

Individualised services for families of children with intellectual & developmental disabilities: evidence from a new approach



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scope
FOR PEOPLE WITH A DISABILITY

Scope's Mission & Values

Scope's mission is to support people with disabilities to achieve their potential in welcoming and inclusive communities. We believe that disability means possibility.



The Scope Approach

The Scope Approach defines "the way we do things at Scope". It applies to how we wish to behave in our dealings with others, both inside and outside the organisation. The approach was developed by people across Scope and incorporates the values embedded in person centred planning, individualised services, community inclusion, and service development and improvement activities.



see the person

- We listen to understand
- We see the potential
- We recognise how you do things and what you achieve
- We take personal responsibility
- We build excellent relationships with our clients and customers



do it together

- We lead in line with Scope's approach
- We work together to achieve shared goals
- We build sustainable partnerships
- We support each other
- We communicate early and honestly



do it right

- We use systems and processes in our work
- We deliver quality outcomes on time
- We understand risks and opportunities
- We are a financially sustainable organisation
- We take pride in the delivery of our Mission



do it better

- We seek creative solutions
- We review and continually improve
- We understand what's working and what's not
- We respond to feedback
- We build capacity in all that we do



About Scope

Aim: “To provide timely, flexible and responsive supports and services to meet the individual needs of children and their families across the state of Victoria.”



ECIS Flexible Support Packages

- Eastern Metropolitan Region of Melbourne.
- New **brokerage model** which aims to:
 - Support **participation** and **inclusion**
 - Ease some **psychosocial pressures** on parents
 - **Compliment** the existing suite of services



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Applying for Packages

- A range of services and supports across many life areas (Scope's mean \$2,223).
- **Family Service Coordinator** develops written application in collaboration with families and submits this application to Assessment Panel.
- Application accompanied by a **Family Service and Support Plan**, or equivalent, and a Support and Expenditure Plan.



Research purpose

- To examine the **effectiveness** of ECIS Flexible Support Packages in achieving its stated objectives, and
- To assess whether it is associated with **key outcomes** reflective of best practice in early childhood intervention.



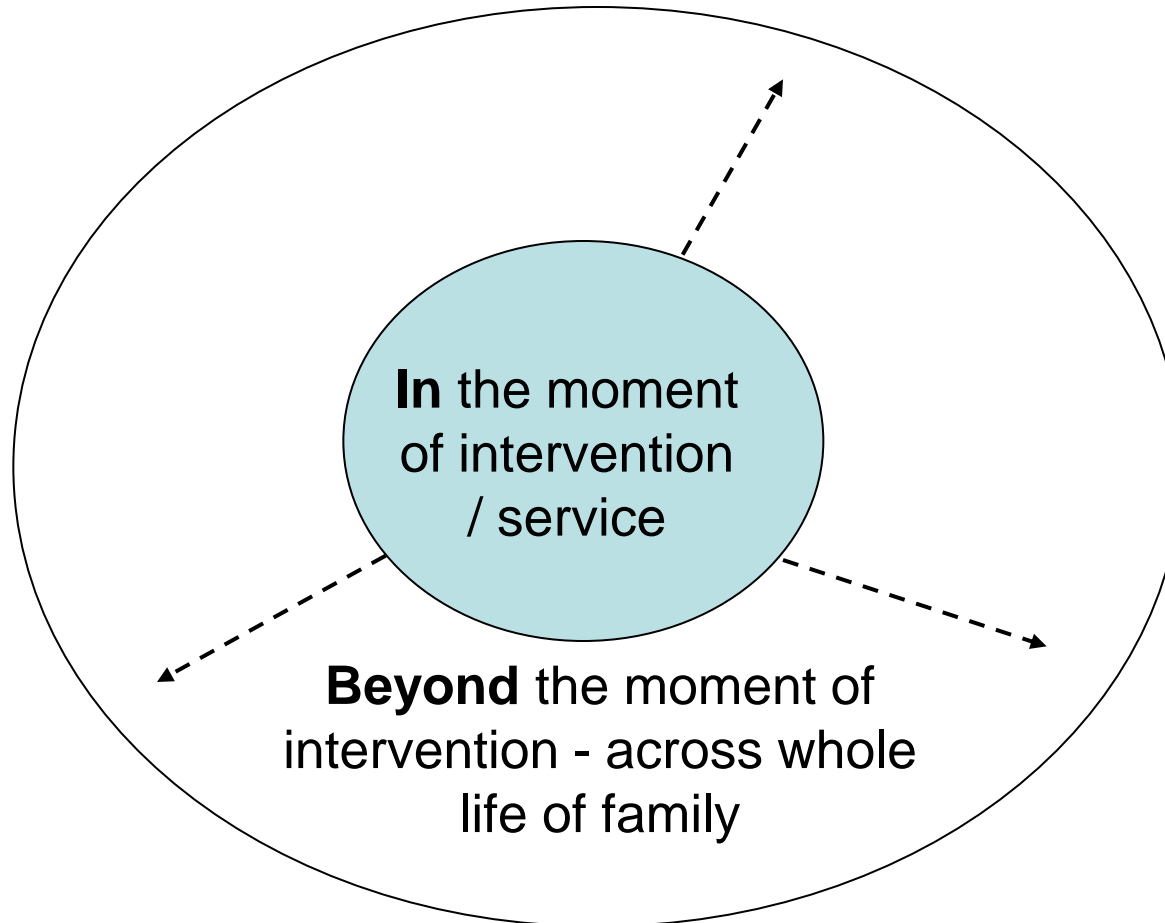
Key outcome areas

- **Family Centeredness**
 - To what extent have services worked in person and family centered ways?
- **Family Functioning and Coping**
 - To what extent does engagement with ECIS FSP have a positive or negative impact on family levels of stress and coping?
- **Impacts and Outcomes**
 - What are the sorts of impacts, across a range of life areas, experienced by families?
- **Family Capacity**
 - To what extent have services used a model of practice that builds on the capabilities of families?
- **Satisfaction**
 - To what extent do families feel that outcomes have been met?



Outcomes - wide frame of interest

Outcomes for the family and child across whole of life (eg ICF)



Questionnaire Method

- Advantages of questionnaire method:
 - wide breadth of information can be gathered efficiently
 - non-threatening to research participants
 - questions can be tailored to the requirements of the present research
 - streamlined and therefore preferable to families
- Challenges of questionnaire method:
 - researchers may not receive carefully considered feedback from families
 - wording may bias a family's response
 - questionnaire may be perceived as 'impersonal'
 - may not provide 'the full story' for some families.



Questionnaire Method

- Processes for questionnaire development:
 - Systematic review of established tools
 - Selection of relevant items, where available, linked to key domains relevant to the program's objectives
 - Inclusion of researcher-developed items tapping the unique characteristics of the program
 - Piloting of questionnaire with families to ensure that families experience the questionnaire as relevant and workable.



Questionnaire Method

Family Centred Practice n=31

Family Stress and Coping n=11

Impacts and Outcomes n=9

Family Capacity n=12

Satisfaction n=3

Measure of Processes Of Care (King, Rosenbaum, & King, 1996)

The Family Centered Program Rating Scale (Murphy, Lee, Turnbull, & Turbiville, 1995)

The Service Coordination Scale (Koren et al., 1997)

Researcher developed items

Perceived Stress Scale (MacArthur, 2006)

Parental Stress Scale (Jones, 1995)

Researcher developed items

Impacts and Outcomes Scale (E. Wilson)

Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992)

Researcher developed items

The Assessment of parent satisfaction (Krahn et al., 1990)



Examples - impacts and outcomes

In each of the following life areas, rate the extent to which the item/s that you applied for through ECIS Flexible Support Packages has had an impact on your family ...		Very Positive Impact	Positive Impact	No impact	Negative impact	Very Negative impact
Personal and family wellbeing	That is, in the area of health and function, happiness, wellbeing, safety, sense of independence and choice.	0 1	0 2	0 3	0 4	0 5
Social life	That is, in the area of friendship and relationship, community involvement and sense of belonging.	0 1	0 2	0 3	0 4	0 5
Political life	That is, in the area of having a say about things that affect you (eg in a local service or community group, about your area, school, funding etc).	0 1	0 2	0 3	0 4	0 5
Cultural life.	That is, being involved in cultural activities (eg. arts, music, theatre, dance at any level). This might be through attending activities or playing an active part. Or being part of your own cultural group.	0 1	0 2	0 3	0 4	0 5
Recreational and leisure life	That is, being involved in recreational or leisure activities at any level. This might be through attending activities, playing an active part or doing what you enjoy.	0 1	0 2	0 3	0 4	0 5



Examples - family stress and coping

In each of the following areas, rate the extent to which the item/s that you applied for through ECIS Flexible Support Packages has had an impact on your family ...	Very Positive impact	Positive Impact	No Impact	Negative Impact	Very Negative impact
The time and energy that your family have for each other	0 1	0 2	0 3	0 4	0 5
The quality of the time that family members spend with each other	0 1	0 2	0 3	0 4	0 5
Happiness from your relationships with the members of your family	0 1	0 2	0 3	0 4	0 5
Opportunities to do the things that are important to your family	0 1	0 2	0 3	0 4	0 5
Your ability to control the important things in your life	0 1	0 2	0 3	0 4	0 5
Feeling that you are on top of things	0 1	0 2	0 3	0 4	0 5



Examples - family capacity

In each of the following areas, rate the extent to which the item/s that you applied for through ECIS Flexible Support Packages has had an impact on you as a parent....	Very Positive Impact	Positive Impact	No Impact	Negative Impact	Very Negative impact
Knowing how to help your child grow and develop	0 1	0 2	0 3	0 4	0 5
Working with others to solve problems with your child when they happen	0 1	0 2	0 3	0 4	0 5
Getting information to help you better understand your child	0 1	0 2	0 3	0 4	0 5
Working with agencies and professionals	0 1	0 2	0 3	0 4	0 5
Knowing what services your child needs	0 1	0 2	0 3	0 4	0 5
Understanding the service system your child is involved in	0 1	0 2	0 3	0 4	0 5
Feeling effective and competent as a parent	0 1	0 2	0 3	0 4	0 5



Results

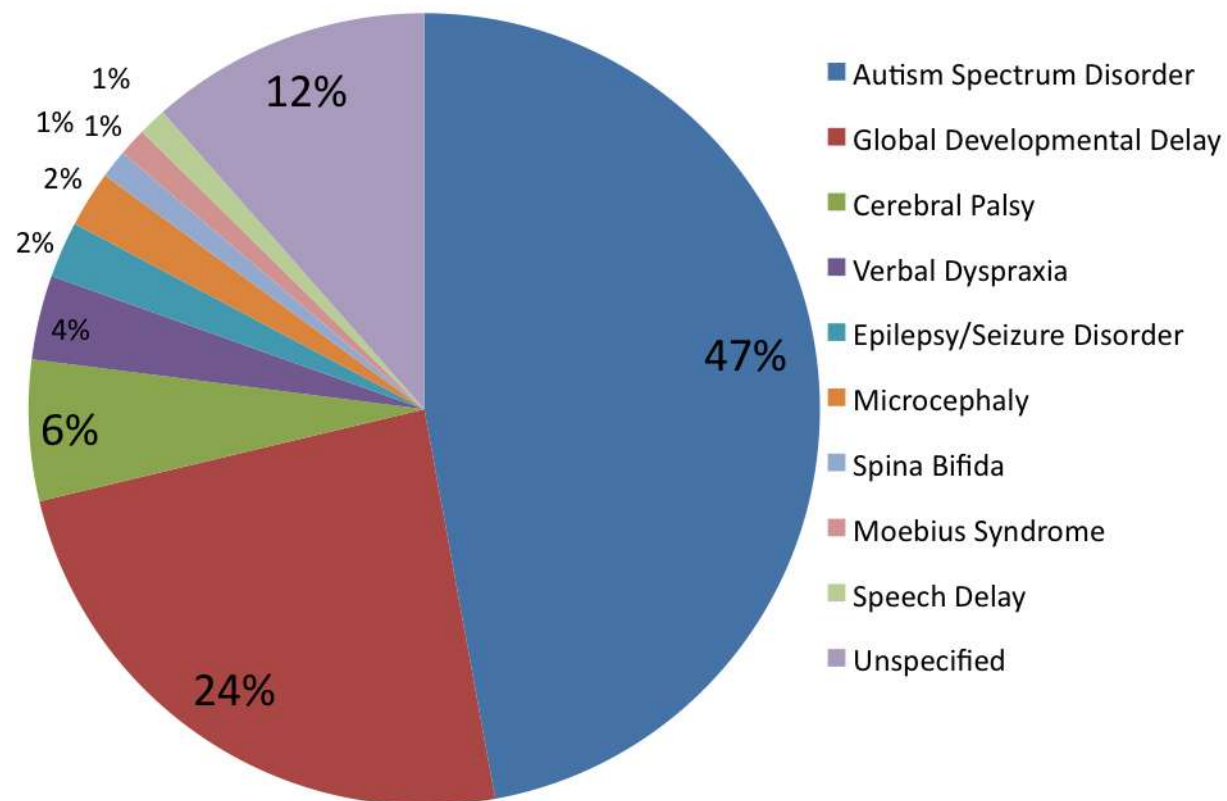
- 187 families sent questionnaires
- 72 questionnaires returned (36% return rate)

Mean	\$2,223
Minimum	\$250
Maximum	\$12,600

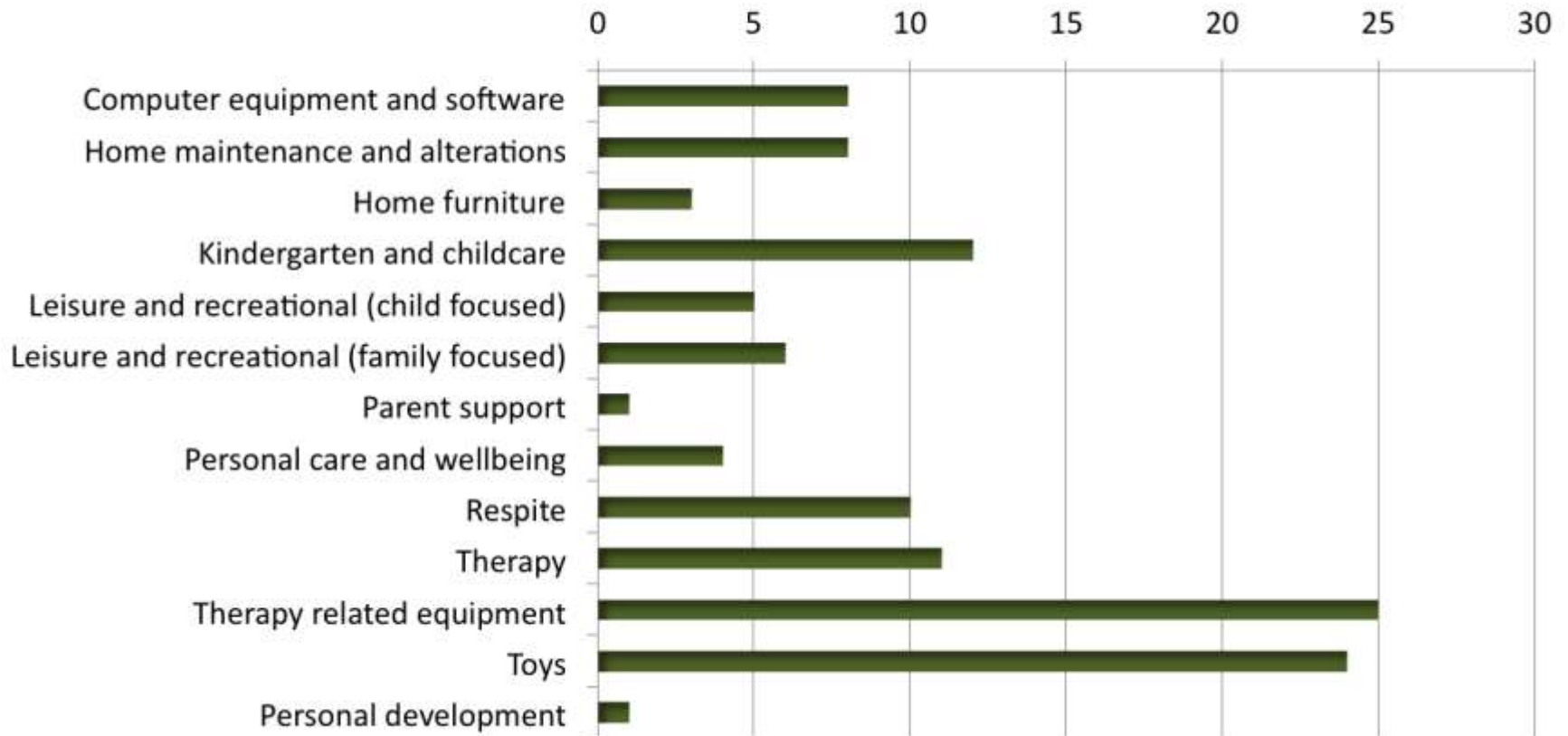
- The amount of funding does not correlate significantly with overall scores on the survey



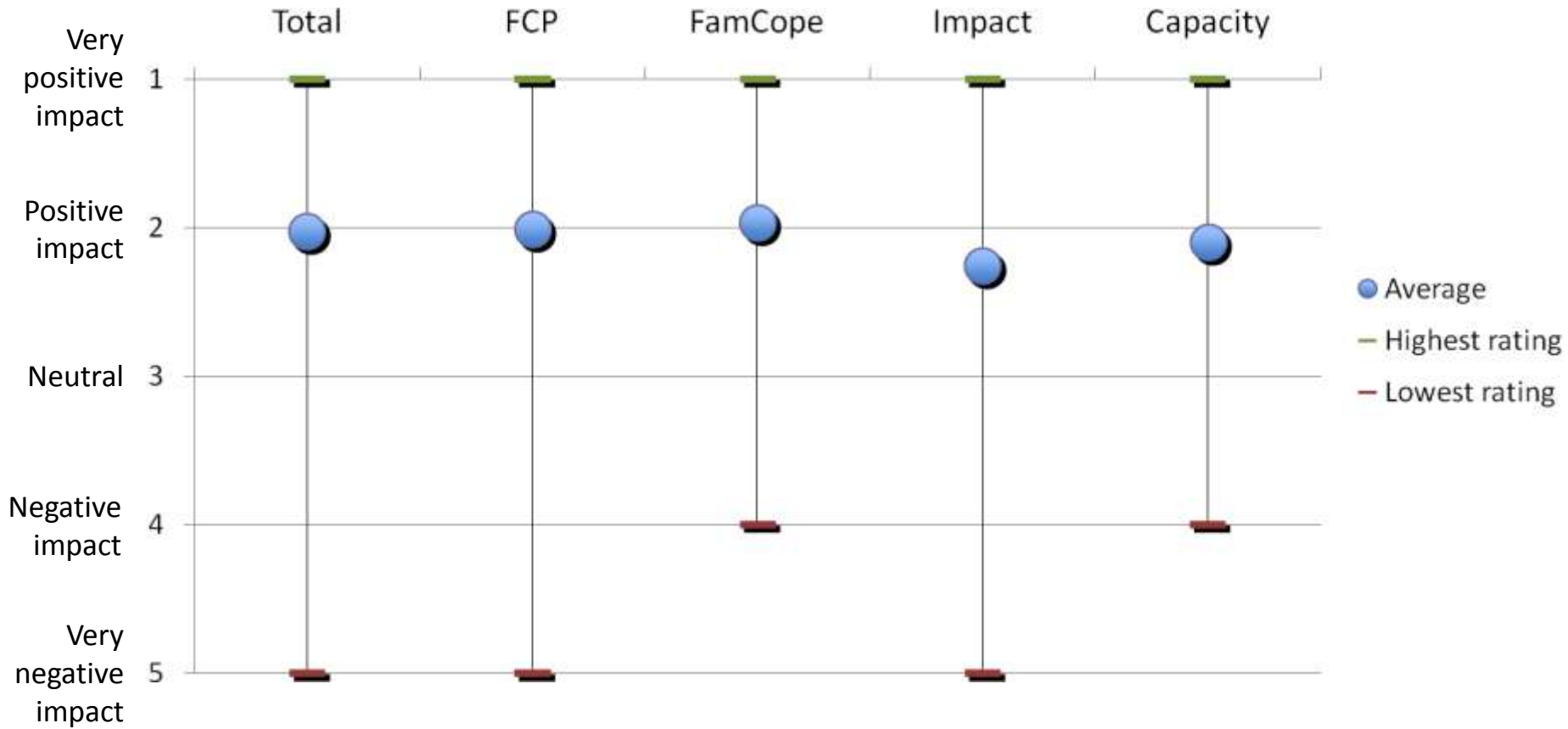
Results – Primary Disability



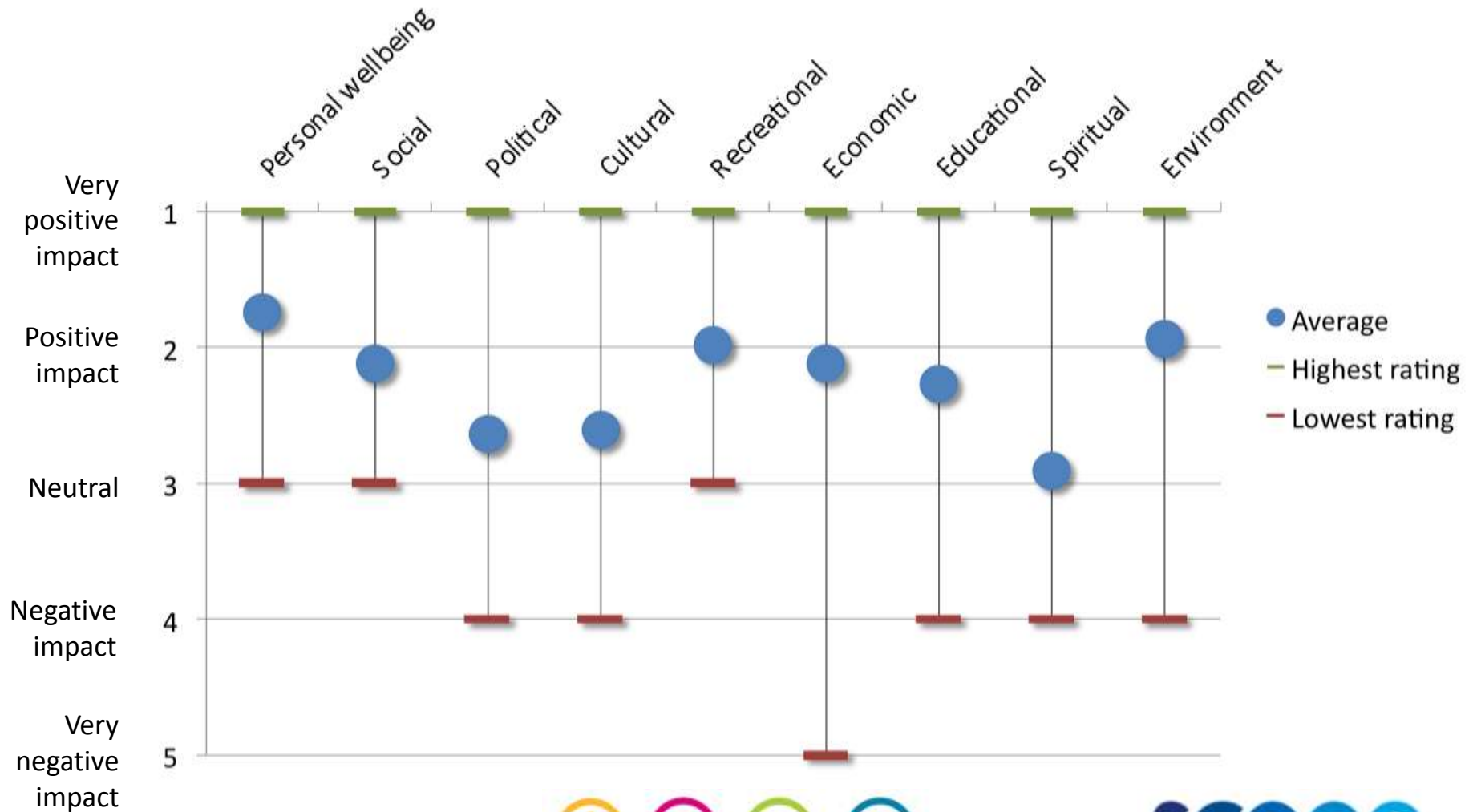
Results - Services and Supports



Results - Survey



Results – Impacts and Outcomes Scale



Highest Ranked Items

Family centeredness

- Looked at the entire needs of the child instead of just the physical needs
- Looked at the needs of the whole family instead of just the needs of the child with a disability
- Accepted you and your family in a non-judgmental way

Family stress and coping

- The quality of the time your family members spend with each other
- Opportunities to do the things that are important to your family
- Feeling that your family can make a positive difference in your child's life

Impacts and Outcomes

- Personal and family wellbeing
- Recreational and leisure life
- Your environment

Family capacity

- Knowing how to help your child grow
- Feeling effective and competent as a parent
- Having ideas and strategies to support your child



Lowest Ranked Items

Family centeredness

- Did not ask your family to repeat information that was already on file
- Kept to a minimum the forms you had to fill out
- Did not have you run all over to organise an application

Family stress and coping

- Feeling that you were on top of things
- Feeling calm with the responsibility of being a parent
- Feeling certain about the here-and-now

Impacts and Outcomes

- Political life
- Cultural life
- Spiritual life

Family capacity

- Getting information to help you better understand your child
- Knowing what services your child needs
- Understanding the service system your child is involved in



Family Feedback

Thank-you for the approval of our application for the trampoline and Boardmaker program.

Our trampoline arrived on Thursday and was assembled on Friday and was a huge surprise for (him) (and his sister) when he arrived home from kinder. His reaction was priceless and that of pure joy and excitement. As I look out my kitchen window now at my two children enjoying just being together and bouncing around happily and safely, is such a pleasure. This is a treat that we just could not afford at the moment and to know that this will assist (him) so greatly in many of his sensory issues is wonderful and also a huge relief for both (him) and us as a family. Our furniture may also last a little longer now that it is not being used as a trampoline!!!

We are expecting the Boardmaker program to arrive shortly and am sure that it also will help tremendously in (his) communication and overall happiness and understanding.



Discussion

- Data suggests that families are reporting overall:
 - Positive experiences associated with ECIS FSP in terms of family centeredness, family coping, and family capacity.
 - Positive impacts and outcomes across a number of life domains, including those directed towards activity, participation & social inclusion.
 - High ratings in terms of general satisfaction, needs being met and families' willingness to return to the program.
 - Items endorsed most negatively are in areas of 'administrative burden' and 'general services information and engagement'



Discussion

- Methodological limitations include the sampling of 'successful applicants' and reliance on a questionnaire method as the main source of data collection.
- Present research is a first and provides a methodological template for future research into ECIS FSP model, as well as research into other individualised service models.
- Present research contributes to the wider fields of outcome measurement research in disability.



Future directions

- Psychometric aspects of tool and subscales
- Wider use of tool - application of tool and subscales to other service contexts
- Tailoring of the tool for different research and service contexts
- Identify ways to gain more data to influence service improvements



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