607.73 (738.98)	2,375.91 (11,227.64)	-8.830	< 0.001*
	Medications and supplements			
	Median (IQR)			
	1,320.00 (1,978.00)	450.00 (877.00)	-0.709	0.478
	Alternative Rehabilitation			
	Median (IQR)			
Direct cost (RM)	939.18 (524.85)	1,826.23 (17,703.27)	-3.926	< 0.001*
Indirect cost (RM)	4,375.00 (7,334.00)	855.00 (5,851.00)	-0.494	0.621
Total Alternative cost per year (RM)	6,726.36 (7,987.00)	4,499.25 (25,239.00)	-0.608	0.543
Total caregivers' cost per year (RM)	7,392.12 (6,848.77)	8,065.53 (36,938.78)	-5.504	< 0.001*

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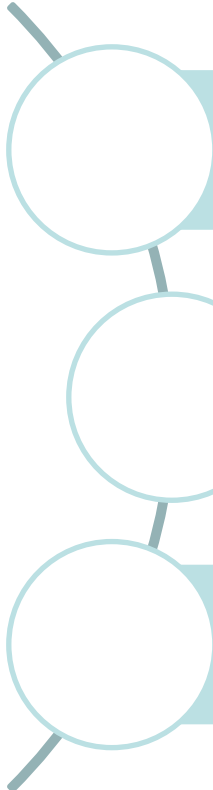
Table 4: Comparison of unit cost for caregivers' mean cost by components (2014)

Unit cost	Centre-based			Home-based		
	Mean cost (RM)	Minimum cost (RM)	Maximum cost (RM)	Mean cost (RM)	Minimum cost (RM)	Maximum cost (RM)
CBR Programme						
Insurance	54.28	50.00	55.00	54.48	50.00	55.00
Additional	72.17	60.00	100.00	-	-	-
Transportation	568.63	24.00	3,840.00	-	-	-
Government rehabilitation						
Additional	102.80	2.00	818.00	126.66	20.00	480.00
Transportation	200.36	6.00	1,280	1,080.14	20.00	9,600.00
Food	172.90	20.00	1,080.00	672.81	20.00	2,400.00
Private rehabilitation						
Treatment	452.72	60.00	1,440.00	404.00	40.00	1,400.00
Additional	67.60	4.00	200.00	500.00	500.00	500.00
Transportation	166.31	20.00	400.00	490.00	20.00	2,400.00
Food	130.00	20.00	360.00	2,430.00	60.00	4,800.00
Alternative rehabilitation						
Treatment	354.78	40.00	2,400.00	441.25	40.00	2,400.00
Additional	2,981.60	4.00	14,400.00	1502.00	4.00	3,000.00
Transportation	565.47	10.00	7,200.00	1,039.64	10.00	7,200.00
Food	559.50	10.00	2,400.00	650.00	10.00	2,400.00

DISCUSSION

- The caregivers' costs incurred from direct and indirect costs spent for participation in the CBR programme and other alternative rehabilitation.
- The median total parents and caregivers' cost for CBR programme was higher among home-based care compared to centre-based care.
- Both groups of parents and caregivers spent significant amount of resources on alternative rehabilitation.

CONCLUSION



Monthly income spent on alternative rehabilitation contributing to the magnitude of the economic burden of the family.

This study provide evidence-based costing for the Department of Social Welfare and World Health Organization.

Significant for health care providers and policymakers to address on effectiveness of CBR programme and awareness of alternative rehabilitation by parents and caregivers of children with disabilities.

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- Department of Social Welfare Malaysia.
- Pusat Pemulihan Dalam Komuniti Negeri Pahang, Terengganu and Kelantan

