



Alliance for Action for Caregivers of Persons with Disabilities

Project 3i

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CEO, CaringSG

Scope of presentation

- Background to SG Together Alliance for Action (AfA) for Caregivers of Persons with Disabilities
- Project 3i & Proof-of-concept
- Upscaling plans & Future

Disability - Prevalence and Disease burden

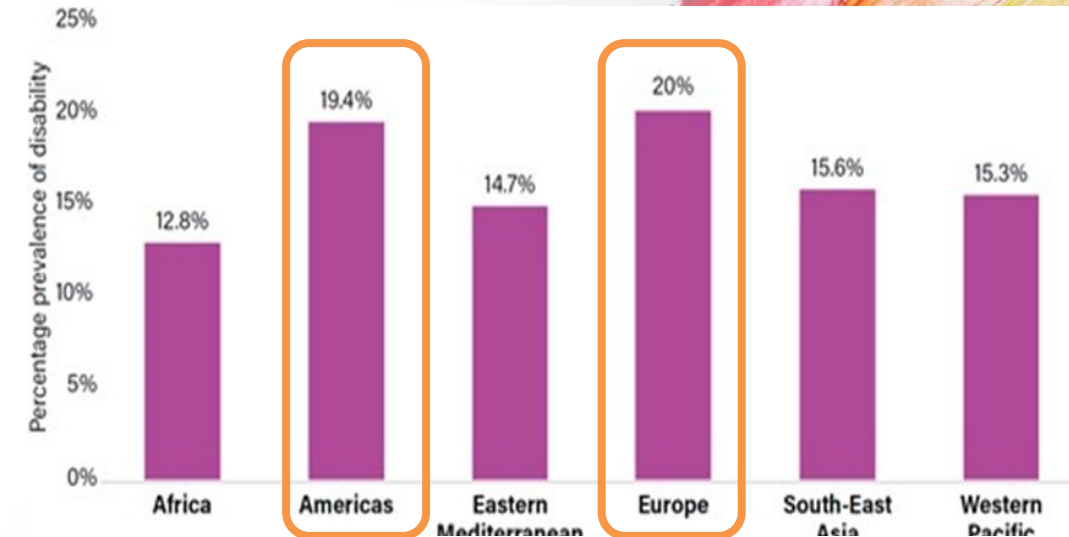
In Singapore

- Overall (including mental disorders/poor mental health & invisible disabilities) = **19%** (760,000) → similar to US & Europe

https://cfps.org.sg/publications/the-singapore-family-physician/article/2009_pdf

<https://doi.org/10.33591/sfp.49.8.u6>

Groups	Ages	Visible ⁶	Invisible ⁷	Psychosocial	Total
Children & youth	0-4	5000 (3%) ¹			95,600
	5-19	13,000 (2.1%) ²	27,000(4.4%) ³	50,600 ⁴ (12%)	
Adults	20-49	59,000 (3.4%) ²		405,500 ⁵ (13.4%)	664,500
	>50	200,00 (13.3%) ²			
Total		277,000	27,000	456,100	760,100



Source: Global Burden of Disease data, 2021

¹ & ⁵ MOH ; ² Enabling Masterplan 2017; ³ MOE; ⁴ NUS YEAR study

⁶ Visible Disabilities – Physical, Sensory, intellectual; Mod-severe Autism

⁷ Invisible Disabilities – Developmental

- **Dependent- related caregiving challenges**

- Difficulties navigating the complex and confusing Disability service landscape
- High caregiving burden
- Lack of respite support and adult services

- **Unmet Caregiver needs**

- Impact on psychological well-being and physical health; lack of self-care
- Reduction in financial resilience; financial needs
- Lack of knowledge and skills in caregiving

- **Impact on Families**

- Strained family relationships and weakened social support
- Increased prevalence of marital discord and family violence



**Caregiver
needs care too**

Alliance for Action (AfA) for Caregiver of Persons with Disabilities



2017-2021

2018-2021

2021

GROUND FEEDBACK

Strengthening support for caregivers of PWDs also highlighted during Emerging Stronger Conversations & Conversations on Singapore Women's Development

FOCUS

Ride on Caregiver Action Map developed by SG Enable, Coalition of Partners (COP) & IPS, with focus on developing solutions related to *self-care and mutual support*

ALIGN TO NATIONAL PLANS

Complement **EMP3** on improving caregivers' well-being and enhancing caregiving capabilities through network of support

CONCEPTION

Formation of AfA by NCSS and SG Enable for caregivers of persons with disabilities announced during COS 2021



An Overview

AfA Implementation

KEY PROJECTS

- **Project 3i** led by CaringSG, to pilot model of community and peer support for caregivers
- **Community Circles** co-led by IPS & CaringSG to rally and connect groups of volunteers to caregivers to offer practical support in daily lives



STRUCTURE

- Led by **SG Enable & NCSS**
- Co-chaired by **CaringSG & ODGSW**
- Driven by a **Core Action Team**, with representatives from 3P partnership to contribute expertise and networks

Collaborations & Sharing

- **Insights & best practices** sharing among SSAs and private providers to uplift the sector
- **Other interested organisations & members of public** contribute as collaborators/partners to AfA projects

CaringSG



A caregiver-led initiative for caregivers of persons with disabilities, set up in **2020**. CaringSG is a registered charity and IPC (since 2023). We support caregivers of all disabilities across all ages.

Board supported by **3 advisors**: Mdm Rahayu Mahzam (Minister of State, MOH & MDDI), Mayor Denise Phua, Dr Gerard Ee

Community Pillars:

- ❑ **>45** caregiver leaders and advocates that work through an informal caregiver support network with reach of >8000 caregivers; 5300 members & 4100 registered caregiver members to date
- ❑ **>400** volunteers & **>50** professional allies



Ms Denise Phua



Dr Gerard Ee Hock Kim



Ms Rahayu Mahzam





Every Caregiver Well & Empowered

CaringSG is a registered charity and Institution of Public Character (IPC) set up by caregivers for caregivers of person with special needs.

JOIN US TODAY!

<https://www.caring.sg>



Compassion



Respect



Inclusive



Partnership



Innovative

3i caregiver support service model

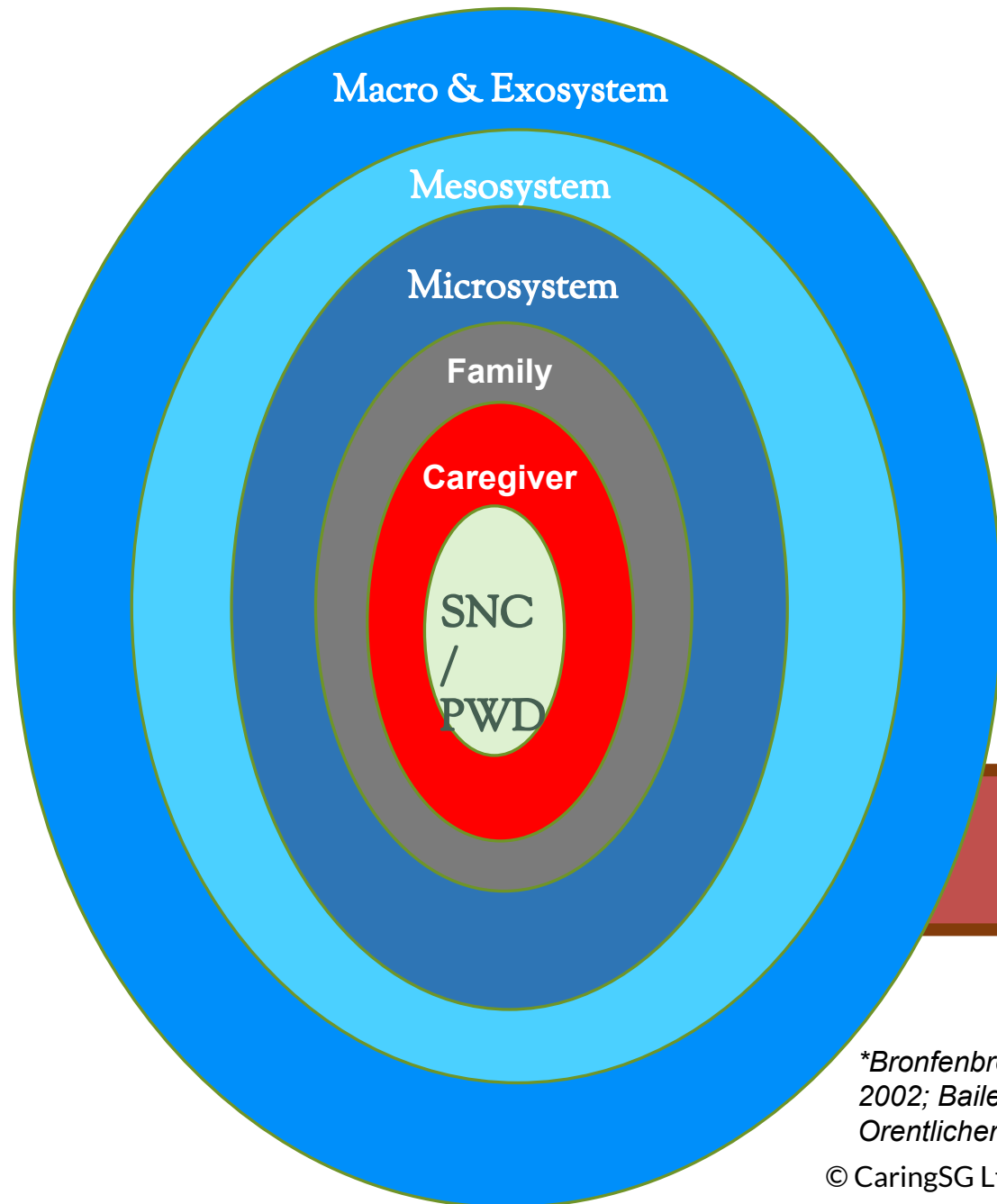
Project 3i of AfA for Caregiver Support



A 3D puzzle with one red piece standing out among grey pieces. The red piece is in the center-right of the frame, and the other pieces are arranged around it, some in the foreground and some in the background. The lighting creates soft shadows, giving the pieces a three-dimensional appearance.

3i caregiver support service model

- **Integrative**
 - bio-psycho-ecological approach
 - Social-health service integration
- **Individualized**
 - Personalised
 - Family-centered
 - Community-based
- **Impact-focused**
 - Outcome-driven
 - Build synergy with partners for greater SROI



Bio-psycho-ecological approach

Importance of informal and formal support systems & life-course approach

**Bronfenbrennar, 1979, Barnett, Clements et al, 2003; Valentine, 1993; Dunst et al, 1990, 1994, 1996, 2002; Bailey et al 1987, 1993, 1998, 2006; Weisner, Matheson et al 2005; Holburn 2001; O'Brien 2004; Orentlicher, 2008)*

Determinants of caregiving quality and caregiver outcomes



synergistic **partnership**
(access, support, participation)



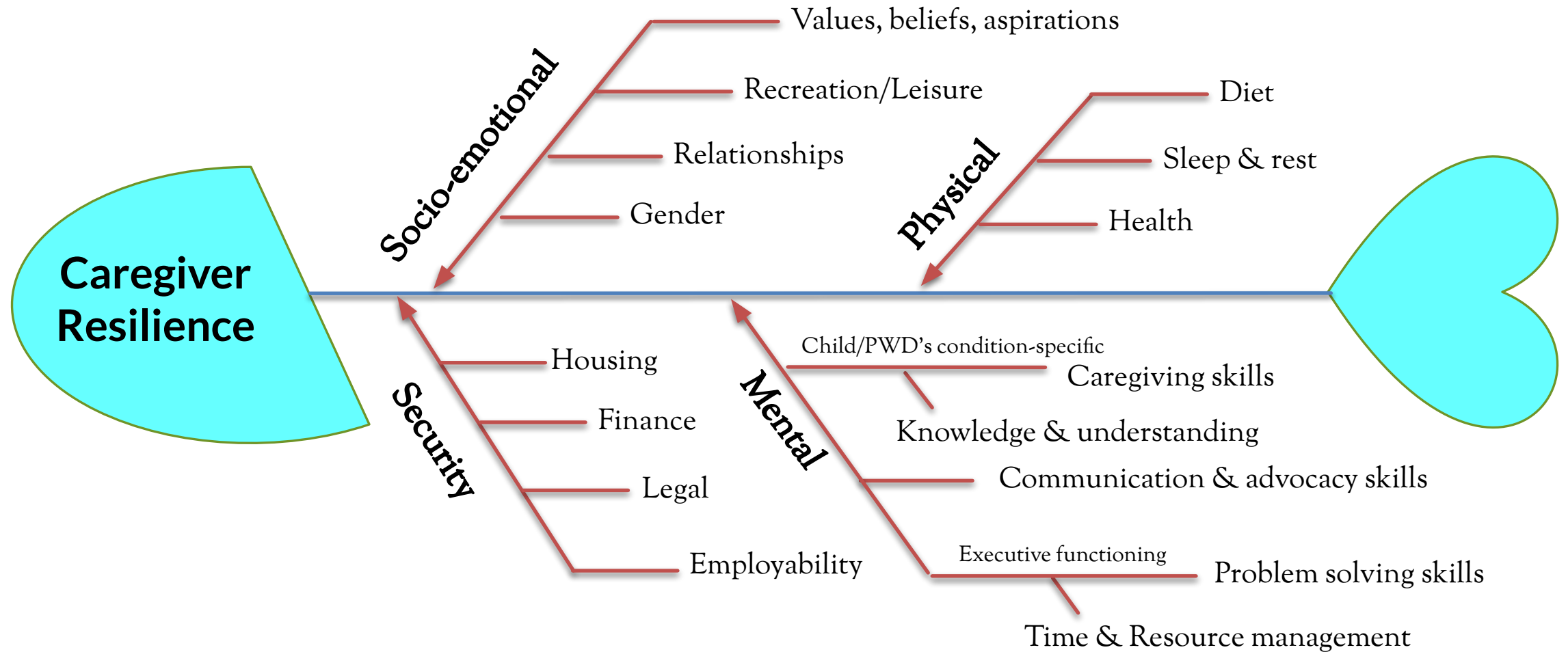
Caregiver **Resilience** **x** Ecosystem **Support** **<** Caregiving **Burden**

→ Poor caregiving and caregiver outcomes (e.g. Stress, sick, burn-out caregivers)

Caregiver **Resilience** **x** Ecosystem **Support** **>** Caregiving **Burden**

→ Good caregiving and caregiver outcomes (e.g. Happy, healthy, able caregivers)

Determinants of caregiver resilience



Caregiver resilience changes over life-course



Child/PWD's age (year)	Caregiver's age (yr)	Socio-emotional/ Family	Physical	Mental	Material
Birth – 7 (pre-school)	25 – 35	Young family; couples adjusting to each other	Energetic & healthy	Learn fast	Starting career; amassing assets
7 – 12 (Childhood)	30 – 45	Settling into middle-age; marital issues	Slowing down	Slowing down	Career stabilising
13 – 19 (Teenage/ young adult)	40 – 60	Mid-life crisis; sandwich generation	Starting to experience health issues	Slowed down	Career peaked/ Risk of retrenchment
19 – death (Adulthood/ Ageing)	55 – death	Retirement; End-of life planning; Anticipatory anxiety	Health issues set in	Plateau/ Burn-out	Steady/declining state

Caregiving burden also changes over life-course

Changing needs of SN child & PWD

Cradle - 7 yr

- Detection & diagnosis of disability
- General child health
- Early childhood education
- Early intervention
- Parenting

7 - 19 yr

- Detection & diagnosis of disability
- General health, mental health, puberty & sexuality
- Education & vocational training
- Sibling & family relationship

19 - 40 yr

- Employability
- Housing & living
- Relationship & family
- Health issues - early onset of chronic diseases, secondary complications & mental issues
- Legal (Deputyship)
- Financial

40 - grave

- As above
- Early dementia & aging
- Planning for care transition (Caregiver demise)
- Advance Care Planning



Support for caregivers & our children

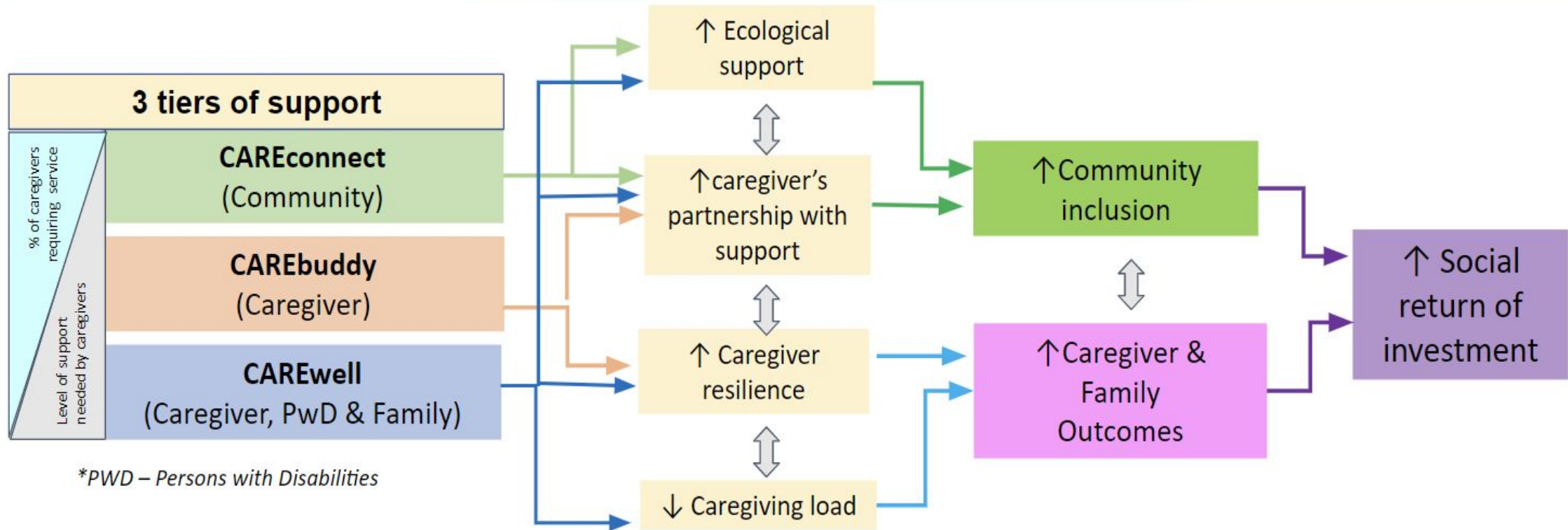
Best supports are

- Timely
- Customized to PWD & Caregiver's individual needs
- Family-centred (microsystem - home-based and help daily routines)
- Community-based (mesosystem – neighbourhood)
- Outcome-focused (empowering)
- Throughout life-course (cradle to grave)

3i Caregiver Support Service Model



integrative **i**ndividualized **i**ntentional



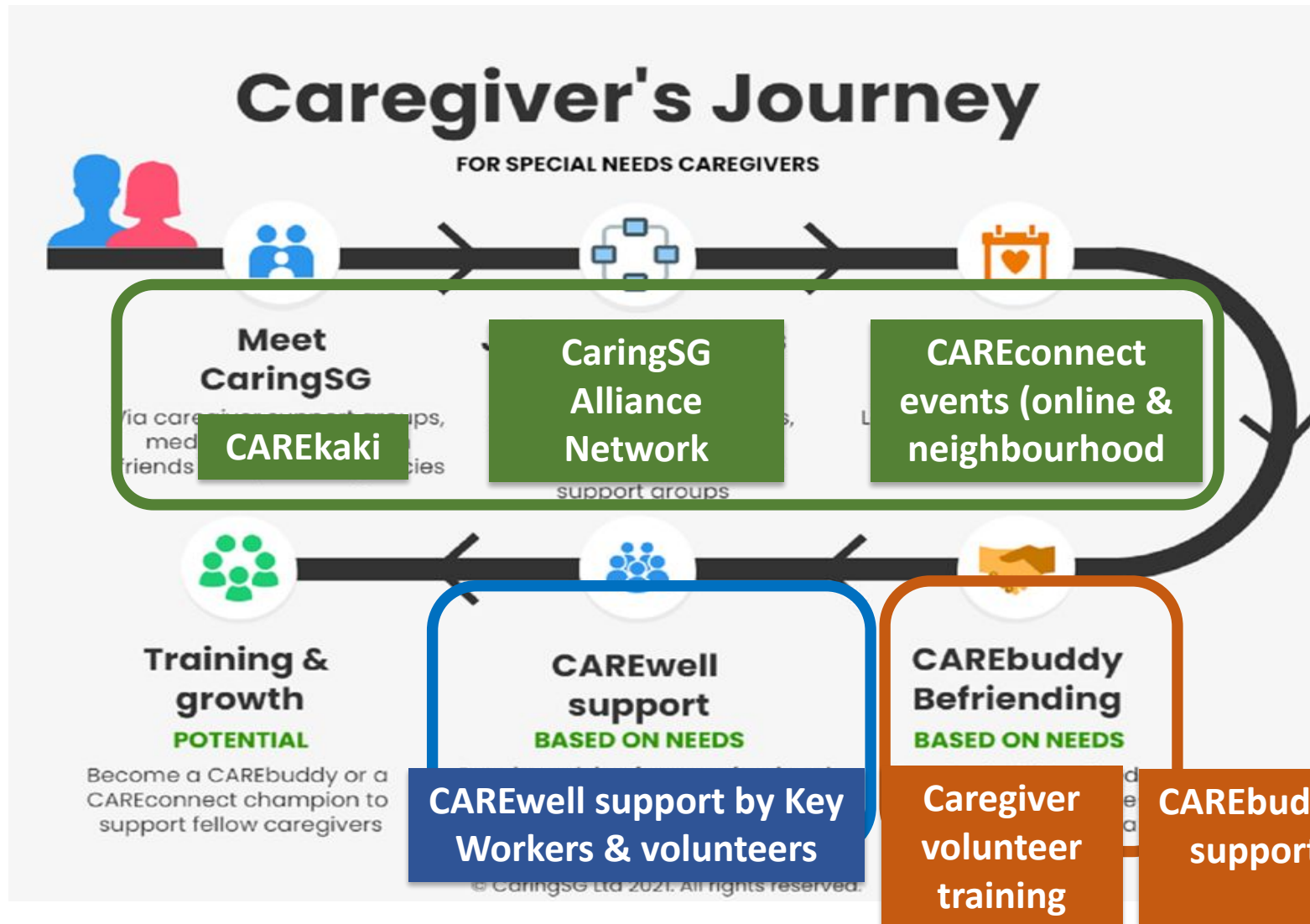
3i Caregiver Support Service model



AIMS of Project 3i

- Connect, enable and empower caregivers of persons with disabilities for a greater belonging, growth, and partnership with mainstream services and community partners
- Build capability of grassroots & community partners for a caring and inclusive neighborhood

3i Caregiver Support Service model



AIMS of Project 3i

- Connect, enable and empower special needs caregivers for a greater **belonging, growth, and partnership** with mainstream services and community partners
- Build capability of grassroots & community partners for a caring and inclusive neighborhood

Implementation of Project 3i



Activities	Period
Exploration & Stakeholder Engagement	Oct 2020 - Jul 2021
Development of 3i programmes	Oct 2020 - Jul 2021
Installation	Jan 2021 - Jul 2021
Phase 1 (Aug 2021 - March 2023)	
Initial Implementation	Aug 2021 - Mar 2023
Program monitoring	Aug 2021 - Mar 2023
Rapid cycle improvement	Oct 2022 - Mar 2023
Formative Evaluation	May 2022 - Mar 2023
Phase 2 (Jan 2023 - Dec 2023)	
Full Implementation	Apr 2023 - Jan 2024
Program monitoring	Apr 2023 - Jan 2024
Summative Evaluation	Apr 2023 - Mar 2024
Sustainability & Scale-up planning	Feb 2024 - Mar 2024

Evaluation of Project 3i



Measurement tools	3i-TOC domains							Programme
	Ecological support (A) - quantity and level of support after access & utilisation	Caregiver-Ecosystem partnership (B) -opportunity to access & utilisation	Caregiver resilience (C) - emotional health, physical health, knowledge/skills/ efficacy/mastery, security	Caregiving load (D) - frequency, level of needs, types of disability/needs; role strain; personal strain	Caregiver outcome (E) - attitude & behaviour, QOL - wellbeing/QOL	Family outcome (F)	Community Inclusion (G)	
Social Impact Measurement (SIM) toolkit	Item 2 (OC3)	Item 1,3,5,7 (OC3 &4)					Item 4,6,8 (OC4)	CAREconnect
Zarit Burden Interview (ZBI)				yes				CAREwell
Carer Wellbeing and Support Questionnaire (CWS)			yes	yes	yes			CAREwell CAREbuddy
Family Outcome survey (FOS)	yes	yes	yes			yes	yes	CAREwell CAREbuddy
WHOQOL-BREF	yes	yes	yes		yes			CAREwell

Impact of CAREconnect



CAREconnect

provides holistic caregiver support by helping caregivers to find support groups among the CaringSG Alliance Network, organisation of CAREconnect events, and volunteer training of grassroots and public to outreach and support caregivers and persons with disabilities.



92%

of caregiver participants at **CAREconnect physical events** agreed that the event helped them to feel more included in their neighbourhood

82%

of caregiver participants at **CAREconnect webinars** agreed that the session was helpful in learning to care for their child/dependent better

78%

of caregivers would recommend **CAREconnect inclusive events** to fellow caregivers

24 webinars

73 CAREconnect events

1 CAREconference

3 CAREcarnivals

Impact of CAREconnect

CAREconnect events & CAREcarnivals

Social Impact Measurement Toolkit	Before event	After event	
Outcome 3 – Increased knowledge of available care and support for caregivers of person with disability	mean (N= 97)	mean (N= 97)	p-value
How would you rate the level of support available to help you access information to plan and make informed decisions?	3.67	4.03	<0.001*
How would you rate the information available to you to help you plan and make informed decisions?	3.66	4.00	<0.001*
Outcome 4.1 – Increased level of participation in social life by caregivers of person with disability	mean (N= 229)	mean (N= 229)	p-value
How would you rate your opportunity to participate in social life?	3.62	3.98	<0.001*
How would you rate your level of participation in social life?	3.60	3.96	<0.001*
Outcome 4.2 – increased level of participation in family life by caregiver of person with disability	mean (N= 211)	mean (N= 211)	p-value
How would you rate your opportunity to participate in family life?	3.70	4.03	<0.001*
How would you rate your level of participation in family life?	3.72	4.02	<0.001*
Outcome 4.4 – increased level of participation in community life by person with disability	mean (N= 230)	mean (N= 230)	p-value
How would you rate your opportunity to participate in community life?	3.57	3.99	<0.001*
How would you rate your level of participation in community life?	3.55	3.96	<0.001*



CaringSG Webinars & CAREconference

Social Impact Measurement Toolkit	Before Webinar	After Webinar	p-value
	mean (N= 332)	mean (N= 332)	
Outcome 3 – Increased knowledge of available care and support for caregivers of person with disability			
How would you rate the level of support available to help you access information to plan and make informed decisions?	3.29	4.02	<0.001*
How would you rate the information available to you to help you plan and make informed decisions?	3.36	4.10	<0.001*

Connecting with community through CAREconnect



Agency types	No.
Caregiver groups	13
Private	68
Professional bodies	2
Public institutions, Schools, government bodies	51
Social Service Agencies	38
Total	172

Social Impact Measurement Toolkit	Before joining as CAN member	After joining as CAN member	p-value
	mean (N= 292)	mean (N= 292)	
Outcome 3 - Increased knowledge of available care and support for caregivers of persons with disabilities			
How would you rate the level of support available to help you access information to plan and make informed decisions?	2.96	3.64	<0.001*
How would you rate the information available to you to help you plan and make informed decisions?	3.05	3.67	<0.001*
Outcome 4.4 - increased level of participation in community life by caregivers of persons with disabilities			
How would you rate your opportunity to participate in community life?	2.96	3.57	<0.001*
How would you rate your level of participation in community life?	2.90	3.49	<0.001*



Impact of CAREkaki



CAREkaki Training survey	% Agree/Strongly Agree mean (N= 48)
Program structure was good	95.8
Instructor(s) created an effective training experience	95.8
Instructor(s) was clear in their delivery	95.8
Instructor(s) was well prepared for the workshop	95.8
Instructor was knowledgeable of the subject matter	100.0
Course content was easy to understand	95.7
Course content was relevant to my role	89.4
The visual aids were used effectively	93.8
Role plays were useful	83.0
Group discussions were useful	95.7
Class activities were useful	95.7
I gained useful knowledge and skills in supporting caregivers	93.8
I can better recognize someone who may be having a disability / special needs	97.9
I am more confident of helping someone with disability / special needs	97.9
I feel more comfortable in dealing with someone with disability / special needs	95.8

6 constituencies
3649 touchpoints by
CAREkaki
287 touchpoints by
CAREchampions

- Boon Lay
- Telok Blangah
- Nanyang
- Kampong Glam
- Bukit Batok East
- Pioneer

Over 81 Grassroots Volunteers Trained as CAREkaki



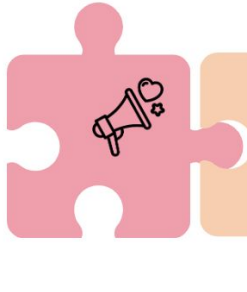
of Grassroots volunteers gained new knowledge and are more confident of helping someone with disability or special needs



of Grassroots volunteers are more comfortable with dealing with this group of residents who have a care recipient with disability or special needs

EMPOWERED GRASSROOTS HELPS CAREGIVERS AND CARE RECIPIENTS IN THE NEIGHBOURHOOD BY

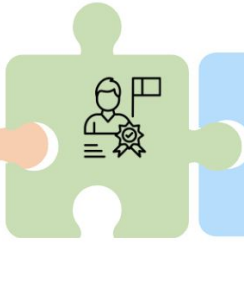
Promoting disability awareness and acceptance among residents



Being a friendly ambassador of hope, empathy and care



Building a stronger social safety net



Leading inclusive initiatives in collaboration with inclusive community and corporate partners

Being a connector to much-needed programs and services



Lessons from CAREconnect & CAREkaki programme

- Mode of CAREkaki training - need to be flexible to cater to individual grassroots needs
- Matching offers to resident's needs - Physical events versus House Visits
- GRO need administrative support
- Importance of leadership driver and systemic intervention
- Need for more effective and seamless data integration across key agencies

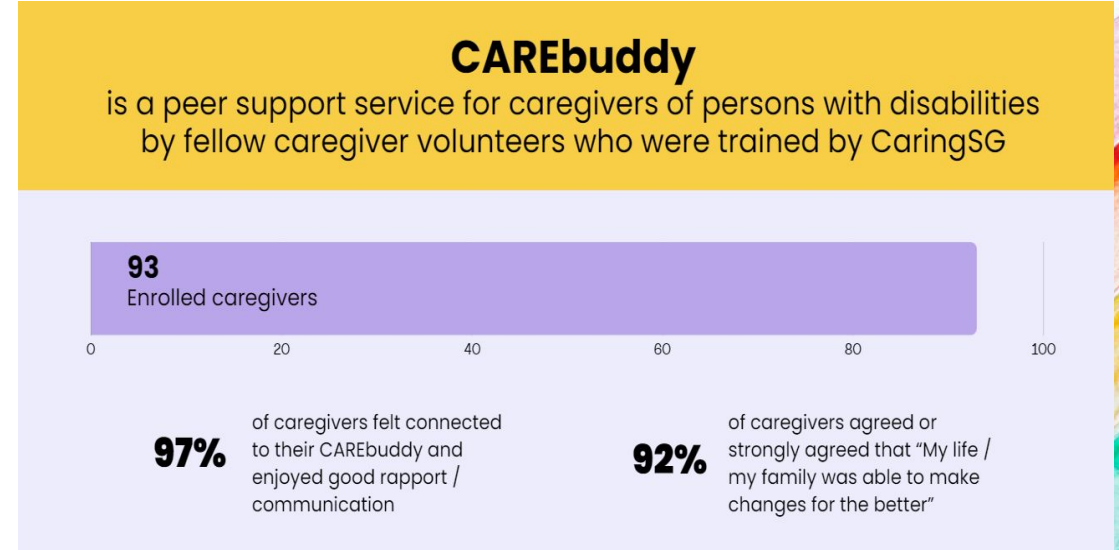


Impact of CAREbuddy support



Family Outcomes Survey	N	Mean Baseline rating	Mean closure rating	Paired t-test p-value
Outcome 1: Understanding your dependent's strengths, needs, and abilities (N=60)	62	3.31	3.75	0.0003
Outcome 2: Knowing your rights and advocating for your dependent	62	2.85	3.65	<0.0001
Outcome 3: Helping your dependent develop and learn	62	2.80	3.45	<0.0001
Outcome 4: Having support systems	62	2.77	3.25	<0.0001
Outcome 5: Accessing the community	62	3.07	3.46	0.0009

Carer Well-being		Mean Baseline rating	Mean closure rating	Paired t-test p-value	
Items During the past 4 weeks, how concerned were you about ...					
11	Reaching 'breaking point' where you feel you can't carry on with things as they are?	62	2.89	3.39	0.0105
Your relationship with family and friends:		62	2.70	3.14	0.0022
13	Drifting apart from family and friends because your caring responsibilities limit the time available to keep in contact with them?	62	2.65	3.00	0.0348
14	Feeling isolated and lonely because of the situation you are in?	62	2.39	2.94	0.0017
15	Not getting the support you need from family and friends?	62	2.74	3.27	0.0003
Your physical health:		62	2.85	3.19	0.0375
20	Your caring role making your physical health worse?	62	2.94	3.31	0.0323
Your emotional health:		62	2.87	3.25	0.0036
21	Being unable to cope with the constant anxiety of caring?	62	2.45	3.00	0.001
22	Feeling depressed?	62	2.85	3.19	0.0494
23	Being unable to see anything positive in your life?	62	3.11	3.60	0.0034
24	Lack of sleep brought about through worry or stress?	62	2.74	3.16	0.0076
The safety of the person you care for:		62	3.49	3.93	0.0033
31	Getting themselves into dangerous situations?	62	3.18	3.79	0.0004
32	Relapsing or deteriorating such that it puts their safety at risk?	62	3.44	3.89	0.0094
General well-being		62			
33	Overall, how would you rate your general well-being, during the past 4 weeks?	62	1.55	1.92	0.0007
Total Questionnaire Score		62	94.23	103.56	0.0034



810 touchpoints by CAREbuddy

- 78% of caregiver beneficiaries found the CAREbuddy programme to be a safe space to share their thoughts and concerns.
- 93% would recommend the programme to other caregivers, and the net promoter score was very high at 52%.
- 83% of caregivers felt more confident and competent as a caregiver after the CAREbuddy support.

Impact of caregiver volunteer training



- 85% to 100% of caregiver volunteers who were trained gave favourable ratings for caregiver volunteer training programme in terms of programme content, delivery mode and trainer quality.
- 97% of caregivers who received the training recommended the course to other caregivers, and the net promoter score was very high at 59%.
- 85% to 100% of Caregiver volunteers reported gaining caregiving knowledge and skills, as well as knowledge, skills and confidence to support fellow caregivers effectively.

Caregiver Volunteer Training

equips caregiver volunteers with knowledge and skills to support a fellow caregiver emotionally, as well as outreach to caregivers in CAREconnect events.

52 experienced caregivers trained to support fellow caregivers

100%

Over 100% of caregivers who attended Caregiver Volunteer training gave feedback that the training objectives were clearly defined.

96%

be more confident in supporting other caregivers

98%

improve their caregiving knowledge

89%

improve their skills in caregiving

Lessons from CAREbuddy programme & Caregiver volunteer training

- Triaging & matching needs to be done by a dedicated team - CAREadvisory team
- CAREbuddy need community of practice & CAREwell's professional support
- Caregiver volunteer training need constant and targeted caregiver group engagement to recruit caregiver volunteers
- Male caregivers may prefer support through participation in events and activities than through 1-to-1 communications



Impact of CAREwell



CAREwell

is a professional support service by a transdisciplinary Key Worker to help caregivers achieve better emotional and mental wellness, improve caregiving ability, and to navigate and access appropriate services effectively



WHOQoL-BREF Domain	Transformed baseline score (N=19)	SD	Transformed closure score (N=19)	SD	Paired t-test p-value
Physical health	75.16	12.62	79.79	16.84	0.1498
Psychological	68.00	13.86	72.42	13.85	0.0534
Social relationship	30.53	12.45	32.84	12.90	0.3306
Environment	99.37	23.67	99.37	24.41	1.0000

Items	Zarit Burden Interview (6-items)	Mean Baseline rating (N=19)	Mean closure rating (N=19)	Paired t-test p-value
2	You don't have enough time for yourself?	3.74	3.47	0.2048
3	Stressed between caring and meeting other responsibilities?	3.84	3.63	0.3597
6	Your dependent affects your relationship with others in a negative way?	2.95	2.68	0.3098
9	Feel strained when you are around your dependent	3.16	3.05	0.6301
10	Health has suffered because of your involvement with your dependent	2.84	2.68	0.4818
17	You have lost control of your life since your dependent's illness?	2.89	2.95	0.8585
	Total 6-item score	19.42	18.47	0.4011

Family Outcomes Survey	Mean Baseline rating (N=33)	Mean closure rating (N=33)	Paired t-test p-value
Outcome 1: Understanding your dependent's strengths, needs, and abilities (N=60)	3.20	3.61	0.0067*
We know the next steps for our dependent's growth and learning. (N=62)	2.88	3.27	0.0256*
We understand our dependent's strengths and abilities. (N=62)	3.18	3.67	0.0212*
We understand our dependent's delays and/or needs. (N=62)	3.30	3.64	0.0464*
We are able to tell when our dependent is making progress. (N=60)	3.45	3.88	0.0061*
Outcome 2: Knowing your rights and advocating for your dependent	2.76	3.27	0.0006*
We are able to find and use the services and programs available to us.	2.61	3.21	0.0001*
We know our rights related to our dependent's special needs.	2.67	3.30	0.0031*
We know who to contact and what to do when we have questions or concerns.	2.70	3.30	0.0019*
We know what options are available when our dependent leaves the program.	2.24	2.97	0.0005*
Outcome 3: Helping your dependent develop and learn	2.73	3.14	0.0052*
We are able to help our dependent get along with others.	2.64	3.03	0.0403*
We are able to help our dependent learn new skills.	2.79	3.18	0.0352*
We are able to help our dependent take care of his/her needs.	2.88	3.27	0.0352*
We are able to work on our dependent's goals during everyday routines.	2.61	3.09	0.0005*
Outcome 4: Having support systems	2.70	3.14	0.0035*
We are comfortable talking to family and friends about our dependent's needs.	3.00	3.55	0.0021*
We are able to talk with other families who have a dependent with similar needs.	2.61	3.12	0.0356*
We have friends or family members we can rely on when we need help.	2.64	3.00	0.0209*
I am able to take care of my own needs and do things I enjoy.	2.39	2.82	0.0139*
Outcome 5: Accessing the community	2.93	3.10	0.2562
Our dependent participates in social, recreational, or religious activities that we want.	2.18	2.70	0.0244*
We are able to do things we enjoy together as a family.	2.52	2.94	0.0244*

Lessons from CAREwell programme

- caregivers and families served by CAREwell program are very complex and high needs
- systemic gaps in the mainstream service landscape for post-18 group
- cliff-effect for caregivers at 7 years old - need for upstream support to reduce downstream regression in persons with disabilities, burnout among caregivers and detrimental effect on family system.



Project 3i

Proof-of-Concept Report

August 2021 - January 2024

Prepared for SG Enable



CAREkaki Programme



IMPLEMENTATION GUIDE

Partnering Grassroots Organisations to Build an
Inclusive Neighbourhood for Caregivers and
Persons with Disabilities and Special Needs




What's next


- **Upscaling**
 - **CAREkaki & CAREconnect** events - to be upscaled to West Coast, Jurong Central & Tampines GRC in 2024-2026 in collaboration with Enabling Service Hub, supported by SG Enable
 - **CAREbuddy** programme to continue to reach out to 100 caregivers from 2024-2026 through systematic collaboration with Social Service Agencies, supported by SG Enable
 - **CAREwell** programme to continue serving high needs caregivers, persons with disabilities and families through support of President Challenge, AmberHeart Foundation & Rao Foundation
- **Future**
 - Need further **action research** into caregiver support programme
 - Need for **integration of disability data across life course** for better social-health service integration

THANK YOU

Stay in touch with CaringSG at:



 www.caring.sg

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 [@caring.sg](https://www.instagram.com/caring.sg)

 vimeo.com/caringsg

How to refer to CaringSG



Self-referred

- Register for membership at **CaringSG website** www.caring.sg
- Caregivers to indicate needs in registration form

Referral by Agencies

- Download **Referral form** from **CaringSG website** <https://caring.sg/contact/>
- Indicate caregiver's needs in referral form
- Email completed form to referral@caring.sg

