

Developmental factors, adaptation and quality of life in children and youth with disabilities

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A study of growing up with spina bifida: Questions for Study

- ◆ What are key challenges/secondary conditions faced in growing up with spina bifida?
- ◆ How do these challenges differ with age?
- ◆ What are key resources & supports for children and families?
- ◆ How do children & families perceive their Quality of Life?

From Whom Have We Learned?

- ◆ Children, adolescents, & young adults with spina bifida (4 age groups)
- ◆ Families of individuals with spina bifida
- ◆ 38% Male/ 62% Female
- ◆ 78% with shunt
- ◆ Lesion Level
 - 35% Thoracic
 - 33% Lumbar
 - 32% Sacral
- ◆ Age-Mean age =13 years (SD = 6)

How Have We Learned?

- ◆ **Cross-sectional-** groups of children at different ages & compare/contrast their activities & achievements
- ◆ **Longitudinal-** follow groups of children over time as they grow and develop

Data collection strategies

| | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 |
|-------------|--------|--------|--------|--------|--------|
| <6 yrs | A | B | C | D | E |
| 6–12 yrs | A | B | C | D | E |
| 13–18 yrs | A | B | C | D | E |
| Over 18 yrs | A | B | C | D | E |

Longitudinal

Cross-Sectional

Spina Bifida study: Challenges/secondary conditions & Achievements

- ◆ Challenges
 - Physical
 - Social & personal
 - Academic
- ◆ Resources & supports
- ◆ Quality of life
- ◆ Looking to the future

Defining secondary conditions in development

- ◆ Definition

- ◆ Secondary conditions are complications, sequelae or consequences secondary to a primary condition or impairment. The primary condition is a necessary but not sufficient cause.

- ◆ Measurement

- ◆ Documentation of the extent to which physical, social and psychological conditions constitute problems for personal functioning

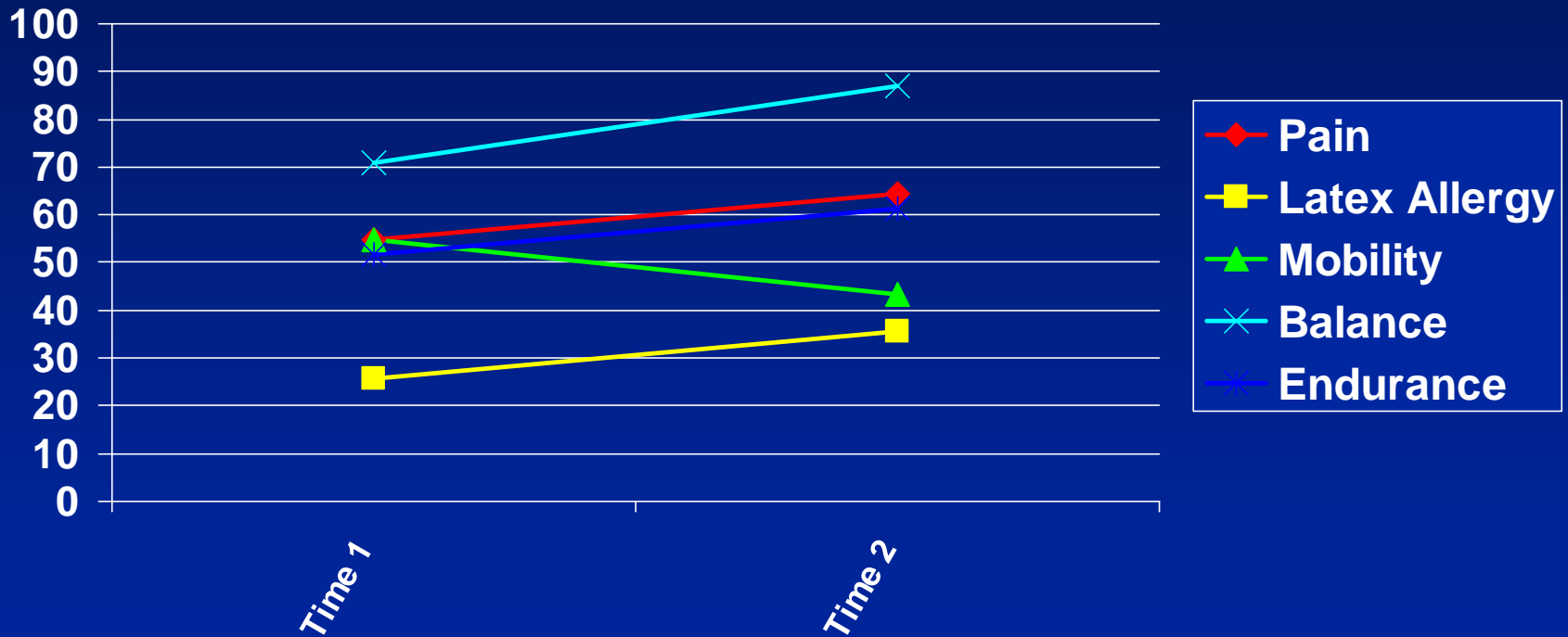
How Are Challenges, Resources, & Future Goals Measured?

- ◆ Survey questions about extent of challenges experienced in
 - Physical
 - Social
 - Personal
 - Academic
- ◆ Survey questions about factors defining quality of life & views of the future

Challenges - Physical

Longitudinal (0-5 years)

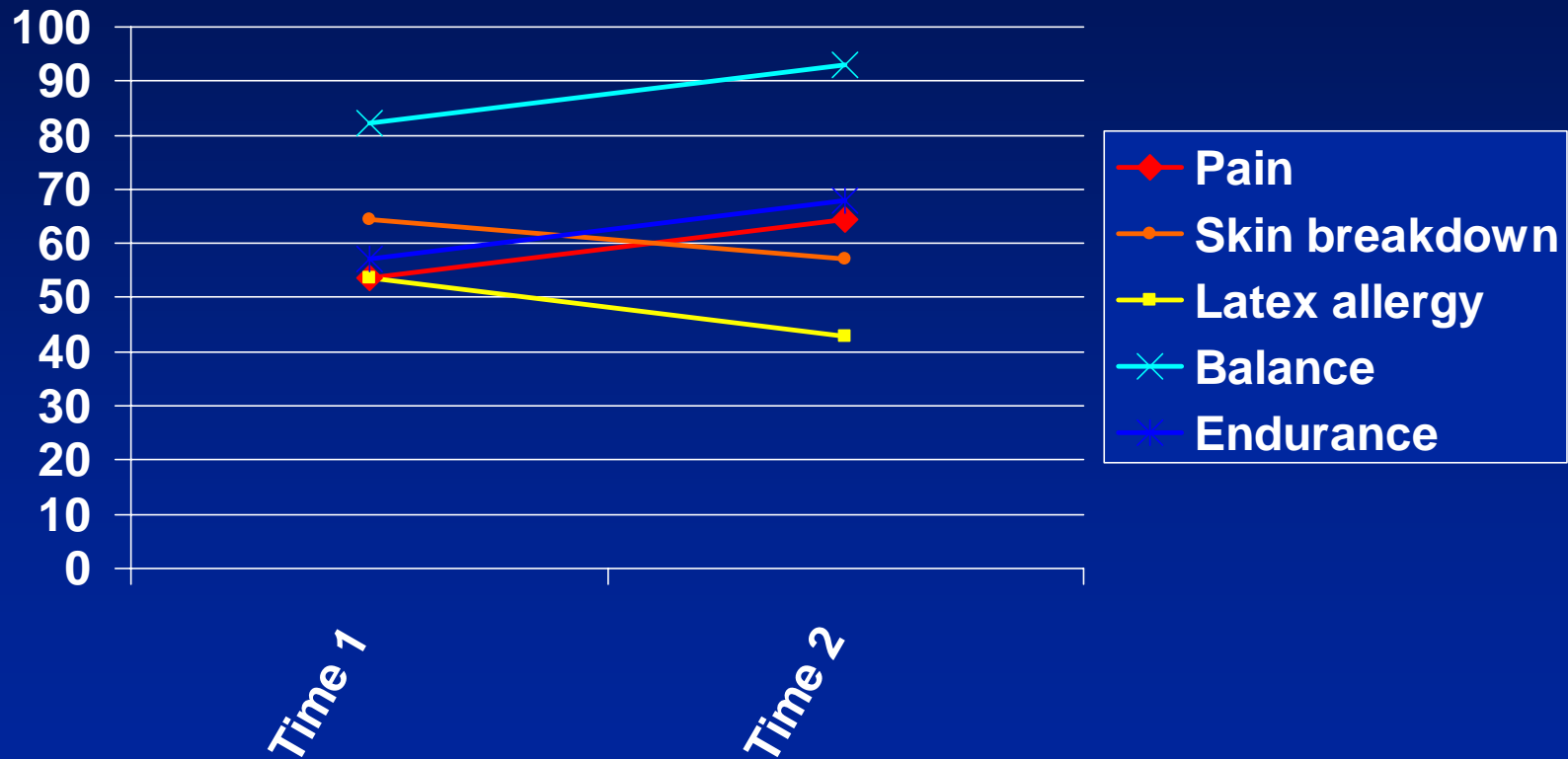
% Problem- Family Report



Challenges - Physical

Longitudinal (6-12 years)

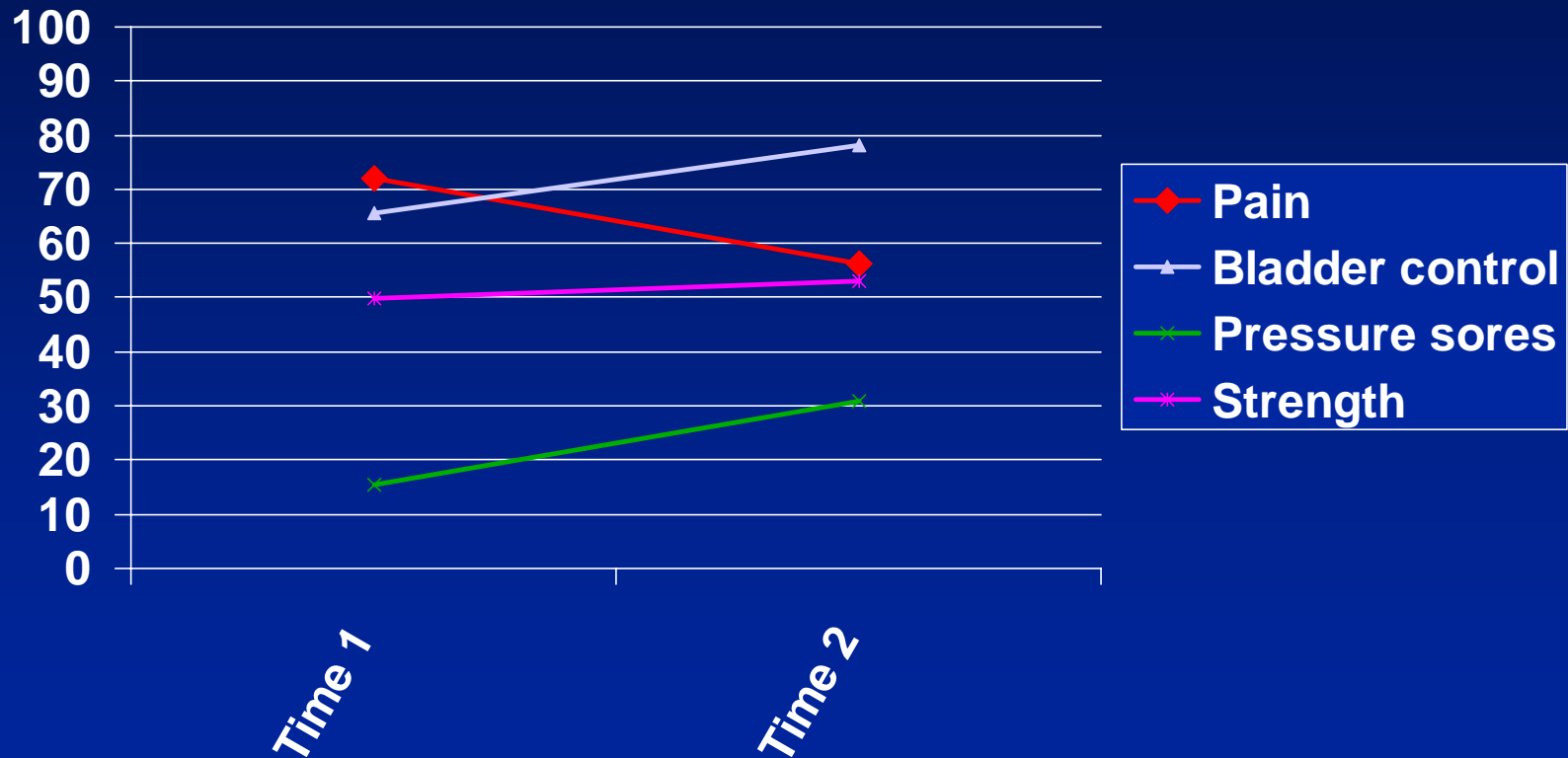
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Challenges - Physical

Longitudinal (13-18 years)

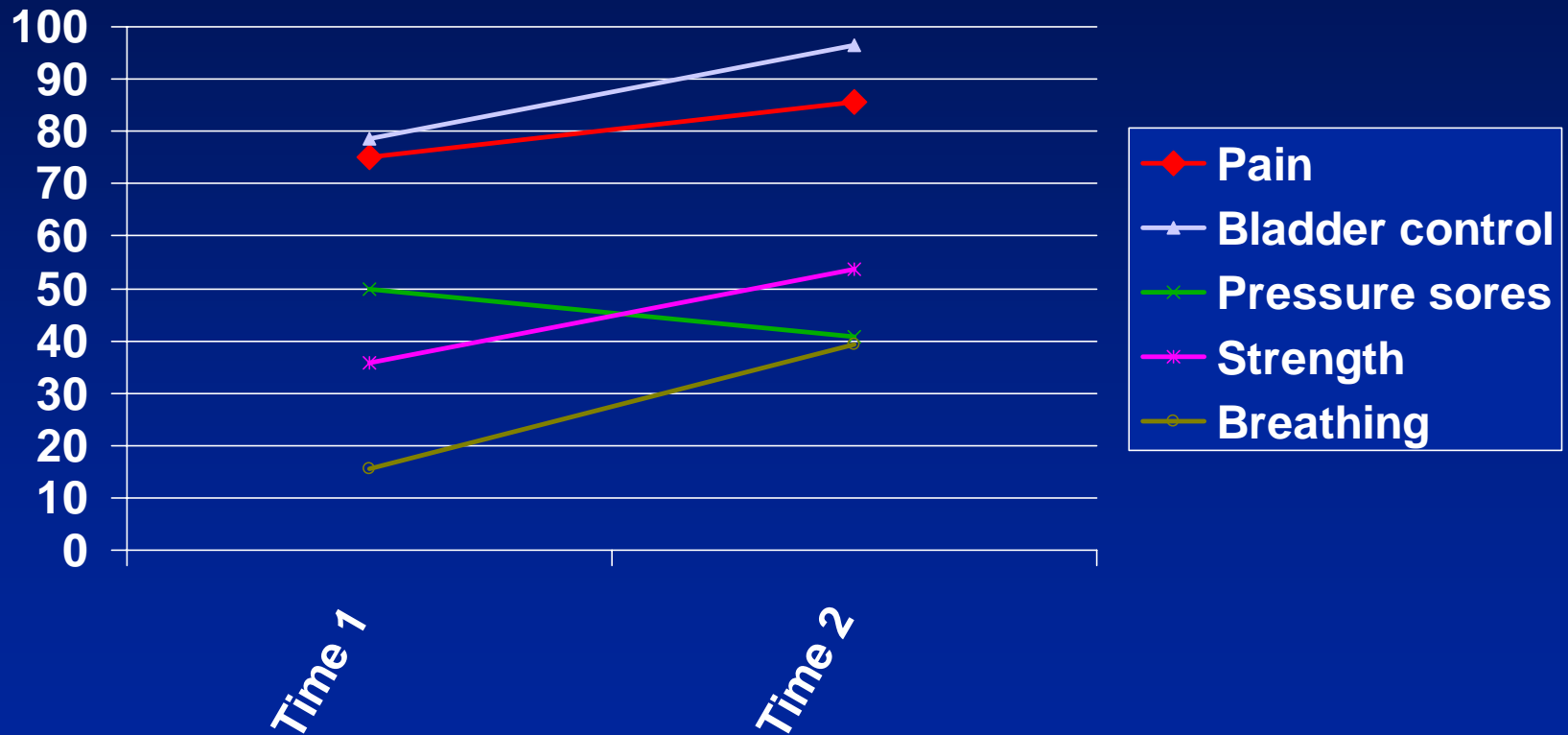
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Challenges - Physical

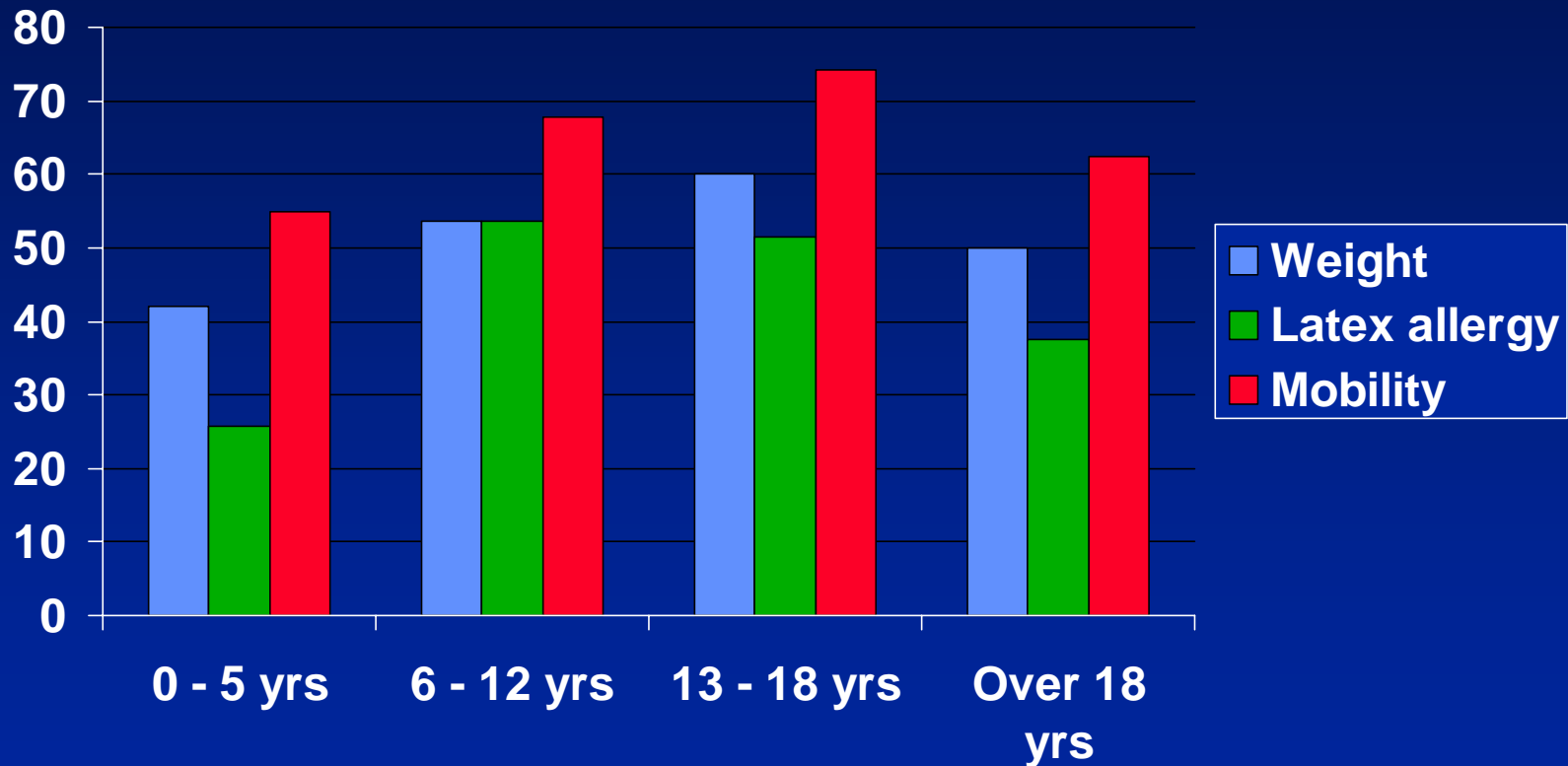
Longitudinal (Over 18 years)

% Problem- Self Report



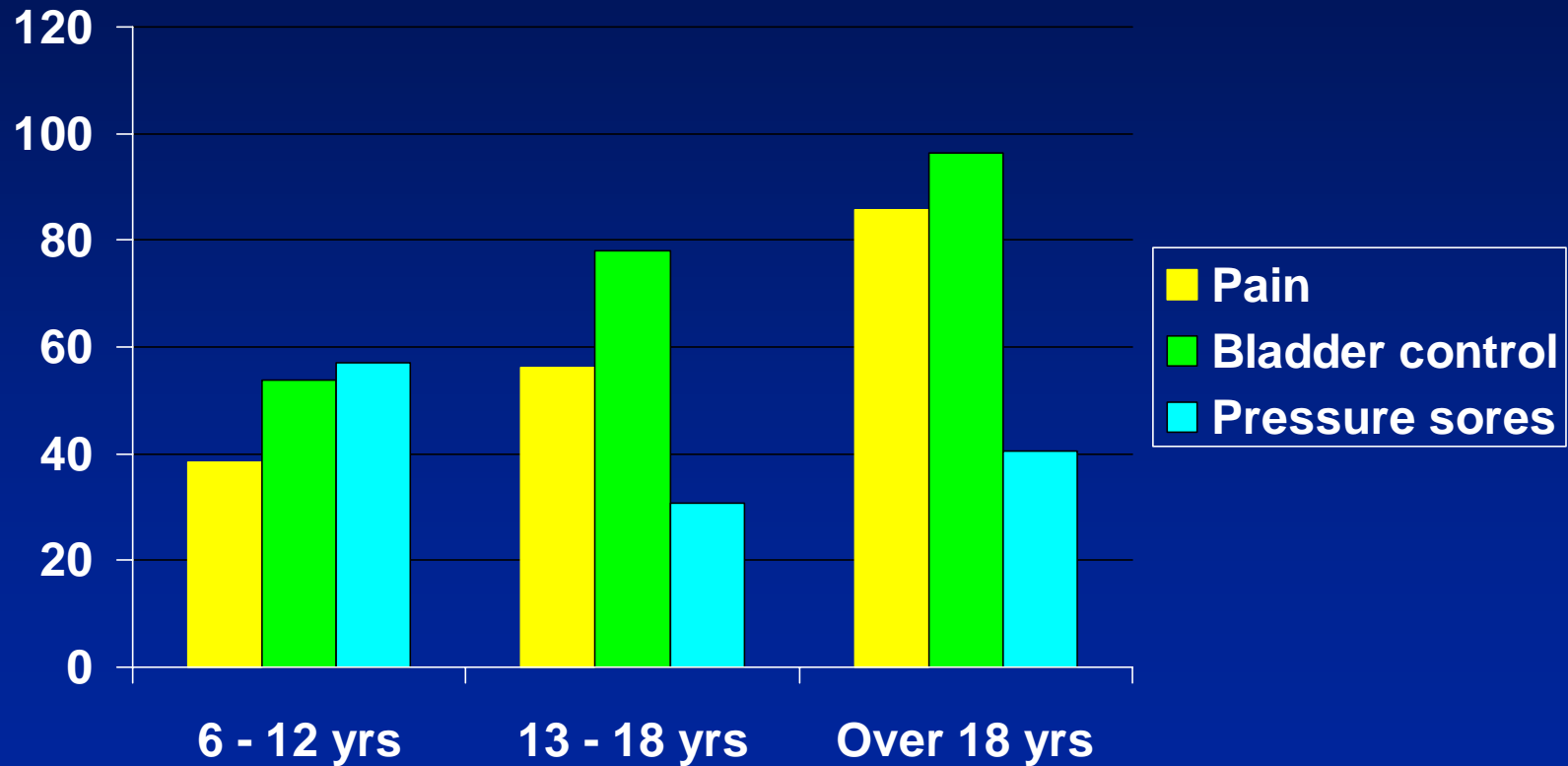
Challenges - Physical

Cross-sectional (Time 1)
% Problem- Family Report



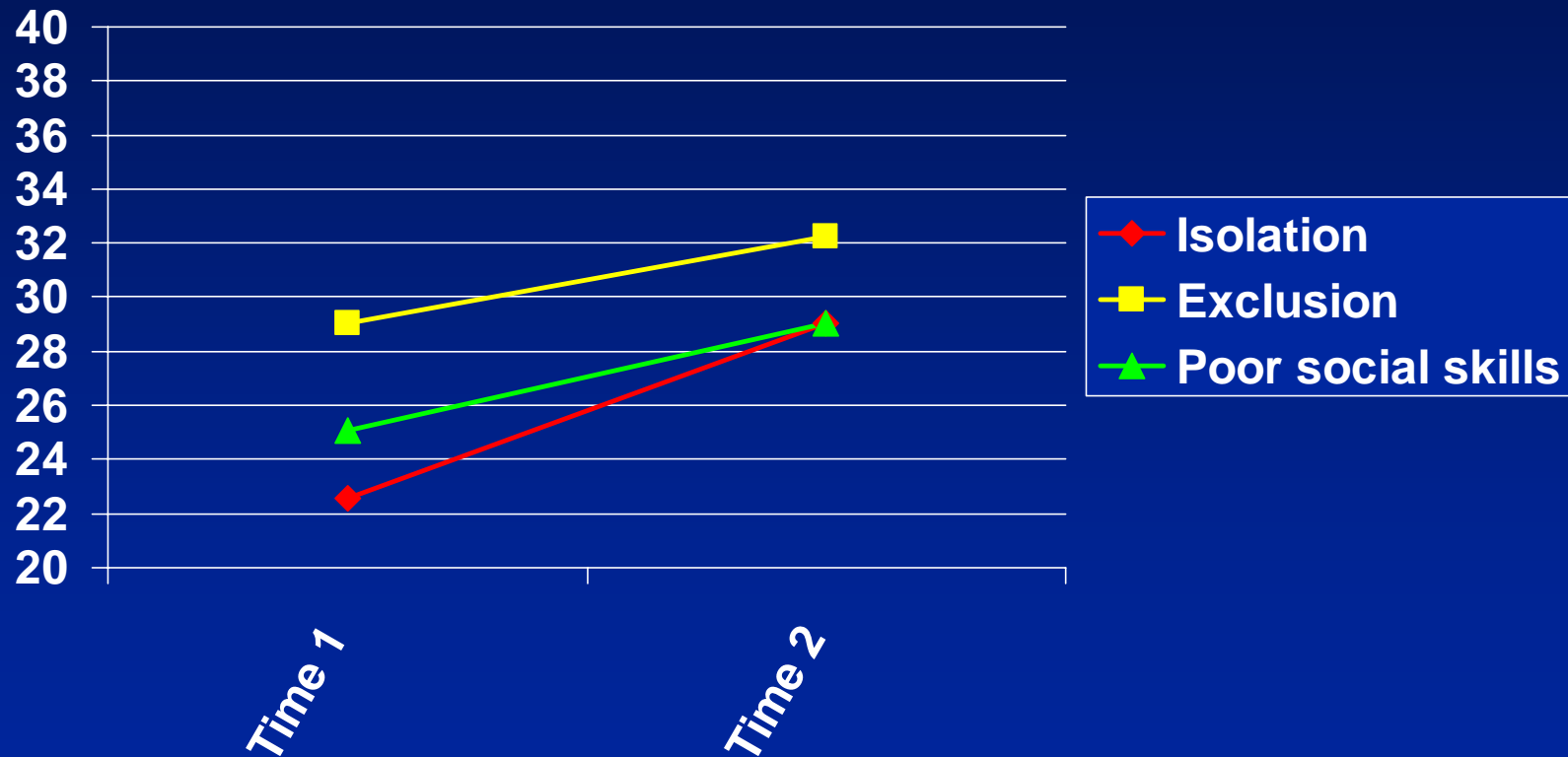
Challenges - Physical

Cross-sectional (Time 2)
% Problem- Self Report



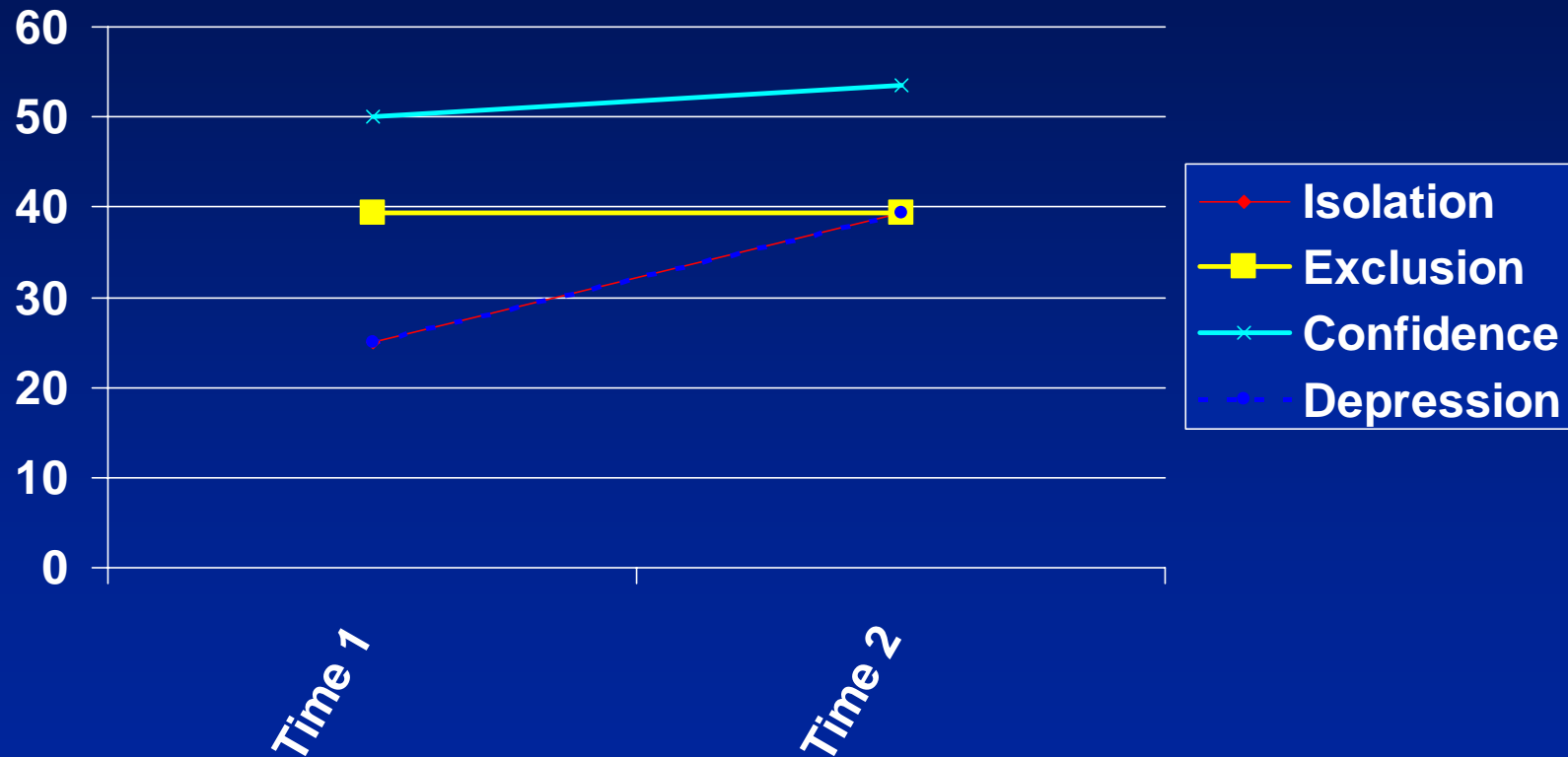
Challenges - Social & Personal

Longitudinal (0-5 years)
% Problem- Family Report



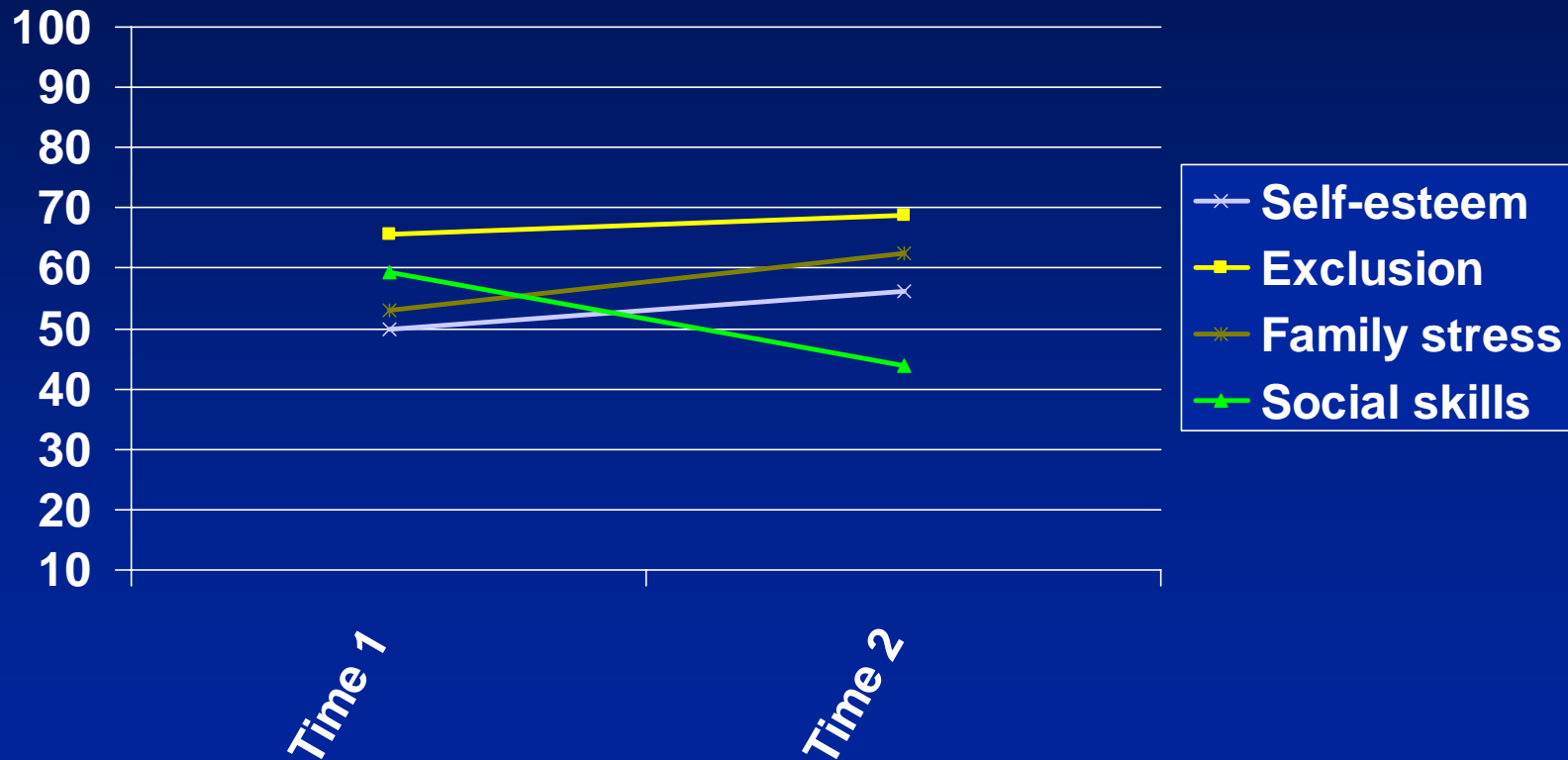
Challenges - Social & Personal

Longitudinal (6-12 years)
% Problem- Family Report



Challenges - Social & Personal

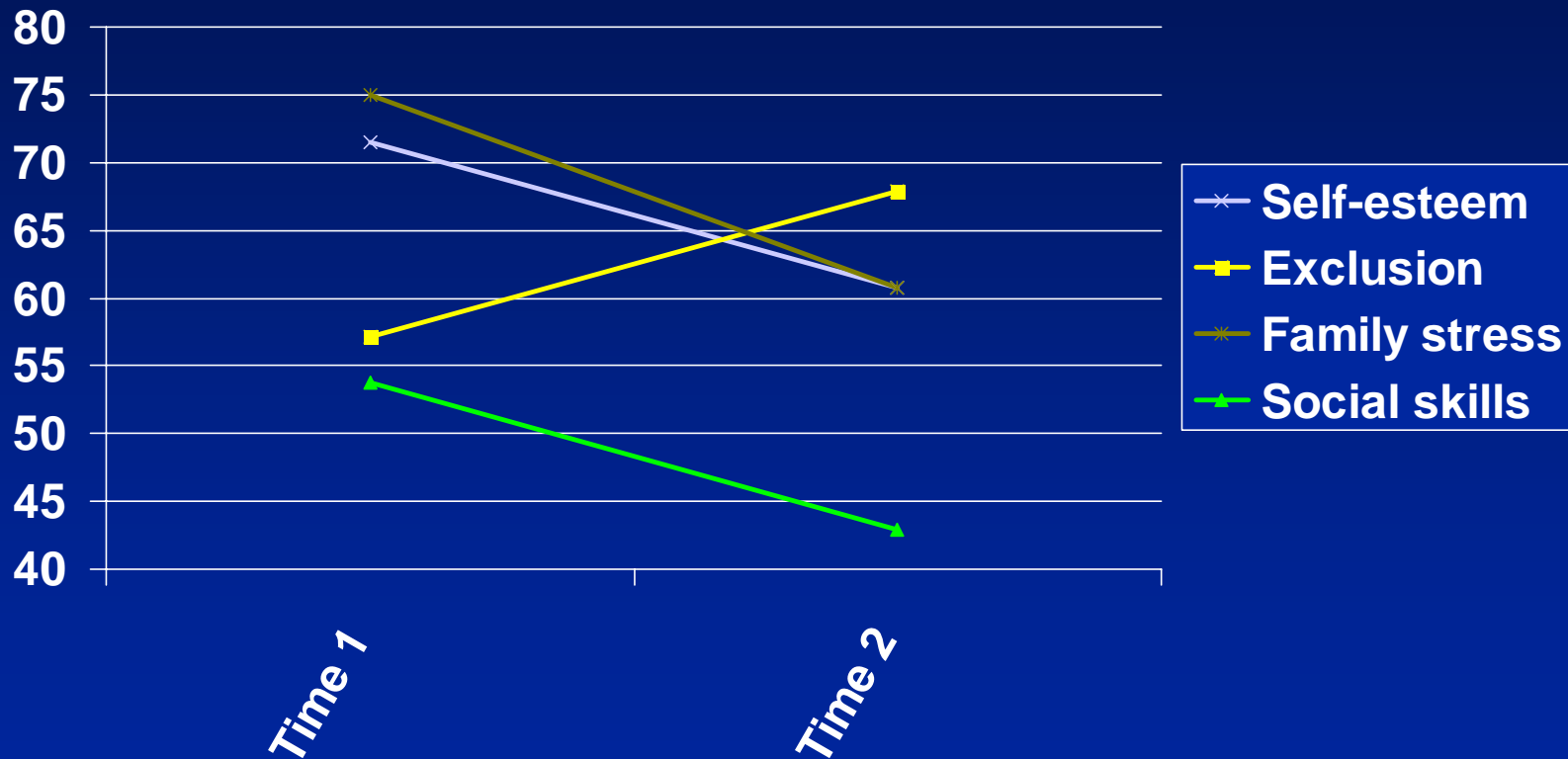
Longitudinal (13-18 years)
% Problem- Self Report



Challenges - Social & Personal

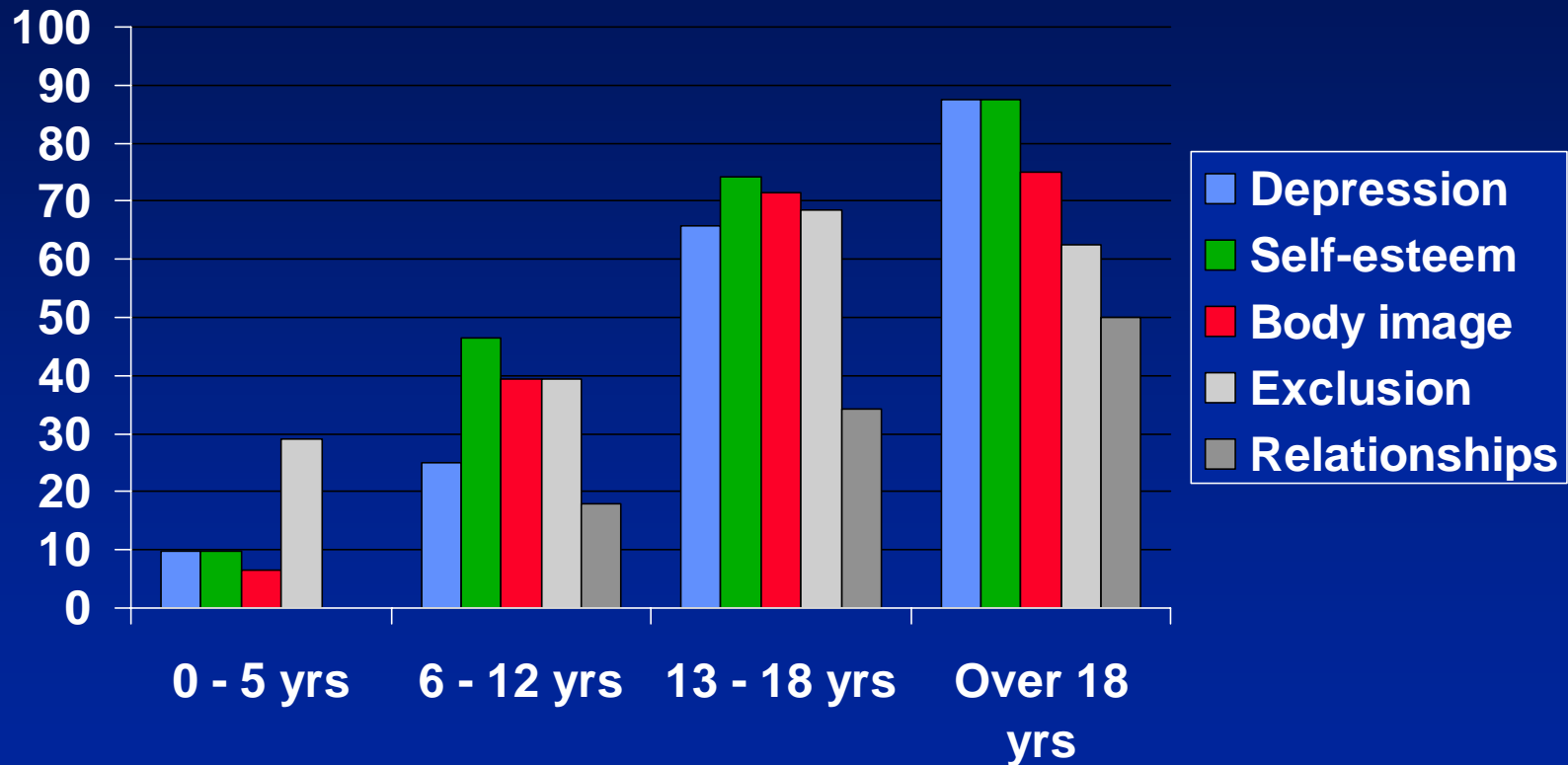
Longitudinal (Over 18 years)

% Problem- Self Report



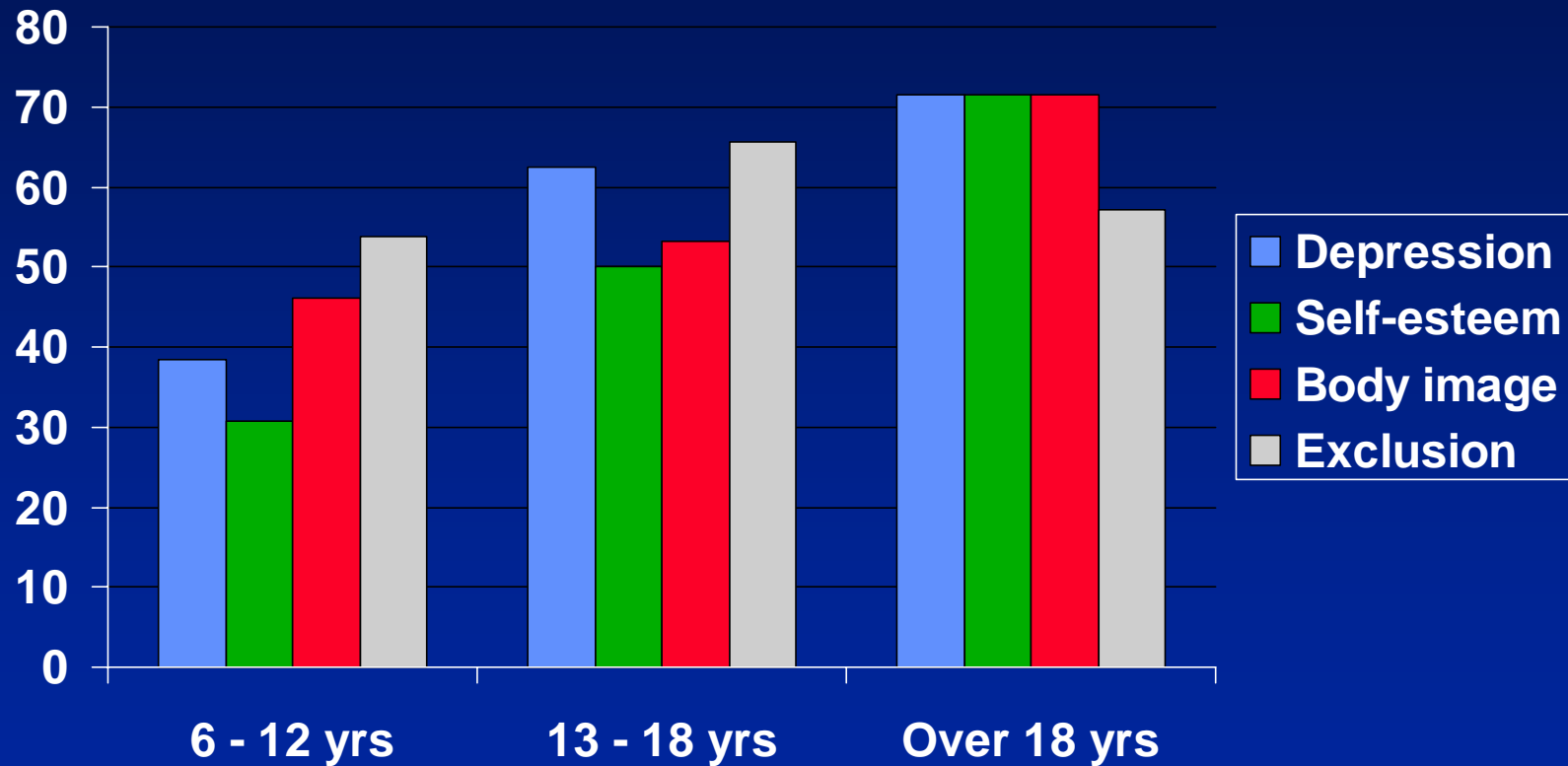
Challenges - Social & Personal

Cross-sectional (Time 1)
% Problem- Family Report



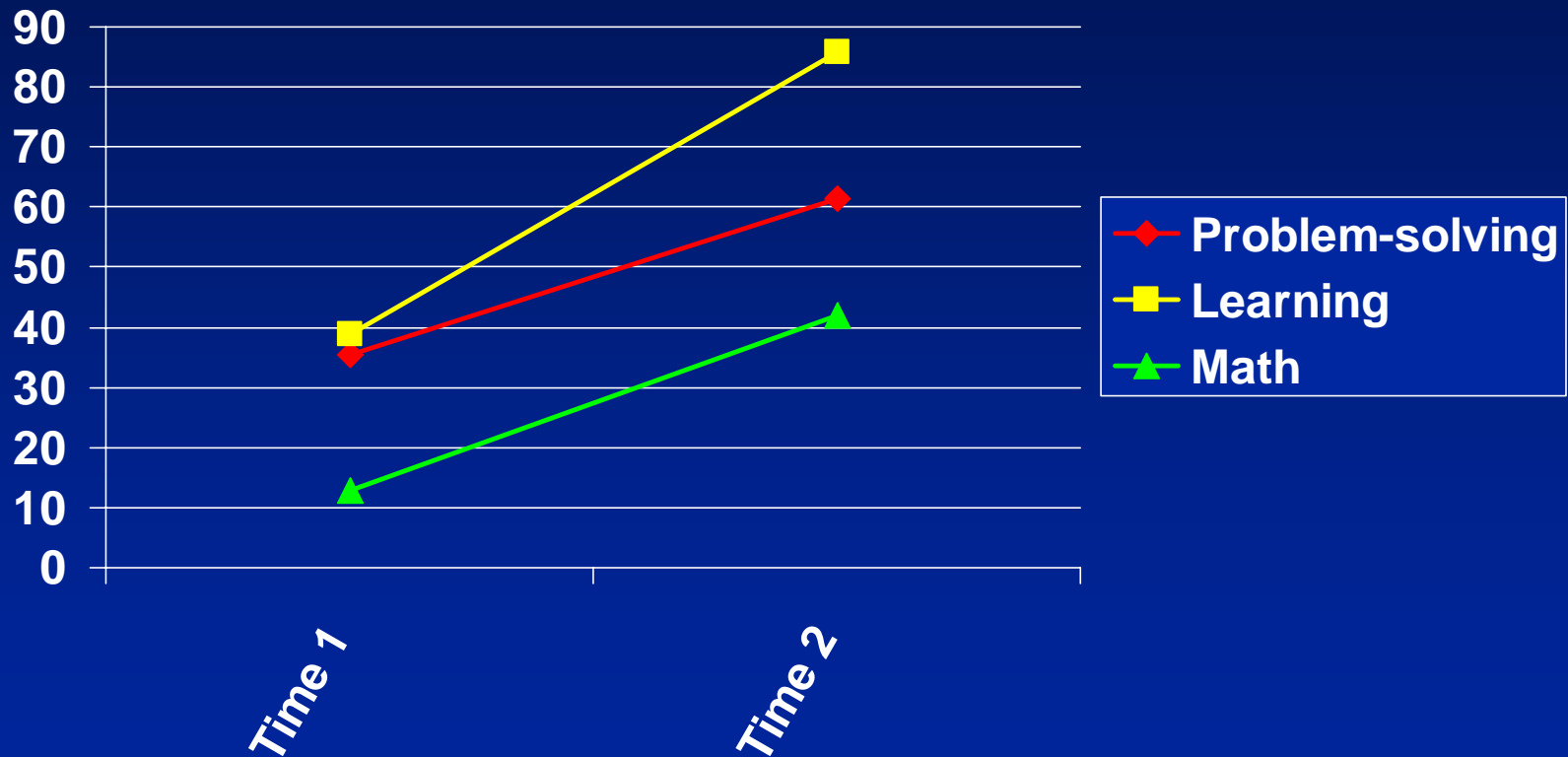
Challenges - Social & Personal

Cross-sectional (Time 1)
% Problem- Self Report



Challenges - Academic

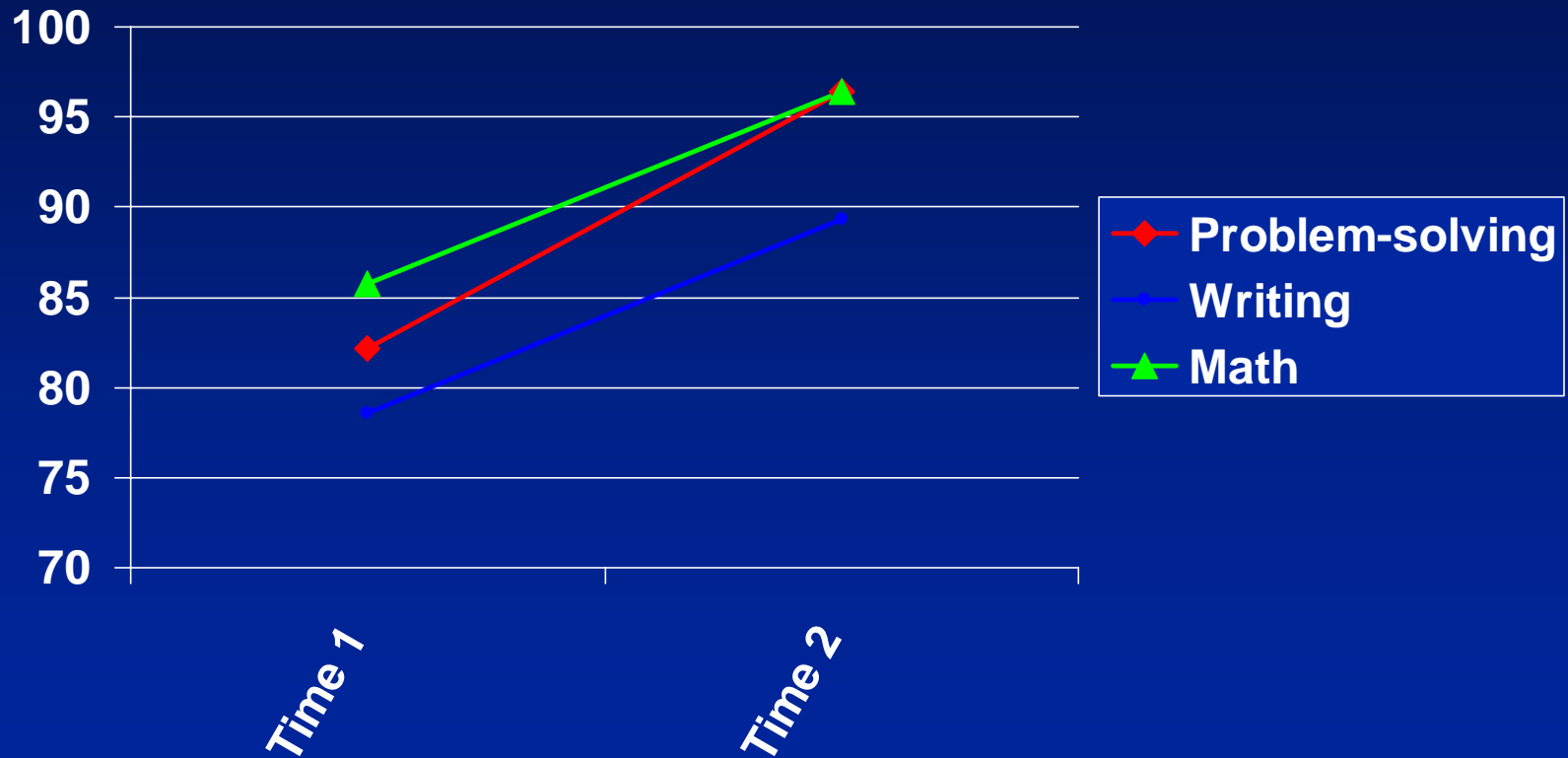
Longitudinal (0-5 years)
% Problem- Family Report



Challenges - Academic

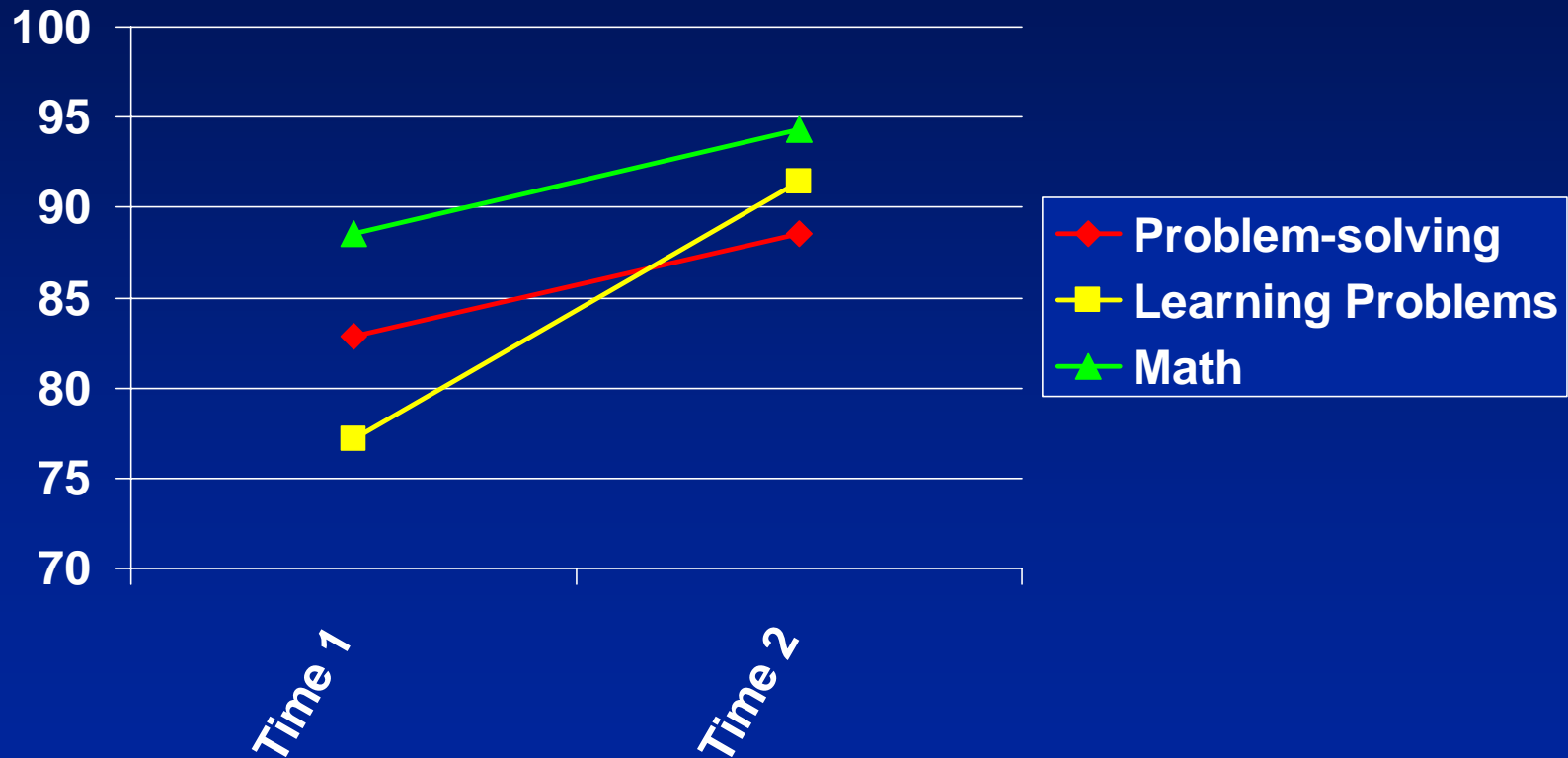
Longitudinal (6-12 years)

% Problem- Family Report



Challenges - Academic

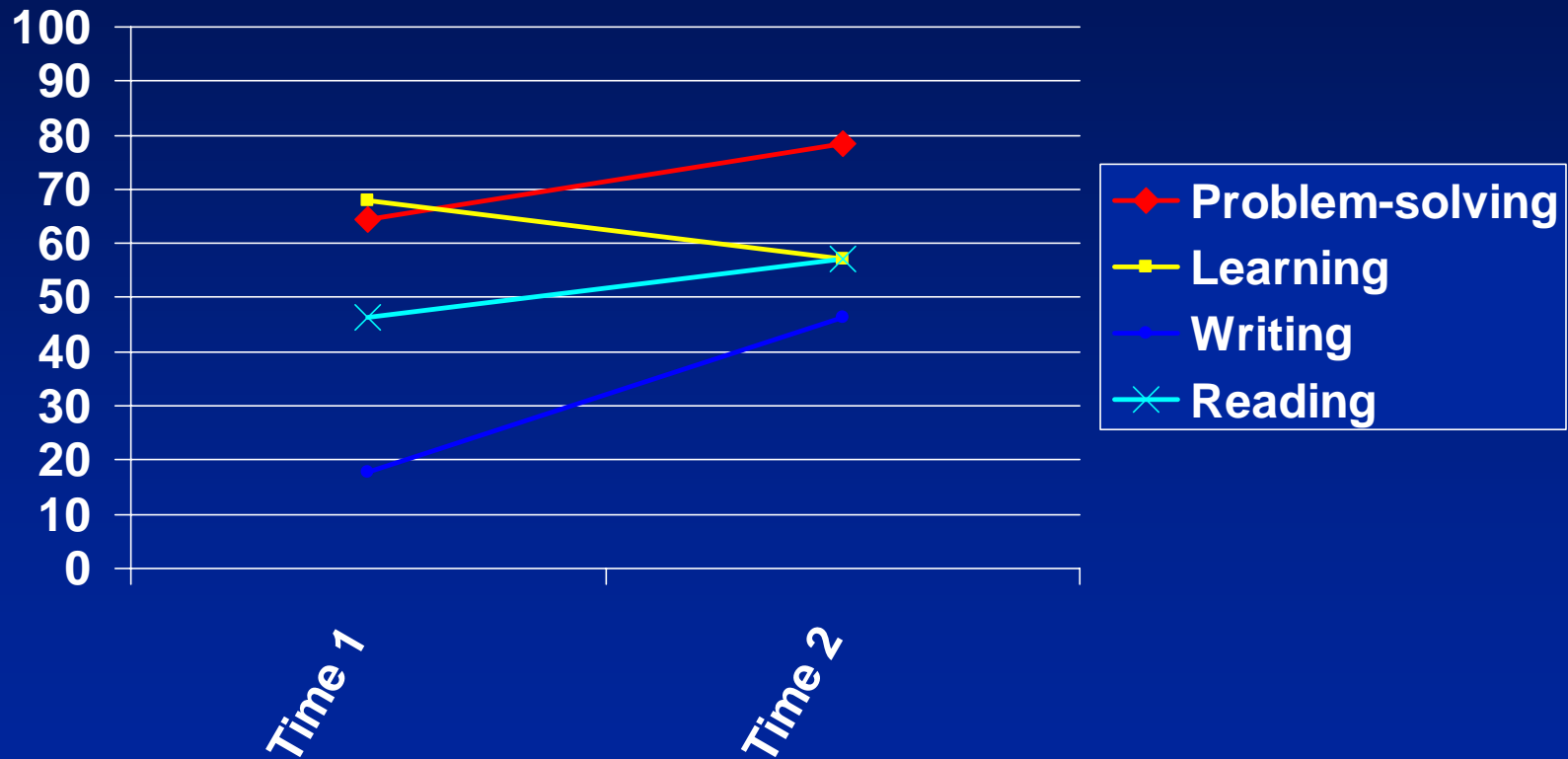
Longitudinal (13 - 18 years)
% Problem- Family Report



Challenges - Academic

Longitudinal (Over 18 years)

% Problem- Self Report



Quality of Life

“Quality of life is defined as an individual’s (a family’s) perception of their position in life in the context of the cultural and value system in which they live and in relation to their goals, expectations, standards, and concerns.”

(Orley, 1994)

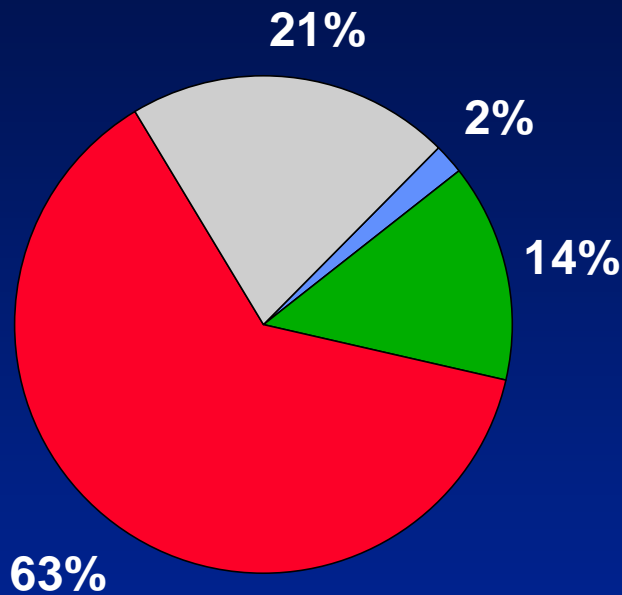
How is QOL Measured?

- ◆ How would you describe your (child's/family's) Quality-Of-Life, overall?

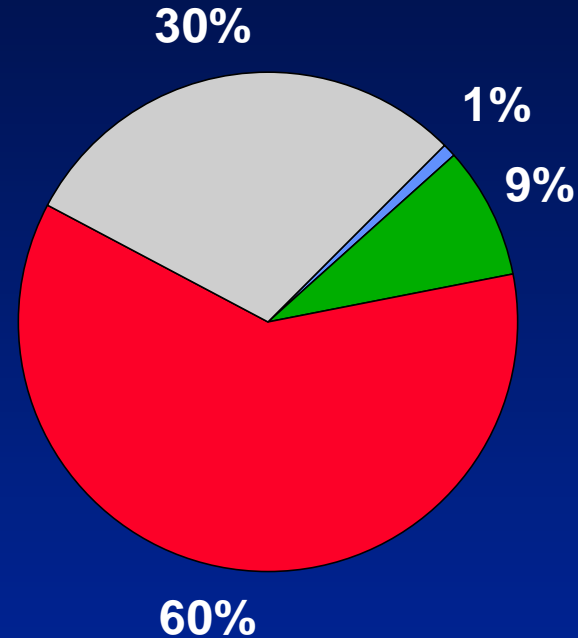
Excellent Very Good Good Fair Poor

- ◆ On what basis did you give that response? What makes you feel that way?

QOL Ratings



Self



Family

Child QOL & Family QOL

Illustrations

| | <u>Rating</u> | <u>Justification</u> |
|--------|---------------|---|
| Child | E | “She is a very independent 3 1/2 year old and she does not give up easily.” |
| Family | F | “We love each other very much and do what we can to help one another, but we always feel we can do better. But for some reason, better is never there.” |

Child QOL & Family QOL

Illustrations

| | <u>Rating</u> | <u>Justification</u> |
|--------|---------------|---|
| Child | G | “I feel she could be more independent, but she is a happy and overall well adjusted young lady. She has a lot of friends and is friendly, but is left out sometimes because of her disability.” |
| Family | VG | “We have all the basic needs of life. We have a family and church family who loves us and is there when we need them.” |

Child QOL & Family QOL

Illustrations

| | <u>Rating</u> | <u>Justification</u> |
|--------|---------------|---|
| Child | P | “No social life, no friends, difficulty in school, doesn’t know what to do with her free time.” |
| Family | VG | “Close family, very supportive, caring.” |

MEETING CHALLENGES: child & youth recommendations

- ◆ “Support groups and books”
- ◆ “If people would talk to the 6th graders at school about spina bifida”
- ◆ “More reliable transportation”
- ◆ “PE and rec stuff at school-nothing is there that I can play with”
- ◆ “More accessibility to public places”
- ◆ “Change opinions of society”

PROMOTING HEALTH: child & youth recommendations

- ◆ “You can do push ups in your chair to reduce pressure sores”
- ◆ “Have a weight loss group for handicapped kids”
- ◆ “More options for exercise that would be appropriate for my disability”
- ◆ “Need to learn to not eat junk food”

PROMOTING INDEPENDENCE: child & youth recommendations

- ◆ “I could be more confident; to get more help in math”
- ◆ “Being around other teens”
- ◆ “Help in school with reading”
- ◆ “I need to get out more and be given more independence”
- ◆ “I’m not sure. Perhaps this research will help you find out”

GRACIAS

THANK YOU!