

Quality of Life Roundtable

Facilitating a common language to understand needs, measure progress and articulate impact

Asian Family Conference (6-7 Nov 2024)

Introduction

Who are we?

How do we measure QOL?

How has it been useful?



The National Council of Social Service (NCSS) is a statutory board under the Ministry of Social and Family Development (MSF). We are the umbrella body for over 500 social service agencies in Singapore.

Vision

Compassionate Society. Impactful Sector. Dignified lives.

Mission

To provide leadership and direction in enhancing the capabilities and capacity of our members, advocating for social service needs and strengthening strategic partnerships, for an effective social service ecosystem.

Values

Passion. Impact. Collaboration. Courage.

NCSS' journey to measure Quality of Life (QOL) started around 2015, to help us better mobilize resources to meet needs

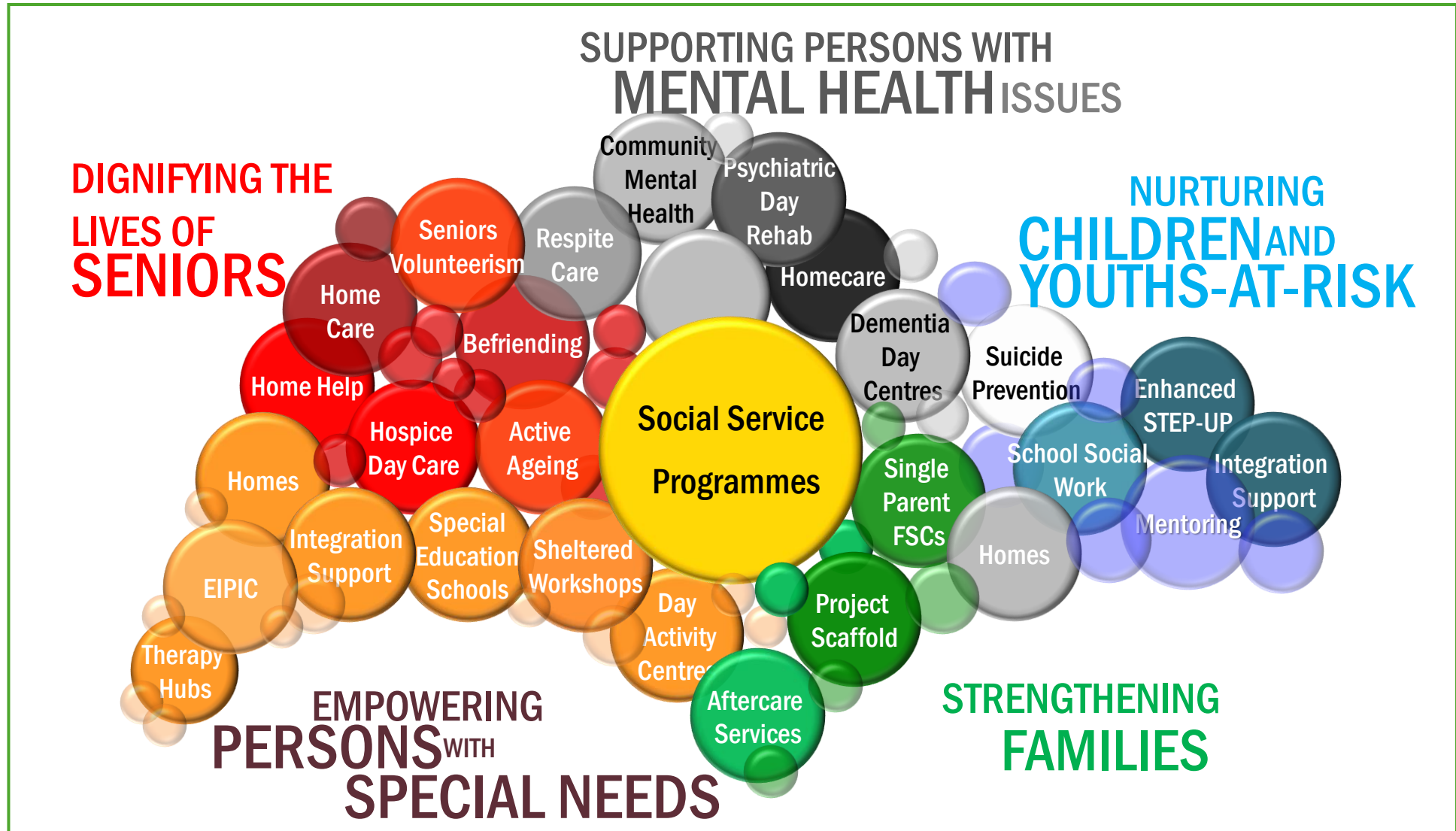


Figure. Visual representation of programmes overseen by NCSS Service Planning and Funding Group, 2015.

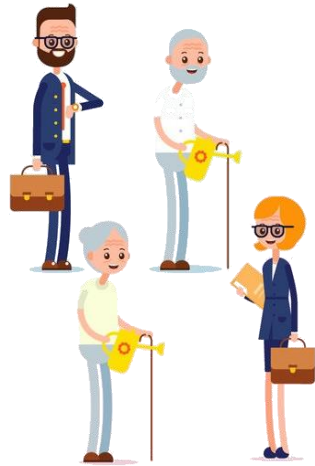
The World Health Organization Quality of Life (WHOQOL) framework was found to be useful for our needs

Quality of Life is:

“An individual’s **perceptions** of their position in life in the **context** of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.”

- WHOQOL Group, 1995

The Measures We Use



For adults and seniors
(≥18 years)



World Health Organization
(1998)



KIDSCREEN Group (2006),
based in European Union



For children and youth
(< 18 years)

1) Physical Domain

- **Dependence on Treatment:** How much do you need any medical treatment to function in your daily life?*
- **Mobility:** How well are you able to get around?
- **Activities of Daily Living:** How satisfied are you with your ability to perform your daily living activities?
- **Work Capacity:** How satisfied are you with your capacity for work?
- **Pain:** To what extent do you feel that physical pain prevents you from doing what you need to do?*
- **Energy:** Do you have enough energy for everyday life?
- **Sleep:** How satisfied are you with your sleep?

2) Psychological Domain

- **Positive Feelings:** How much do you enjoy life?
- **Concentration:** How well are you able to concentrate?
- **Body Image:** Are you able to accept your bodily appearance?
- **Self-Esteem:** How satisfied are you with yourself?
- **Negative Feelings:** How often do you have negative feelings such as blue mood, despair, anxiety, depression?*
- **Meaningful Life:** To what extent do you feel your life to be meaningful?

- **Subjective Wellbeing:** How would you rate your quality of life?
- **Perceived Health:** How satisfied are you with your health?

3) Environment Domain

- **Safety:** How safe do you feel in your daily life?
- **Physical Environment:** How healthy is your physical environment?
- **Financial Resources:** Have you enough money to meet your needs?
- **Information:** How available to you is the information that you need in your day-to-day life?
- **Leisure:** To what extent do you have the opportunity for leisure activities?
- **Home Environment:** How satisfied are you with the conditions of your living place?
- **Health and Social Services:** How satisfied are you with your access to health and social services?
- **Transport:** How satisfied are you with your transport?

4) Social Relationships Domain

- **Personal Relationships:** How satisfied are you with your personal relationships?
- **Sexual Activity:** How satisfied are you with your sex life?
- **Social Support:** How satisfied are you with the support you get from your friends?

Additional family questions adapted from WHOQOL-100

- **Family Relationships:** Do you feel happy about your relationship with your family members?
- **Family Support:** How satisfied are you with the support you get from your family?

- Responses to each facet are transformed from a 5-point scale to a 0-100 score, with higher scores denoting higher QOL (*Reverse Coded)
- Domain scores are calculated as the average of their constituent facet scores.
- Overall QOL score is calculated as the average of the four domain scores.

1) Physical Well-being

- **Self-rated health:** In general, how would you say your health is?
- **Feeling fit and well:** Have you felt fit and well?
- **Physically active:** Have you felt physically active?
- **Able to run well:** Have you been able to run well?
- **Full of energy:** Have you felt full of energy?

2) Psychological Well-being

- **Life enjoyable:** Has your life been enjoyable?
- **Good mood:** Have you been in a good mood?
- **Had fun:** Have you had fun?
- **Not feeling sad:** Have you felt sad?*
- **Without feelings of depression:** Have you felt so bad you didn't want to do anything?*
- **Not felt lonely:** Have you felt lonely?*
- **Self-esteem:** Have you been happy the way you are?

3) Autonomy and Parent Relation

- **Enough time for self:** Have you had enough time to yourself?
- **Free time:** Have you been able to do the things that you want to do in your free time?
- **Enough time with parents:** Have your parent(s) had enough time for you?
- **Treated fairly by parents:** Have your parents treated you fairly?
- **Talk to parents:** Have you been able to talk to your parent(s) when you want to?
- **Enough money to do the same things as friends:** Have you had enough money to do the same things as your friends?
- **Enough money for expenses:** Have you enough money for your expenses?

4) School Environment

- **Happy in school:** Have you been happy at school?
- **Getting on well in school:** Have you got on well at school?
- **Paying attention:** Have you been able to pay attention?
- **Get along with teachers:** Have you got along well with your teachers?

5) Social Support and Peers

- **Time with friends:** Have you spent time with your friends?
- **Fun with friends:** Have you had fun with your friends?
- **Receiving and giving help:** Have you and your friends helped each other?
- **Rely on friends:** Have you been able to rely on your friends?

Additional questions related to Social Acceptance (Bullying) adapted from KIDSCREEN-52

- **Not afraid of peers:** Have you been afraid of other girls and boys?*
- **Not teased by peers:** Have other girls and boys made fun of you?*
- **Not bullied by peers:** Have other girls and boys bullied you?*

- Responses to each facet are transformed from a 5-point scale to a 0-100 score, with higher scores denoting higher QOL (*Reverse Coded)
- Domain scores are calculated as the average of their constituent facet scores.
- Overall QOL score is calculated as the average of the five domain scores.

The inclusivity of the WHOQOL-BREF and KIDSCREEN tools, alongside other properties made them appealing

Inclusive

- Can be applied to different vulnerable groups
- Providing a common benchmark

Person-Centred

- Driven from thinking about the aspirations of the individual as a person *first*, without making any assumptions about their disadvantage or what they need

Comprehensive

- Holistically captures essential areas of life
- Possible to administer additional modules to capture additional needs due to disability, health conditions (e.g. WHOQOL-DIS; WHOQOL-OLD; DISABKIDS)

Wide Appeal

- Derived through extensive discussion, expert reviews, field testing & psychometric work internationally
- Relatively short (≤ 30 items) and completed under 15 mins for most
- Demonstrated to be valid and reliable locally

The tools have been internationally validated across more than 30 countries and used across the different target populations.

To date, NCSS' quality of life research has spanned adults in the general population, children and youths, persons with disabilities, persons with mental health conditions, seniors, and caregivers



**Adults
≥ 18 Years Old**

Collected in 2015:
Adults & Seniors: 2,000
Persons with Conditions: 1,500

Collected in 2022:
Adults & Seniors: 6,000

2022 – 2030 (ongoing):
Persons with Disability: 2,000

Collected in 2024:
Adults & Seniors: 2,000



**Children and Youth
< 18 Years Old**

Collected 2017 – 2019:
Children and Youth: 8,000
Children with Conditions: 2,000

2023 – 2024 (ongoing):
Children and Youth: 3,000
Children with Conditions: 2,000



Caregivers

Collected 2017 – 2019:
Of Persons with Conditions: 4,500

2023 – 2024 (ongoing):
Of Children and Youth: 1,200
Of Children with Conditions: 1,200

2022 – 2030 (ongoing):
Of Persons with Disability: 2,000



**During COVID-19
(May 2020 – Mar 2022)**

**4 Waves of Quick-Dip Telephone Polls
(N ≈ 1000, of Gen Pop & Conditions)**

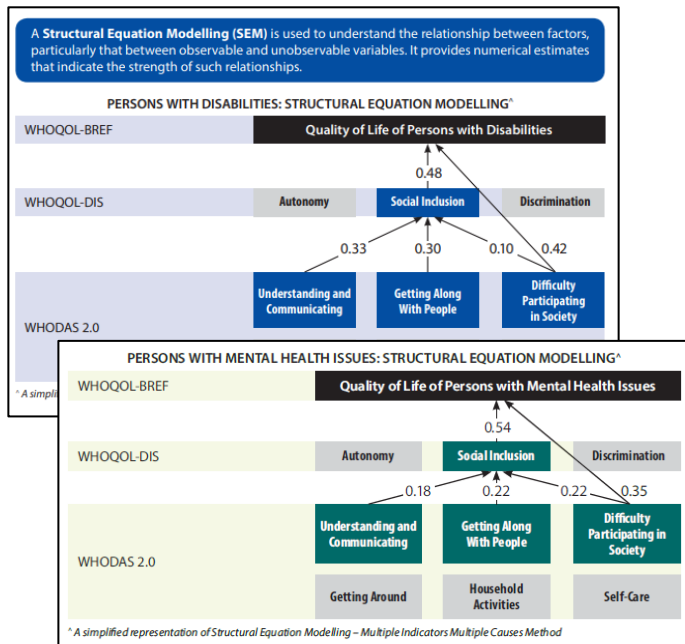
- W1: Circuit Breaker (May – Jun 2020)
- W2: Phase 2 of Reopening (Sep – Oct 2020)
- W3: Phase 3(HA) of Reopening (Mar – May 2021)
- W4: Transition Phase (Dec 2021 – Mar 2022)

Note. Figures indicate collected sample sizes, rounded to nearest hundreds. 'Persons with Conditions' refers to persons who have a disability, mental health condition, chronic illnesses, and includes children with developmental and specific learning difficulties, and frail elderly.

QOL has helped us to...

1. Provide Perspective on the Importance of Social Inclusion

Analyses found addressing **social inclusion can achieve the greatest effect** to overall well-being for adults with disabilities and mental health conditions.



▲ Source: NCSS Quality of Life Study, 2015



▲ Findings are used to inform messaging of public education campaigns (e.g. *Beyond the Label*)



2. Highlight the Importance of Having Help for Caregivers

Caregivers who **received help** in caring for their loved ones **reported a better quality of life**. However, almost 2 in 5 provided care to their loved ones alone.

Equality in FAMILY and in SOCIETY

We must take care of our caregivers. Women carry more of our caregiving load, devoting much time and energy to care for loved ones.

Ease caregiving load:

- Broaden Household Services Scheme to include basic child and elder-minding services
- Provide more affordable, accessible, and comprehensive respite care options for caregivers of seniors
- Enhance access to affordable and quality preschools

Relieve caregivers' financial strain and encourage care in the community:

- Enhanced Home Caregiving Grant
- Provide further support to help caregivers care for their elderly loved ones at home
- Expanded the Seniors' Mobility and Enabling Fund to better support seniors with the cost of mobility and assistive devices
- Continue schemes that support retirement adequacy for seniors, e.g., Silver Support Scheme, Matched Retirement Savings Scheme, Retirement Sum Topping-Up Scheme

Care for caregivers' well-being:

- Form community-based peer support networks for caregivers
- Support women and their children with a Child & Maternal Health and Well-being Strategy
- Promote the Agency for Integrated Care as a one-stop resource centre for caregivers of seniors
- Enhance support for caregivers of persons with disabilities and children with developmental needs

Logos: Celebrating Women, MSF, TOGETHER, go9

THE STRAITS TIMES SINGAPORE

President's Challenge 2023 to focus on caregivers



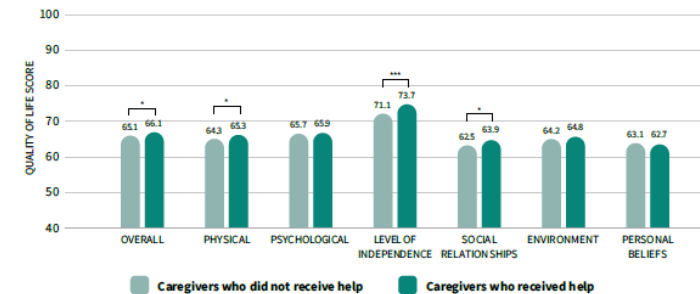
President Halimah Yacob interacting with caregivers and staff during a visit to Caregivers Alliance Limited on July 21, 2022. PHOTO: MINISTRY OF COMMUNICATIONS AND INFORMATION

Finding #5 Having help matters.

Compared to caregivers who received help²⁷ in caring for their care recipient, caregivers who did not receive help reported lower overall quality of life scores driven by deficits in physical health, independence, and social relationships.



Average Caregiver WHOQOL-BREF Scores by Help Received or Not (Controlling for Differences in Demographic and Caregiving Characteristics^a)



^aControl variables: caregiver's age, gender, education, and income; care recipient's age and health condition; no. of care recipients, living with care recipient or not, caregiving intensity and duration

Finding #6

However, 37% of caregivers had to provide care to their loved ones alone, with almost two-thirds of them citing the lack of availability of other helpers as a factor.

Reasons for not receiving help*	No. of caregivers (%) (n = 558)
I am the only person available to take care of the care recipient	64.0%
I have the responsibility to care for the care recipient	24.6%
I do not need help in my caregiving duties	16.1%
I do not have enough financial resources to seek help	12.0%
I do not know where to seek help	9.5%
Others	3.4%

A higher proportion of those who did not receive any help were:

- Females
- Aged 50 and above
- Single
- Spouses of their care recipient
- Caregivers of Persons with Mental Health Conditions
- Caregivers of adult care recipients
- Living in smaller households
- Of lower socioeconomic statuses (SES)

* This question was only administered to caregivers of adults with disabilities or chronic illnesses

▲ Source: NCSS Quality of Life Study on Caregivers, 2018

3. Support National Masterplans: Enabling Masterplan 2030



QUALITY OF LIFE STUDIES

The Quality of Life (QoL) studies are a research series that have been conducted by NCSS since 2015. The studies investigate the subjective well-being of groups in need of more support, and of Singaporeans in general. Thus far, the target groups that have been tracked include:

Adults and Seniors
This was the first QoL study conducted in 2015. NCSS surveyed around 1,000 adults with disabilities, as well as adults with mental health conditions and the general population.¹

Children and Youth
The QoL study was expanded to children and youths below 18 years in 2018. NCSS surveyed a sample of children and youths with developmental needs (DN), special educational needs (SEN) and/or disabilities, as well as those with chronic illnesses and/or mental health conditions. The sample also included children and youths without any health conditions.

Caregivers
A study on the QoL and needs of caregivers was also conducted in 2018. Caregivers of persons with DN, SEN and/or disabilities, caregivers who were caring for frail elderly, and/or persons with mental health conditions and/or chronic illnesses were surveyed.

Data from these studies offer EMP2030 with a quantitative baseline for the quality of life for each of these target groups.

The following indicators will use data from the QoL series of studies:

- i. QoL: QoL score of children and youth with disabilities (<18 years old).
- ii. QoL: QoL score of younger adults with disabilities (18 – 49 years old).
- iii. QoL: QoL score of older adults with disabilities (≥ 50 years old).
- iv. Area 1: Early Years: QoL indicator for children with developmental needs aged 6 and below that tracks their well-being in school.
- v. Area 2: Schooling Years: QoL indicator for children with disabilities aged 7 and above that tracks their well-being in school.
- vi. Area 5: Inclusive Living: Persons with disabilities' reported scores on their satisfaction with their access to opportunities to participate in social activities.
- vii. Area 7: Caregiving Support: Survey responses on wellbeing of caregivers.
- viii. Area 7: Caregiving Support: Caregivers' reported scores on access to caregiver services (e.g. caregiver support groups, information on caregiving) if needed.
- ix. Area 14: Inclusive Communities: Survey results on persons with disabilities' perceptions.

Data from the QoL Studies will be available approximately every 3 years.

¹ Reports from the findings from the first QoL study conducted in 2015 are available for adults with disabilities, adults with mental health conditions, and seniors.

- The Enabling Masterplan 2030 (EMP2030) is a **national roadmap to guide efforts to create a more inclusive Singapore by 2030.**
- EMP2030 is the first to include concrete, quantitative indicators and targets, to measure the collective progress towards achieving tangible change. **The QOL research series is one of the key data sources contributing to this effort.**

EMERGING FROM COVID-19:

DOING MORE FOR THOSE IN NEED

From the circuit breaker period to Phase 2 of Singapore's reopening, the National Council of Social Service (NCSS) conducted over 1,800 phone interviews to understand how COVID-19 had affected the quality of life (QOL) of Singaporeans.



QOL OF SINGAPOREANS IN PHASE 2 OF SINGAPORE'S REOPENING VS THE CIRCUIT BREAKER PERIOD

While QOL for the general population appeared to be on the recovery in Phase 2 of Singapore's reopening of the economy, the QOL for specific groups like seniors and persons with disabilities had not improved since the Circuit Breaker period.

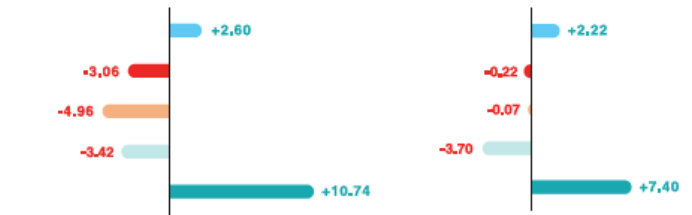
On the other hand, persons with mental health conditions who remained connected to social services showed improvements in their QOL, thus demonstrating the importance of seeking help.

Changes on selected QOL facets between Circuit Breaker and Phase 2:

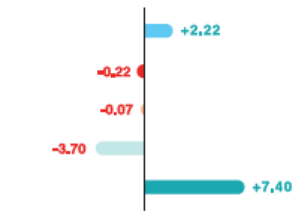
GROUPS



Work Capacity



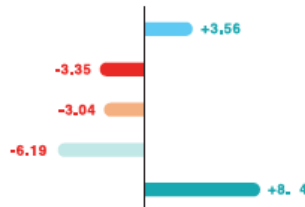
Social Support



Energy and Fatigue



Activities of Daily Living



4. Understand the Impact of the COVID-19 Pandemic

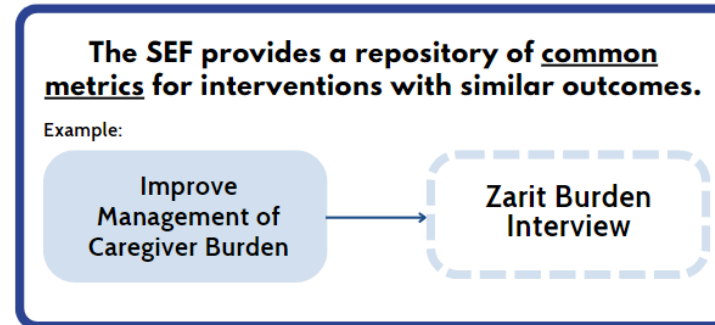
- While the general population appeared to recover over the course of the pandemic, the QOL of seniors and persons with disabilities did not.
- On the other hand, persons with mental health conditions who remained connected to social services showed improvements in their QOL.

5. Measure sector-wide impact through the Sector Evaluation Framework

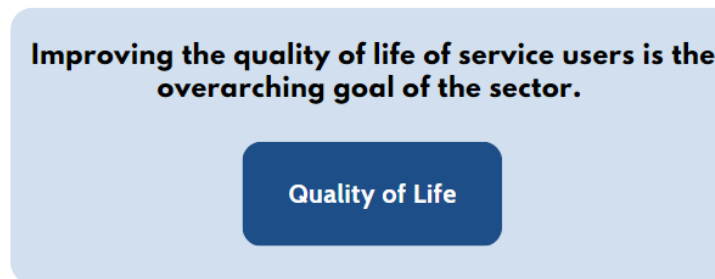
The SEF is a **sectoral outcome measurement framework** that aims to:

- **Introduce consistency** in how programme outcomes are measured across the sector,
- Provide a **common language** for social service agencies, funders, and the Government **to articulate impact**, as one social service sector.

1 Sector Outcomes



2 Monitoring Indicator



Each programme collects:

- 1 metric for each intended outcome
- QOL measure

Roundtable Discussion

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Thank You!