

Subjective measurement of participation and environmental barriers and facilitators in population surveys : use of standardized tools with a sub-sample of the Quebec Activity Limitations Survey (QALS)

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**LIVING IN OUR ENVIRONMENT:
The Promise of ICF**

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Context

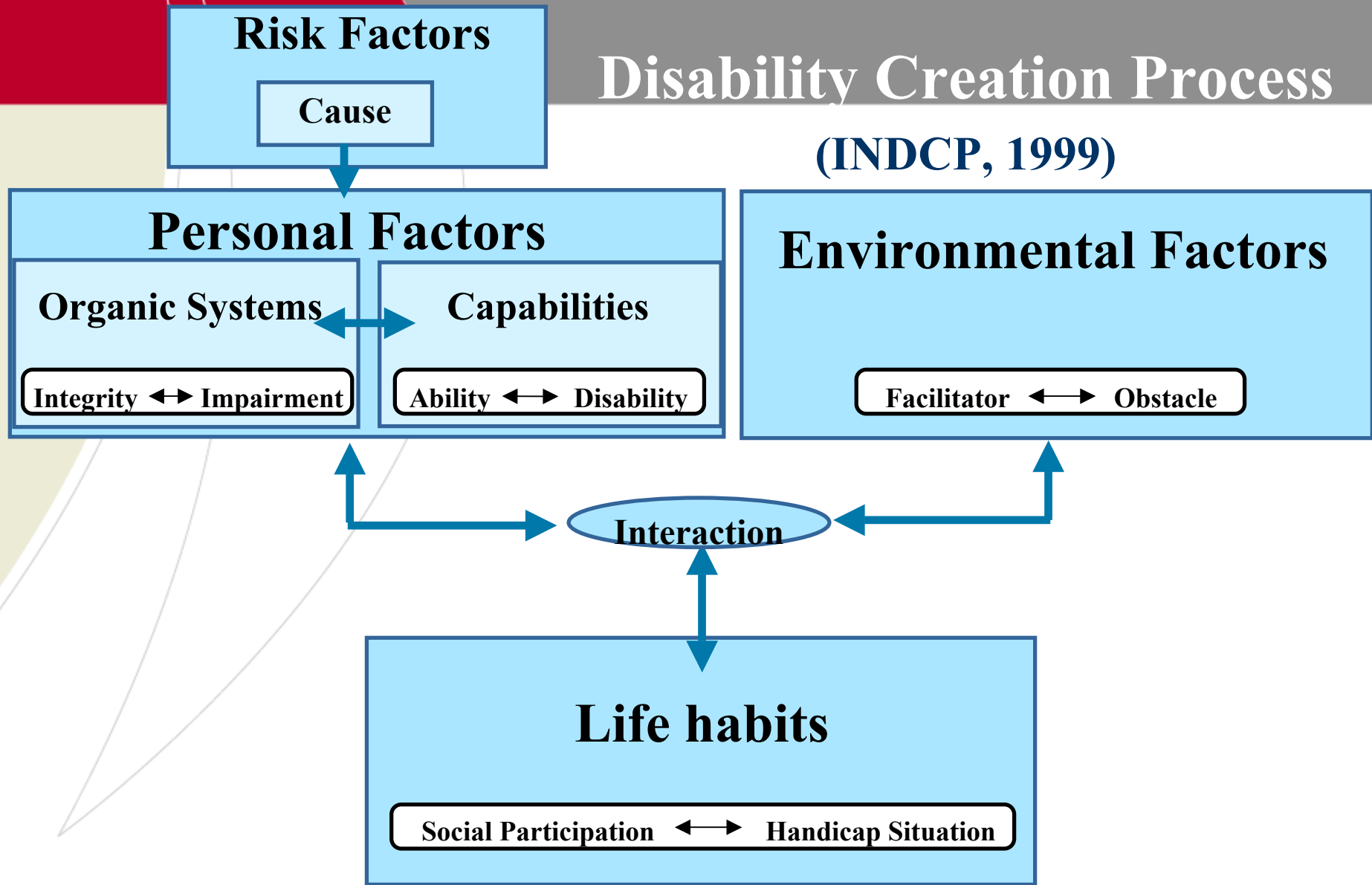
Partial results of a research on Personal and Environmental Factors associated to poverty progression (Income + Social Participation) of people with disabilities in Quebec— Funded by Fonds québécois de recherche Société et culture (FQRSC) (2003-2005).

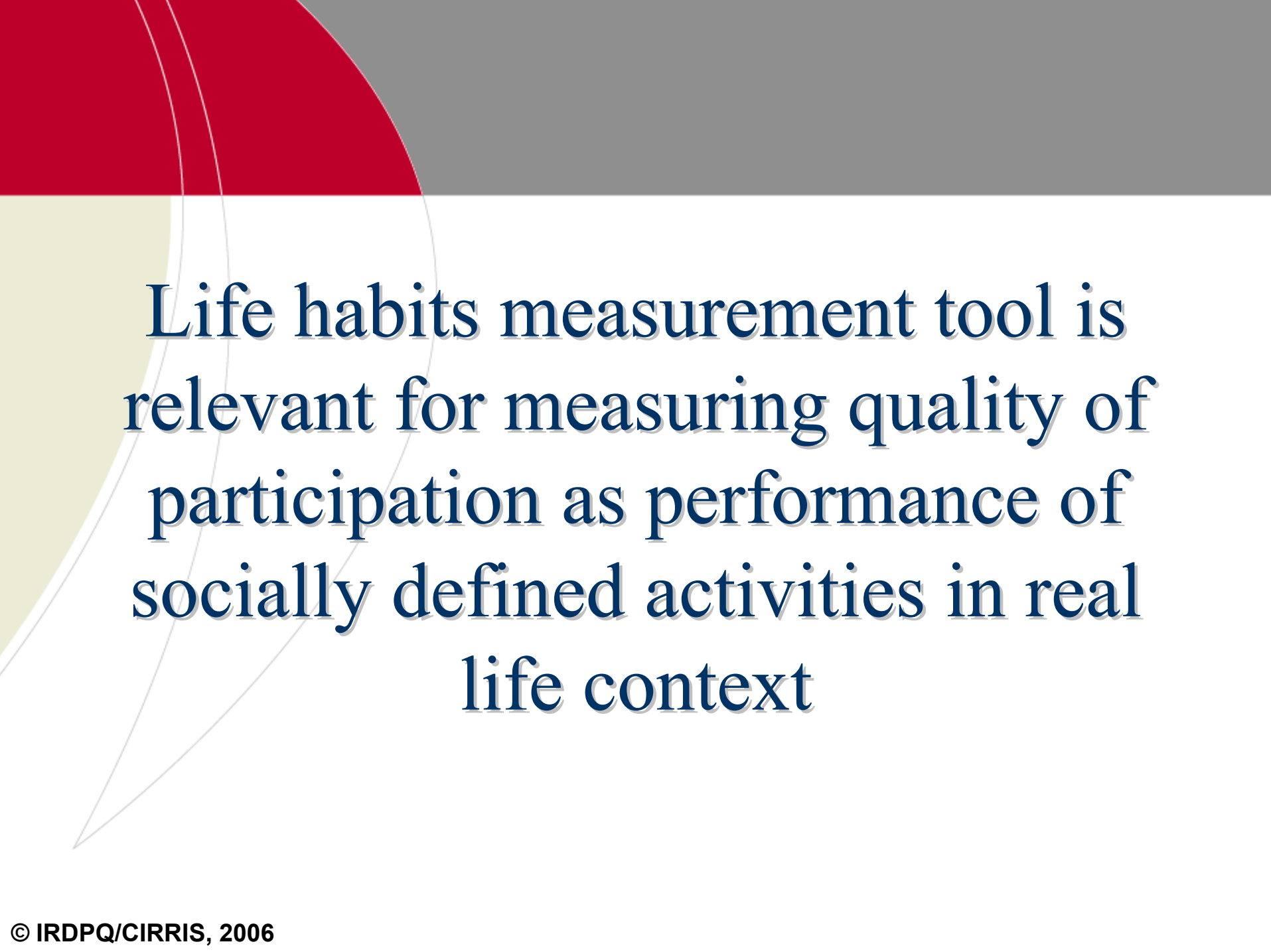
Methods

The collection of data was done by phone with a sub-sample (n= 259) of adults with disabilities identified in the Quebec activity limitations survey (QALS-1998), administered by Statistique-Québec (n =3070).

As, the original questionnaire did not document in a conceptually coherent, sufficient and useful way environmental factors and participation dimensions in order to understand their interactions, both Life-H and MQE short versions were added to the sub-sample survey assessing five years later the progression of poverty (2003).

Disability Creation Process (INDCP, 1999)





Life habits measurement tool is relevant for measuring quality of participation as performance of socially defined activities in real life context

Life Habits

Social Participation ↔ **Handicap Situation**

Life Habits

A *daily activity or social role* valued by the person and his/her socio-cultural context ensuring his/her survival and well-being throughout lifetime.

Examples:

- Getting into and out of bed
- Attending to his/her personal hygiene
- Sleeping properly (comfort, duration...).
- Taking part in social activities
- Taking care of children

Specific measurements of LIFE-H

- The degree of accomplishment of life habits from 2 sub-scales :
 - 1) *the level of difficulty and;*
 - 2) *the type of assistance required.*
- The satisfaction regarding the accomplishment of each life habit.
- **Long form** (240 items): More in-depth analysis (90 min.)
- **Short form** (69 items) : General screening (30 min.)
- **Short version** (16 items) : Tracking (10 min.)

The accomplishment scale of LIFE-H

	Level of accomplishment	Type of assistance required
9	Accomplished with no difficulty	(No help)
8	Accomplished with no difficulty	(Technical aid or adaptation)
7	Accomplished with difficulty	(No help)
6	Accomplished with difficulty	(Technical aid or adaptation)
5	Accomplished with no difficulty	(Human assistance)
4	Accomplished with no difficulty (Human assistance and technical aid or adaptation)	
3	Accomplished with difficulty	(Human assistance)
2	Accomplished with difficulty	(Human assistance and technical aid or adaptation)
1	Accomplished by substitution	
0	Not accomplished	
N/A	Not applicable	

Format of LIFE-H (example)

**Answer the following two questions.
(Check the appropriate boxes.)**

1 For each of the following life habits, indicate
A. How the person generally accomplishes it,
and
B. The type of assistance required to
accomplish it.

2 For each of the following life habits, indicate
the level of satisfaction with the way it is
accomplished.

Note: Keep in mind that answers should reflect the person's usual way of carrying out life habits.

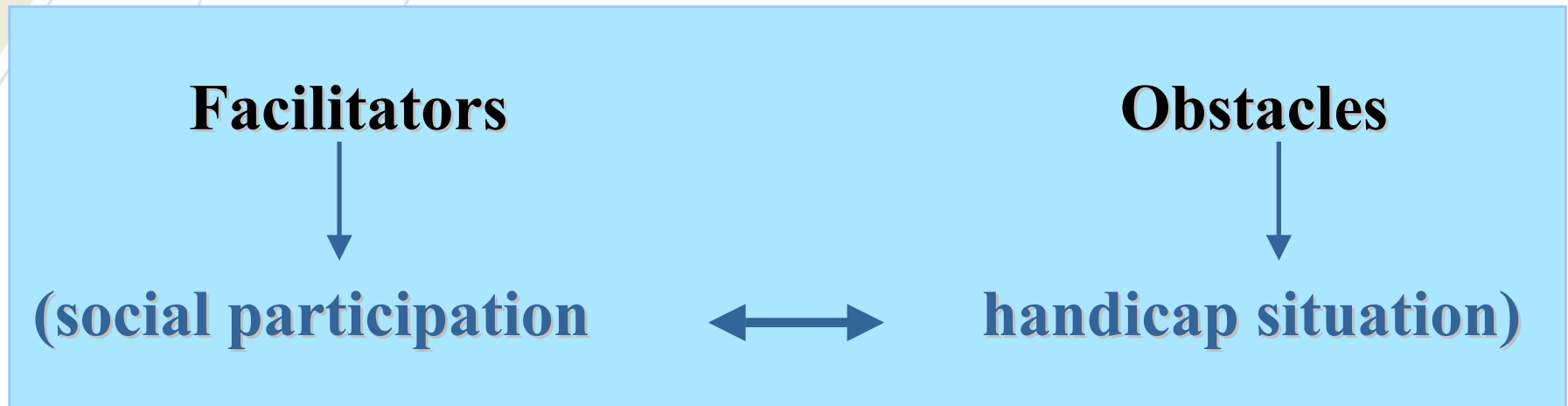
Question 1		Question 2
A	B	
Level of Accomplishment (Check only 1)	Type of Assistance (Check 1 or more, as required)	Level of Satisfaction (Check only 1)
<i>No difficulty</i>	<i>No assistance</i>	<i>Very dissatisfied</i>
<i>With difficulty</i>	<i>Assistive device</i>	<i>Dissatisfied</i>
<i>Accomplished by a proxy</i>	<i>Adaptation</i>	<i>More or less satisfied</i>
<i>Not accomplished</i>	<i>Human assistance</i>	<i>Satisfied</i>
<i>Not applicable</i>		<i>Very satisfied</i>



Environmental factors

Objective of the Measure of the Quality of Environment (MQE)

To evaluate the influence of environmental factors on the quality of participation (accomplishment of life habits) of a person or a specific population in relation to their functional capabilities .



Design of MQE

- 109 (*long form*) or 26 (*short form*) questions relating to environmental factors' QCDCP taxonomy (1991) easily crosswalkable with ICF one .
- A self-administered questionnaire that assesses the perceived influence of environmental factors
- Determination of an influence scale

Categories of Environmental Factors (MQE)

- | | ICF |
|---|---------|
| 1. Support and Attitudes (social network) | (e3-e4) |
| 2. Incomes, Job and Income Security | (e5) |
| 3. Governmental and Public Services | (e5) |
| 4. Physical Environment and Accessibility | (e1-e2) |
| 5. Aids, Devices and Technology | (e1) |
| 6. Equal Opportunity & Political Orientations | (e5) |

The influence scale of the MQE

Following each item....

While taking into consideration your abilities and personal limits, indicate to what extent the following situations or factors generally influence your daily life.

Score	Correspondance
-3	Major obstacle
-2	Medium obstacle
-1	Minor obstacle
0	No influence
1	Minor facilitator
2	Medium facilitator
3	Major facilitator
n	Does not apply
p	I do not know

Format of MQE (example)

Indicate to what extent the following factors or situations influence your daily activities and social roles by taking into account your abilities and personal limits.

Influence Scale



I do not know

N/A

Support and attitudes of your family and friends

1-	Your family situation (you live alone, with a spouse, or with children).	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>
2-	Support from the members of your family (presence, physical or household assistance).	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>
3-	Support from your friends.	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>
4-	Support from your neighbours.	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>
5-	The attitudes of your family towards you.	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>
6-	The attitudes of your friends towards you.	-3 -2 -1 0 1 2 3	<input type="checkbox"/>	<input type="checkbox"/>

Characteristics of the sample

<u>Current age (years)</u>	57 (± 14)
<u>Gender</u>	
Male	42,5%
Female	57,5%
<u>Nature of the disability</u>	
motricity	64,5%
communication	8,5%
psychism	4,2%
multiples limitations	22,8%
<u>Since 1998, your principal disability</u>	
decreased	14,3%
is remained stable	31,3%
is variable	18,5%
increased	35,9%



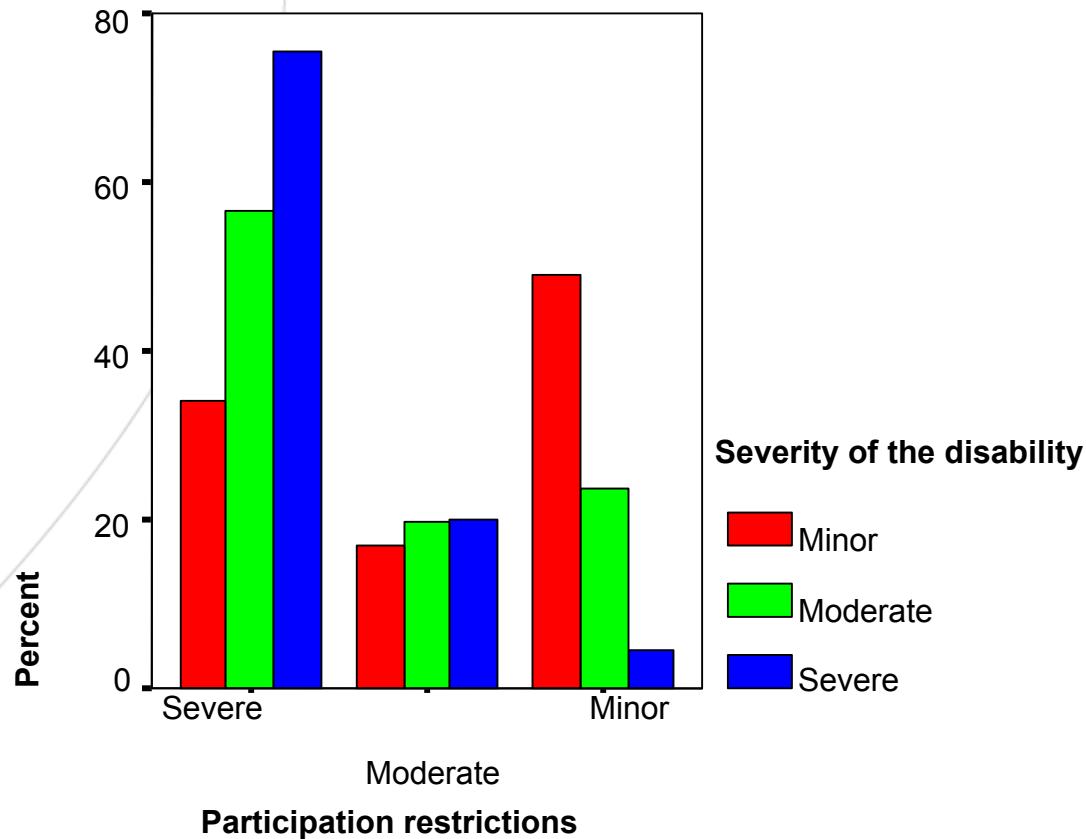
Results part 1

Social participation restrictions

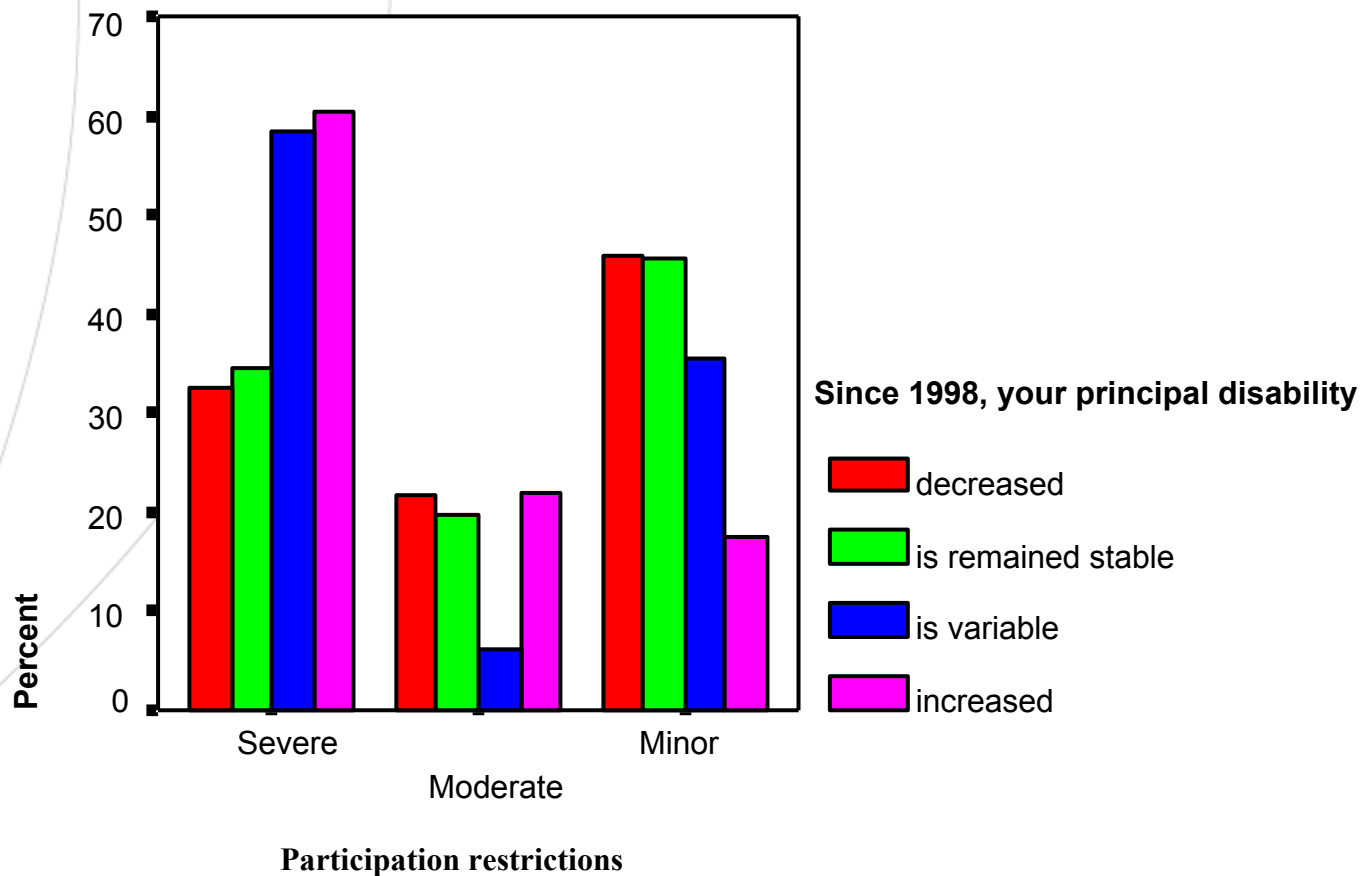
Significant participation restrictions in the accomplishment of 4 life habits

Life habits	Participation restrictions		
	Severe (score ≤ 3)	Moderate (score 4-7)	Minor (score ≥ 8)
Carrying out activities related to your home (maintenance, furnishing, and equipment)	47,9	18,3	33,9
Shopping and accessing services in your community	27,4	9,7	62,9
Participating in recreational activities (arts, sports, hobbies, outings, etc.)	23,2	26	50,8
Maintaining your physical fitness and your mental well-being	25,4	32,8	41,8

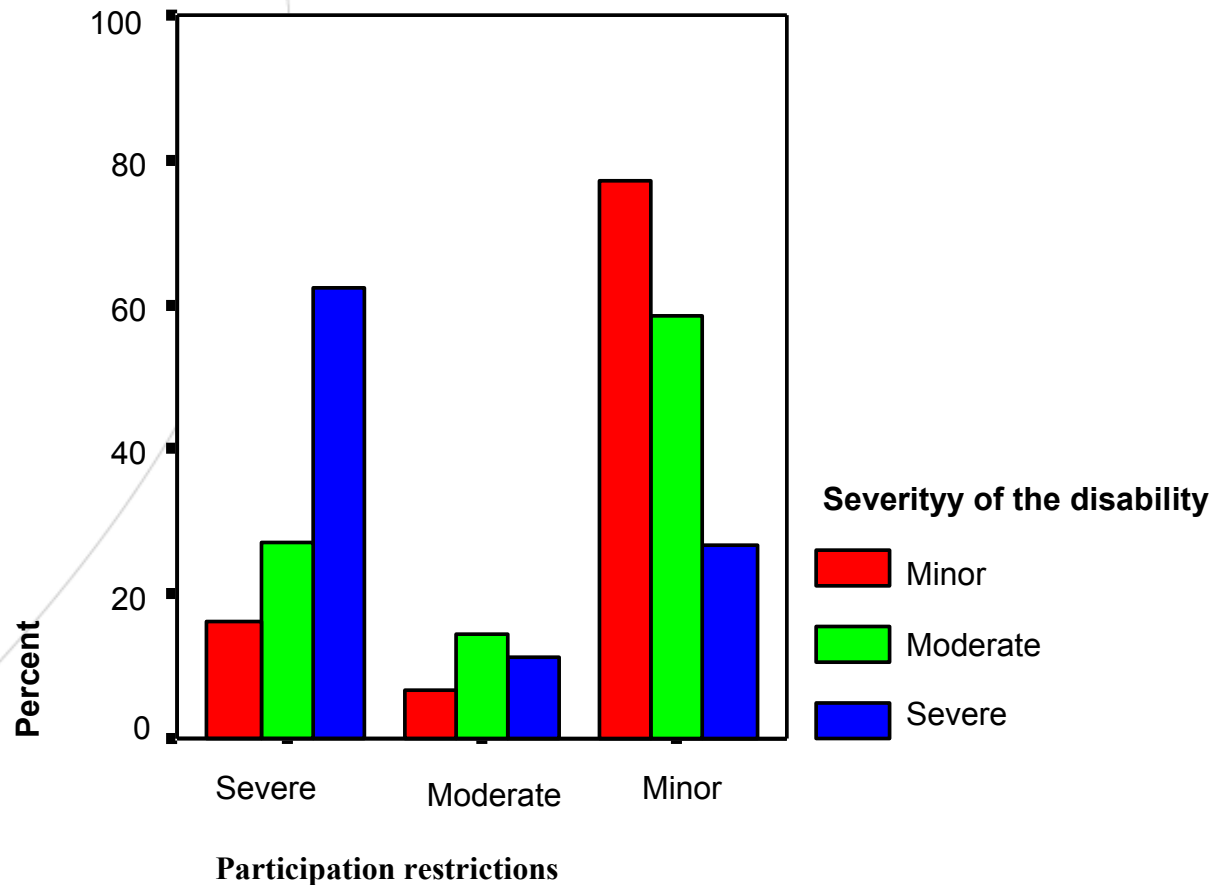
Carrying out activities related to your home and severity of the disability (functional)



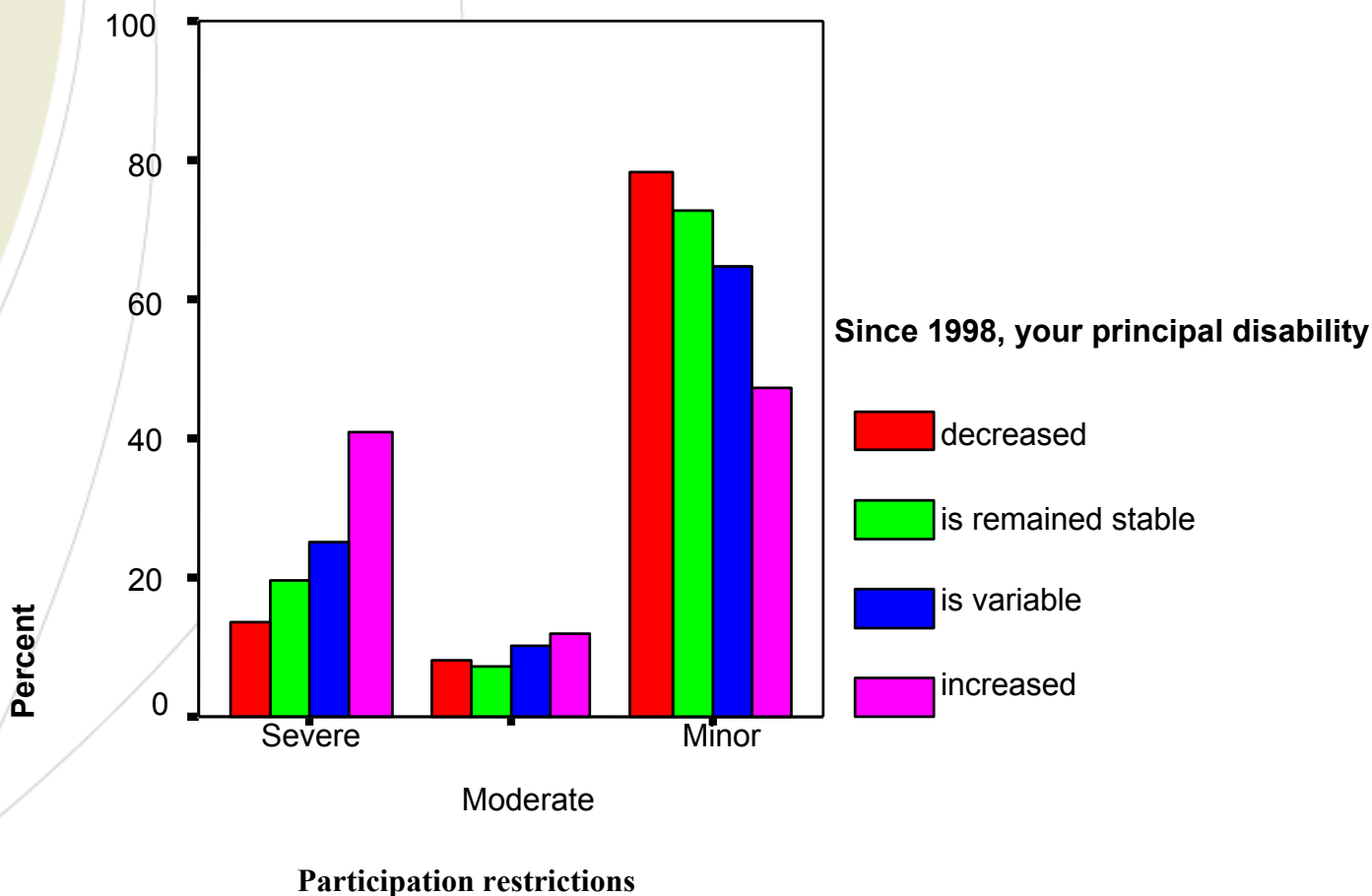
Carrying out activities related to your home and change of the principal disability



Shopping and accessing services in your community and severity of the disability



Shopping and accessing services in your community and change of the principal disability





Results part 2

Environmental factors

Factors identified as facilitators to the quality of social participation:

% of subjects

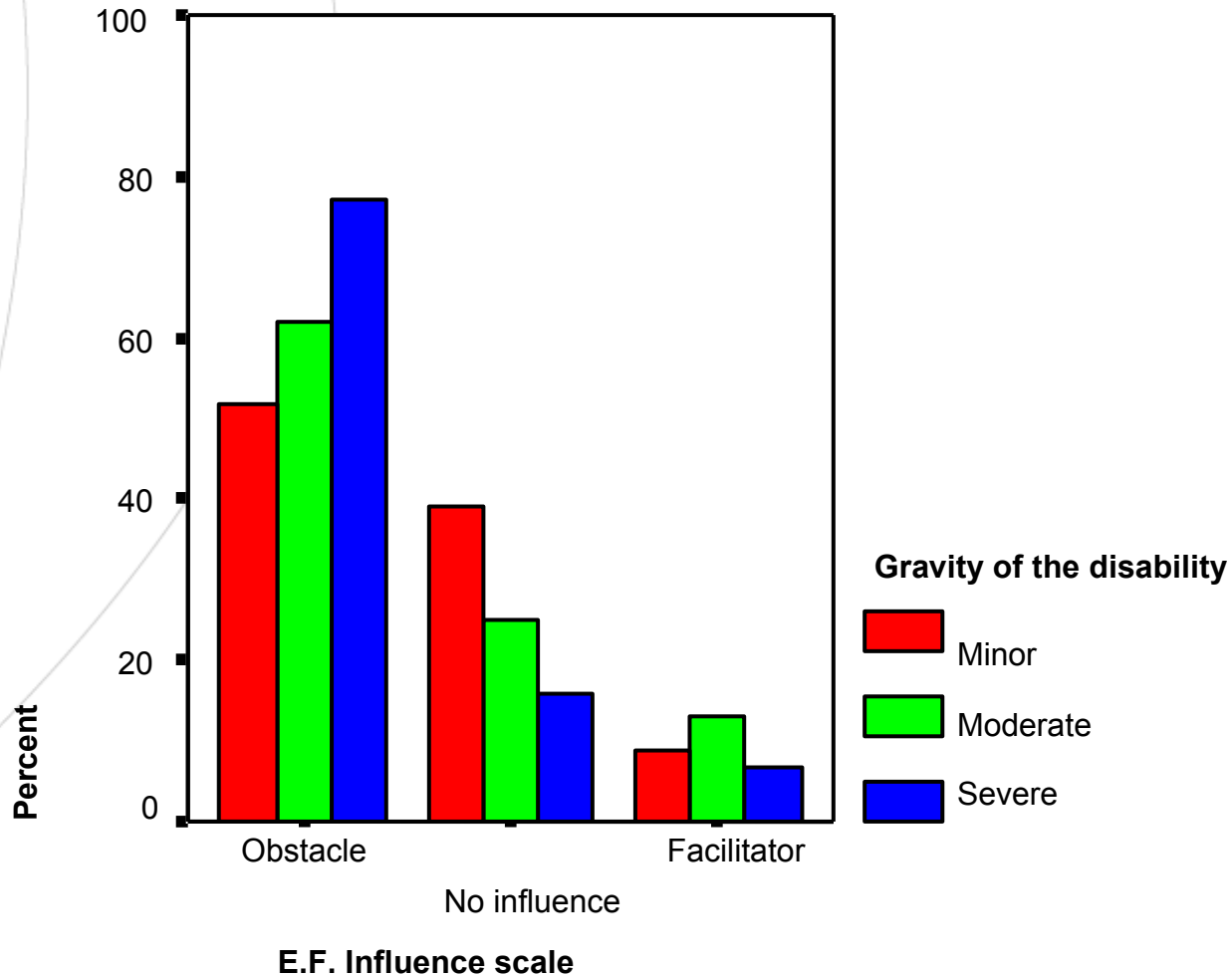
- **Support from those around you** (family, friends, colleagues) 75
- **Personal vehicle that you use** 72
- **Electronic communication** (telephone, Internet, fax) 69
- **Assistive devices** (availability, use, maintenance) 67
- **Home care services** (health, housekeeping, rehabilitation) 67
- **Attitudes of those around you** (family, friends, colleagues) 62

Factors identified as obstacles to the quality of social participation

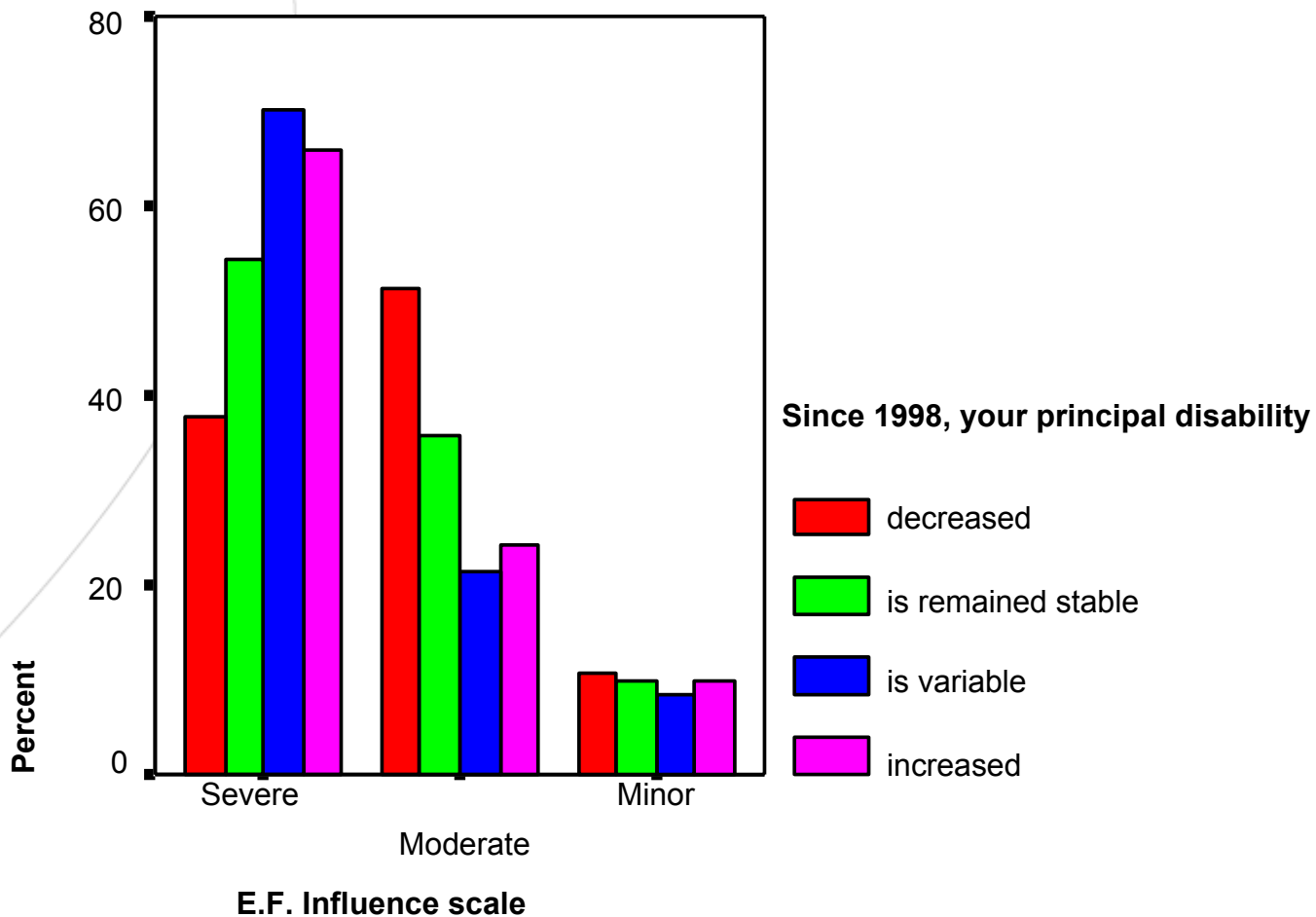
% of subjects

- Climatic conditions 59
- Time allowed to carry out tasks 56
- Noise or sound intensity 42
- Rules and administrative procedures 33
- Personal income 32
- Current availability of jobs in your community 29

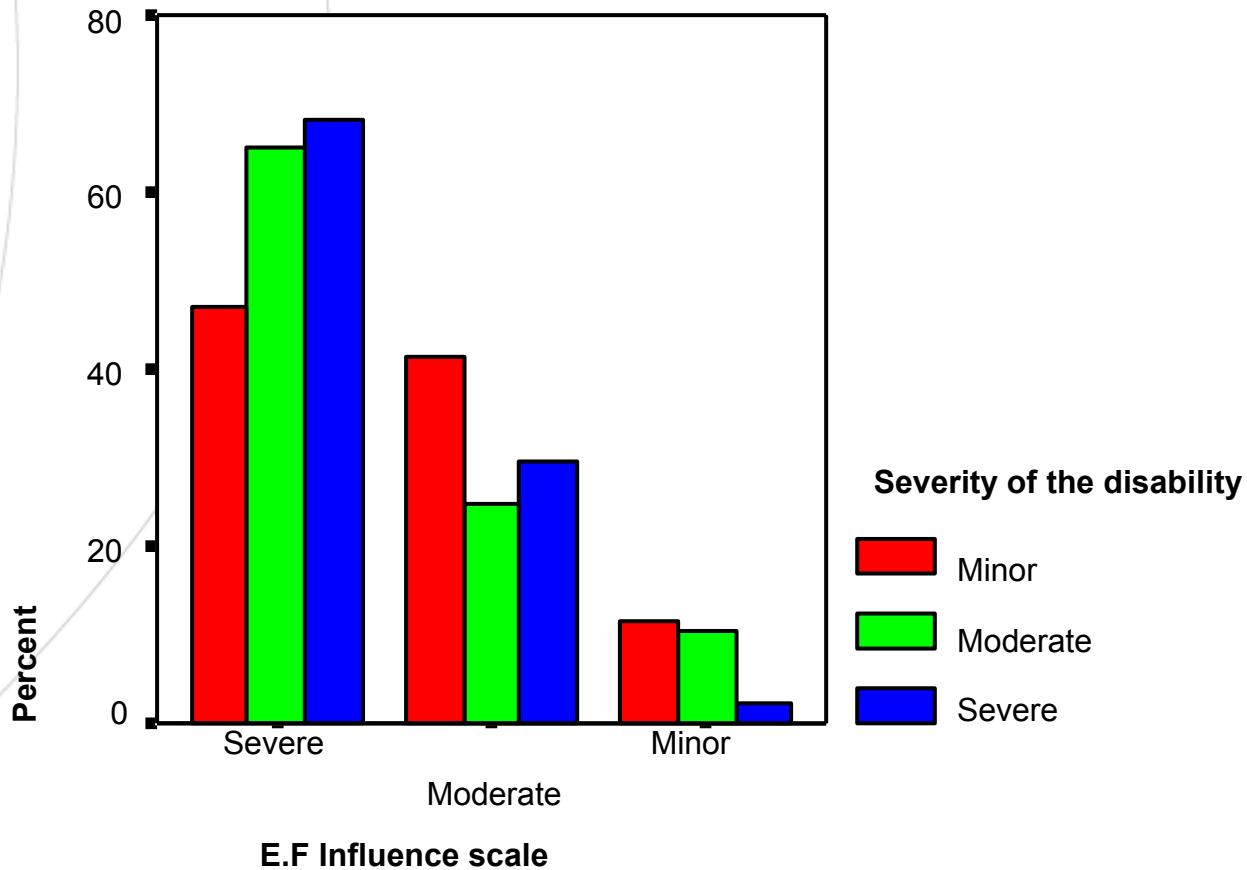
Climatic conditions and severity of the disability



Climatic conditions and change of the principal disability



The time allowed to carry out tasks and severity of the disability

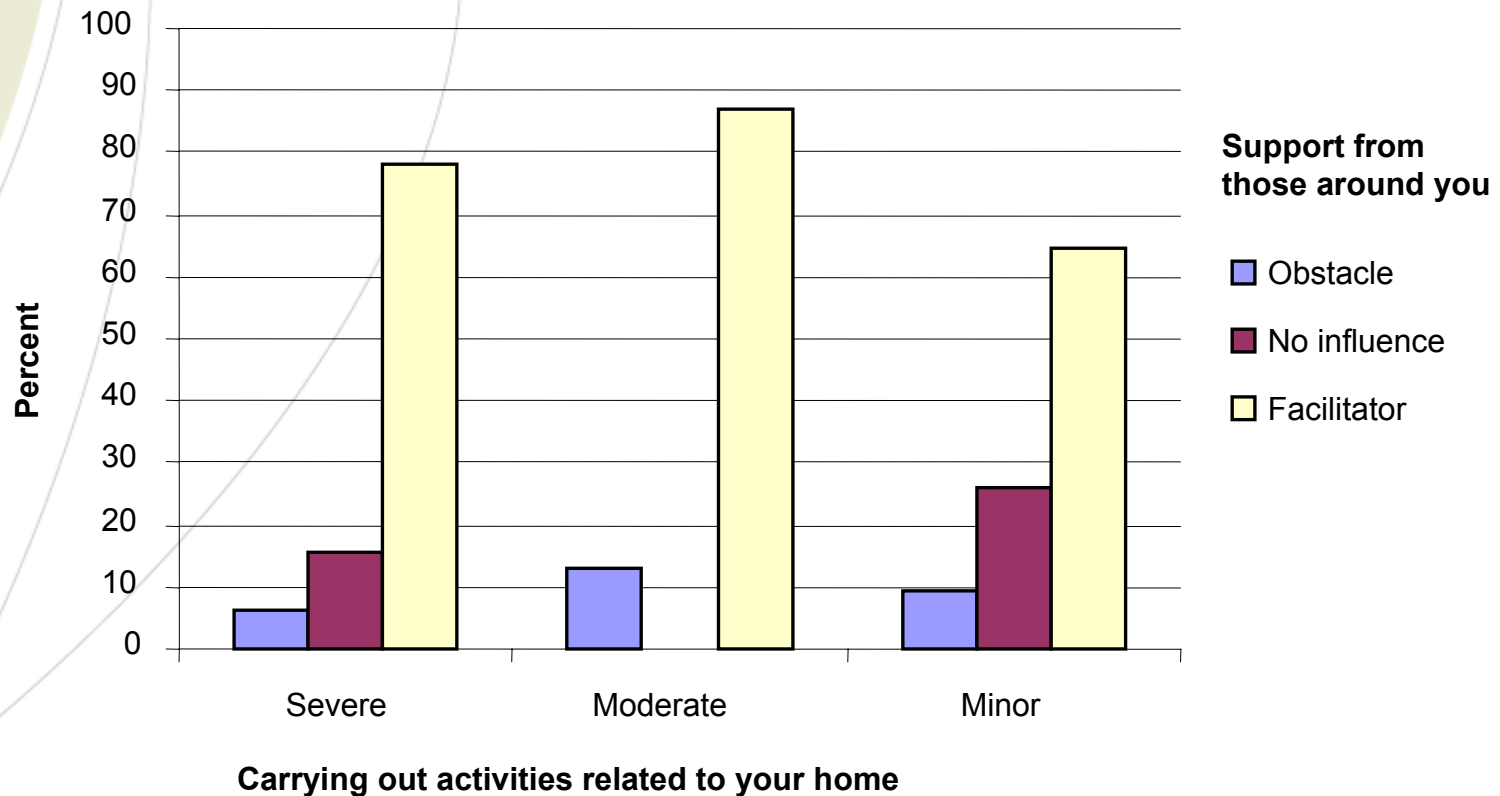




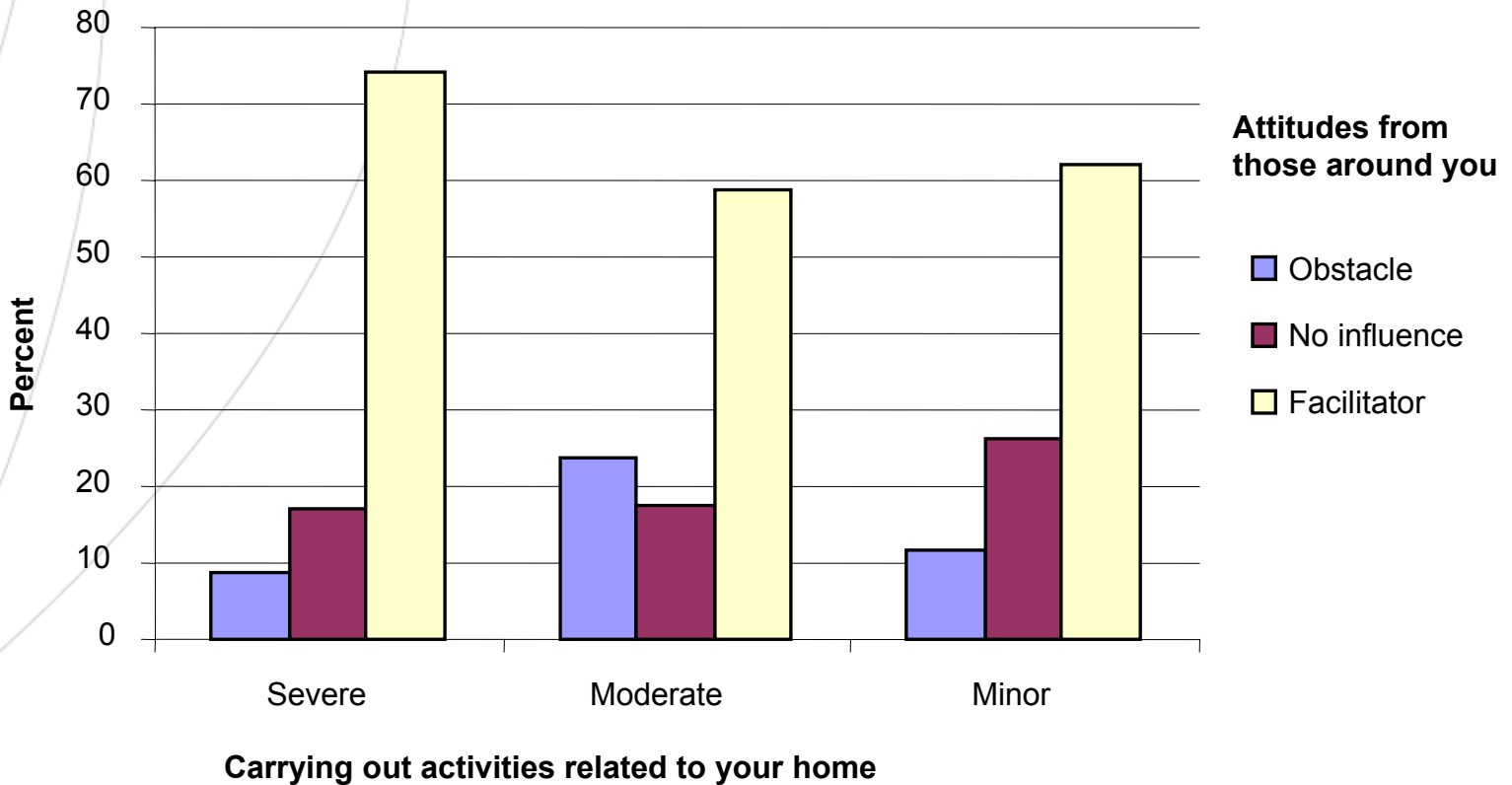
Results part 3

Exemplifying the interaction between
perceived quality of participation and
perceived influence of environmental
factors

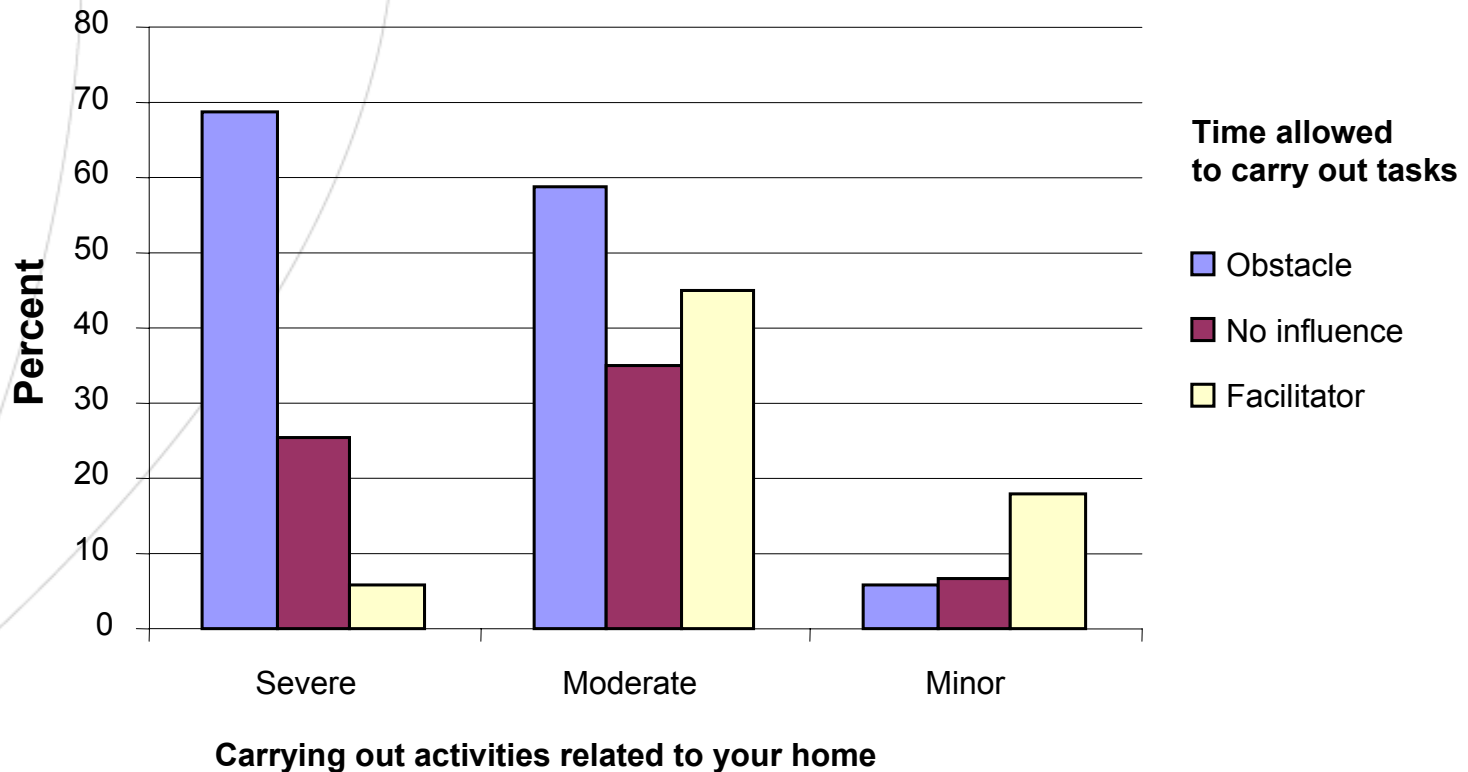
Carrying out activities related to your home and support from those around you



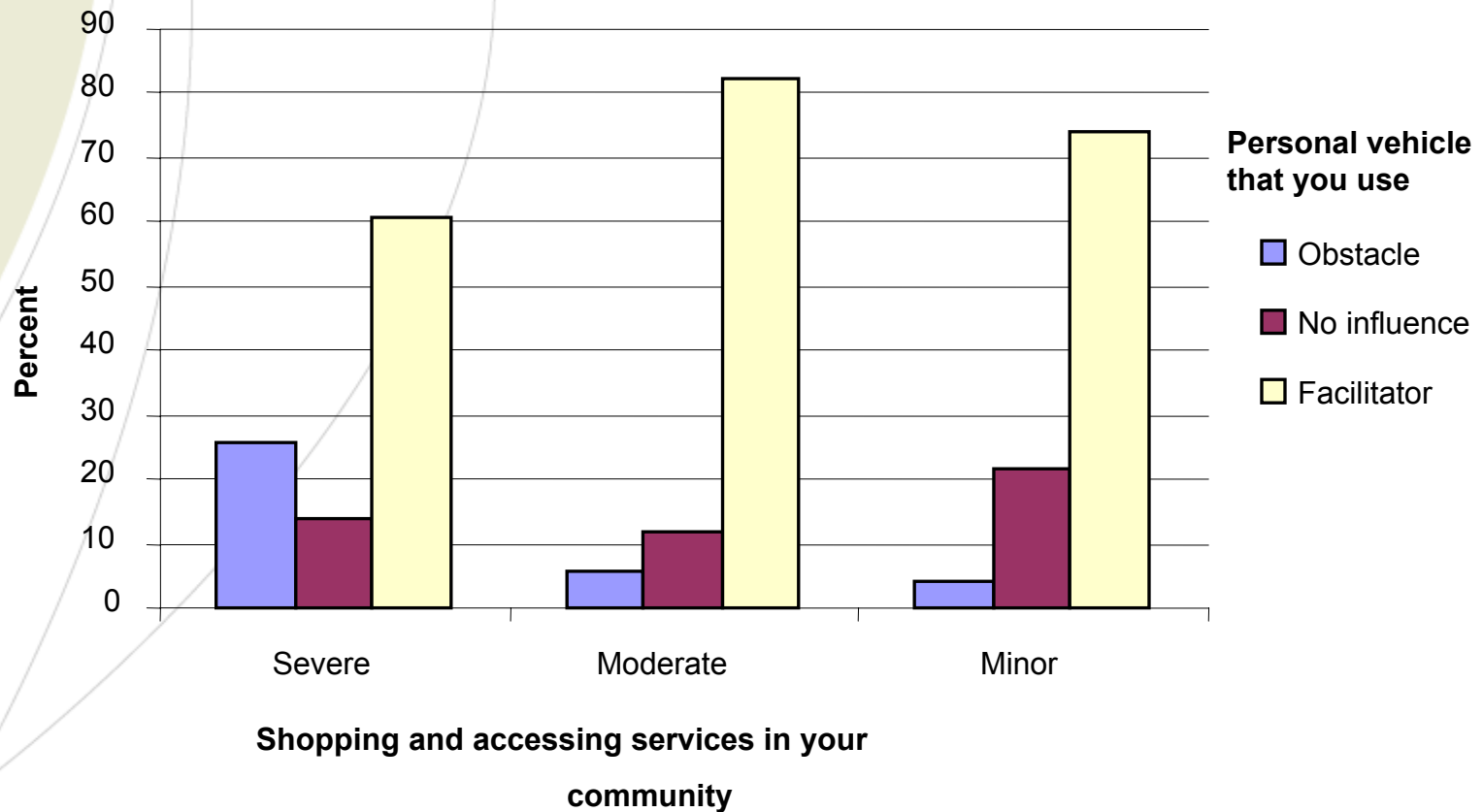
Carrying out activities related to your home and attitudes of those around you



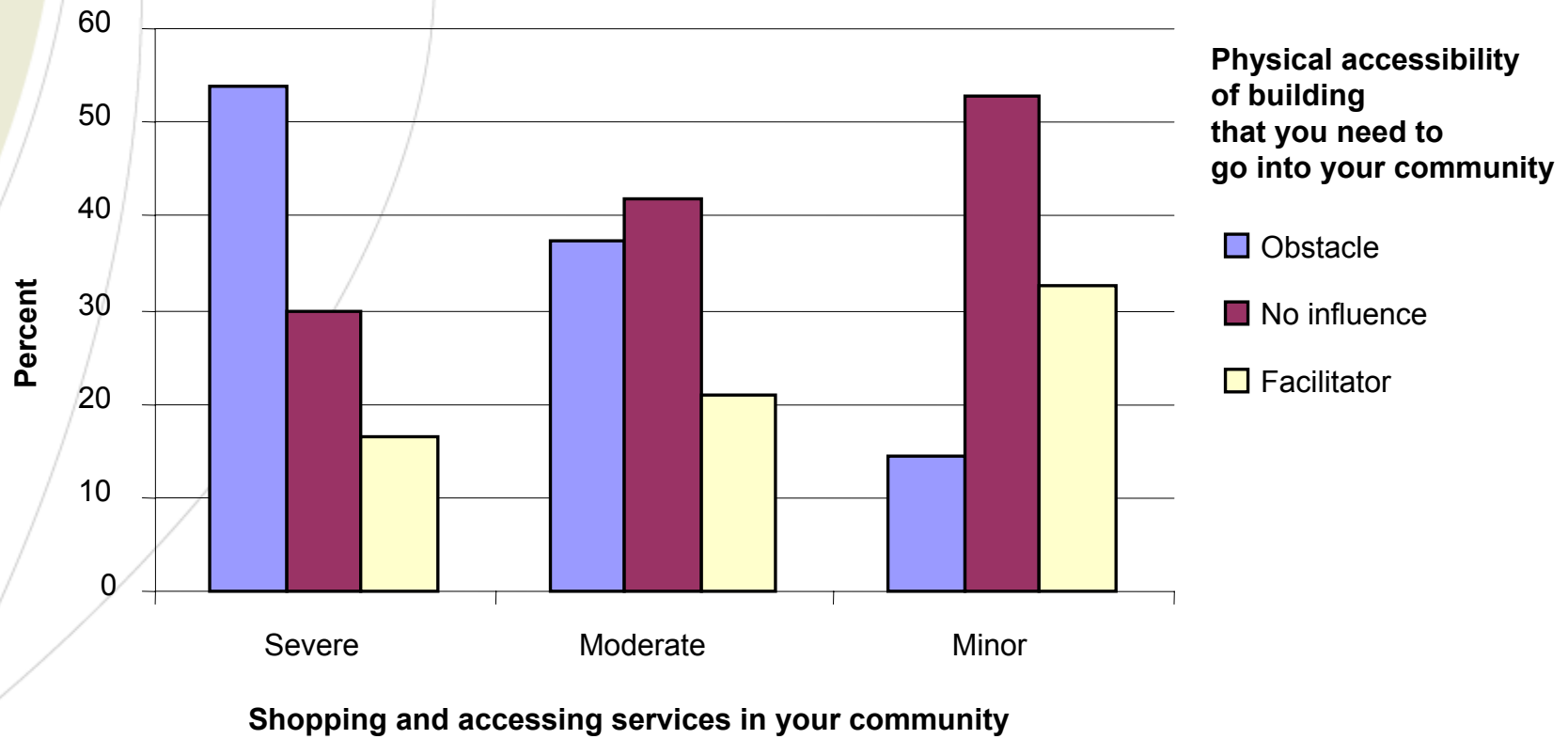
Carrying out activities related to your home and time allowed to carry out tasks



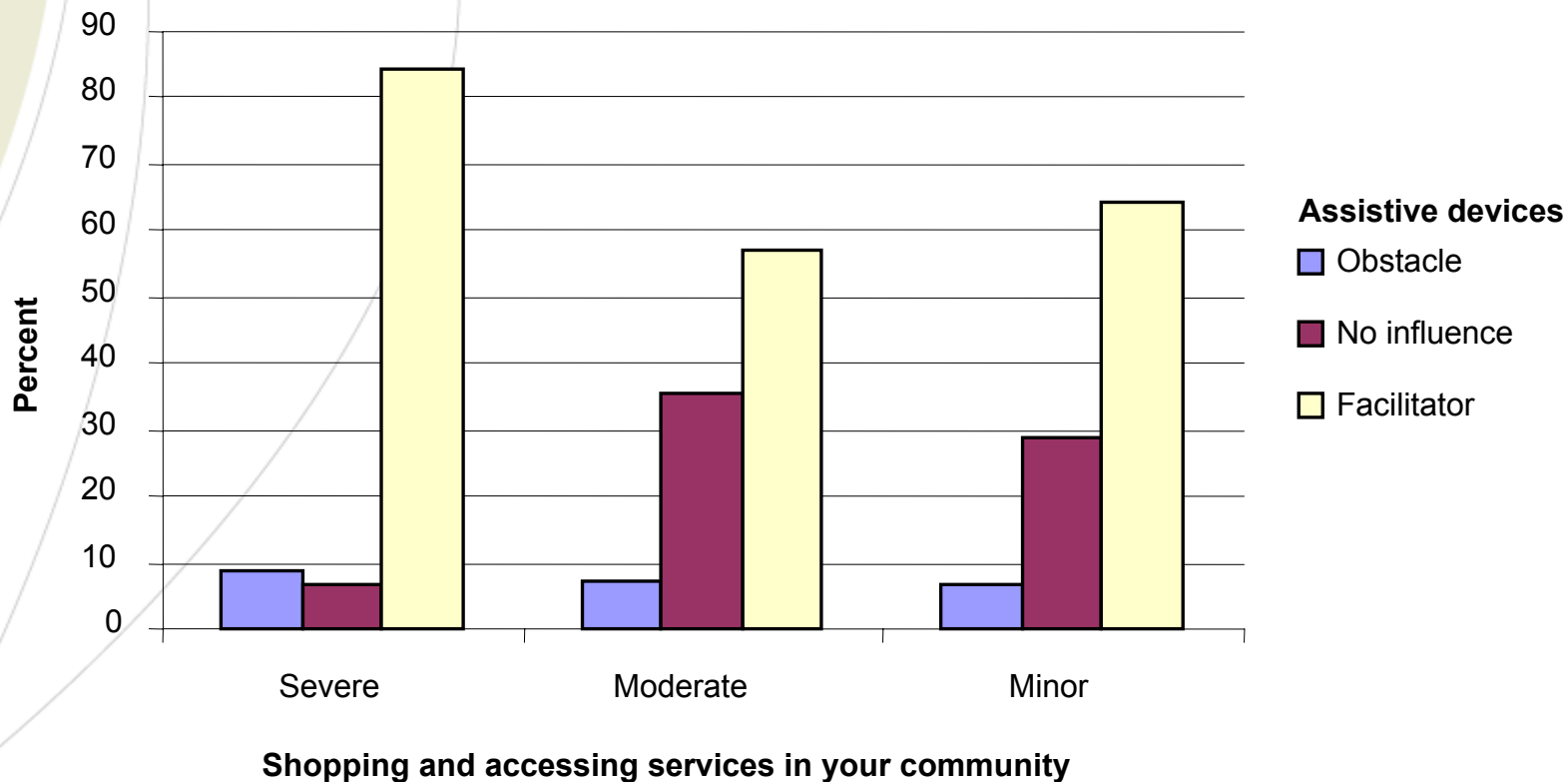
Shopping and accessing services in your community and personal vehicle that you use



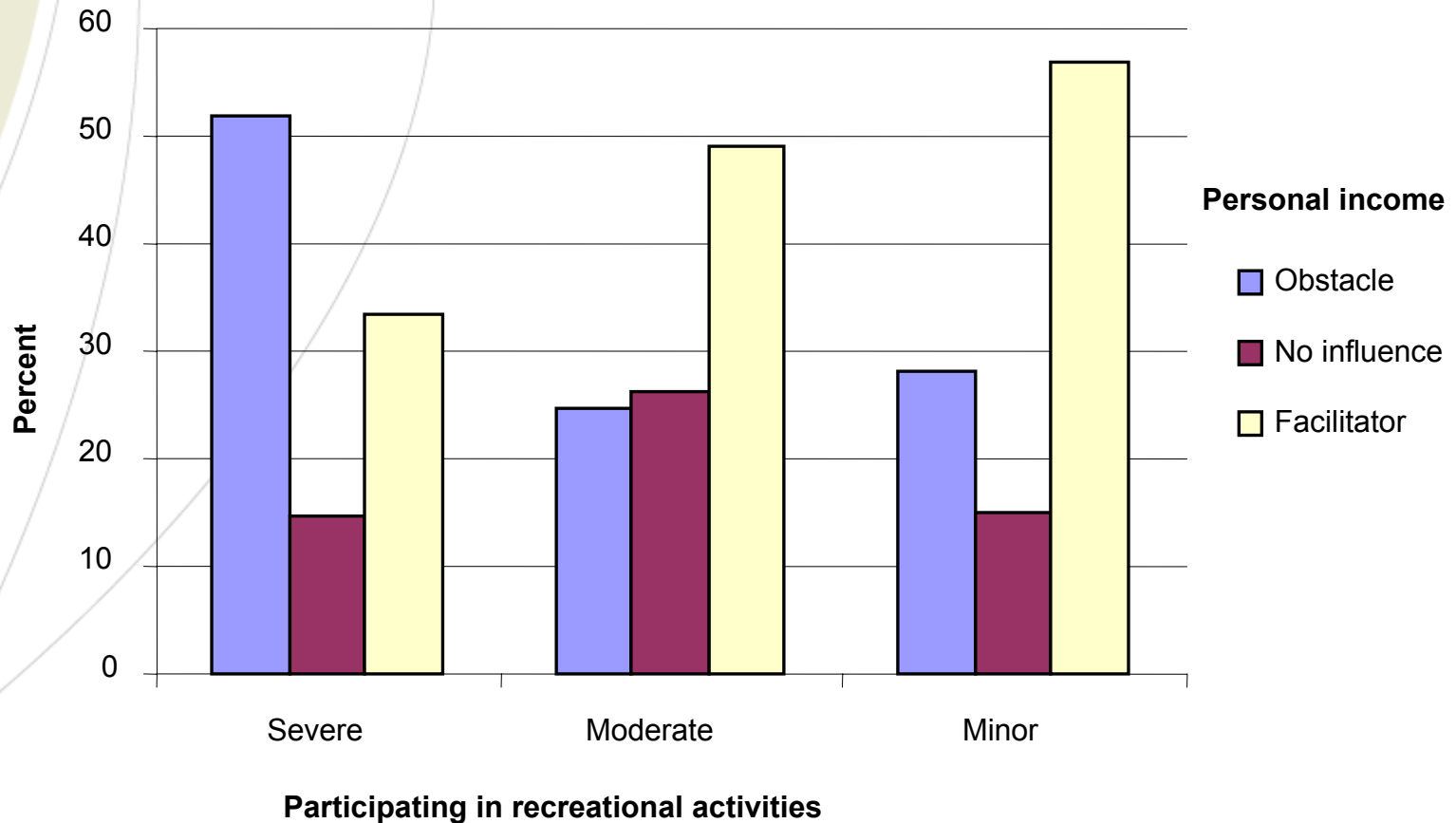
Shopping and accessing services in your community and physical accessibility of building that you need to go into your community



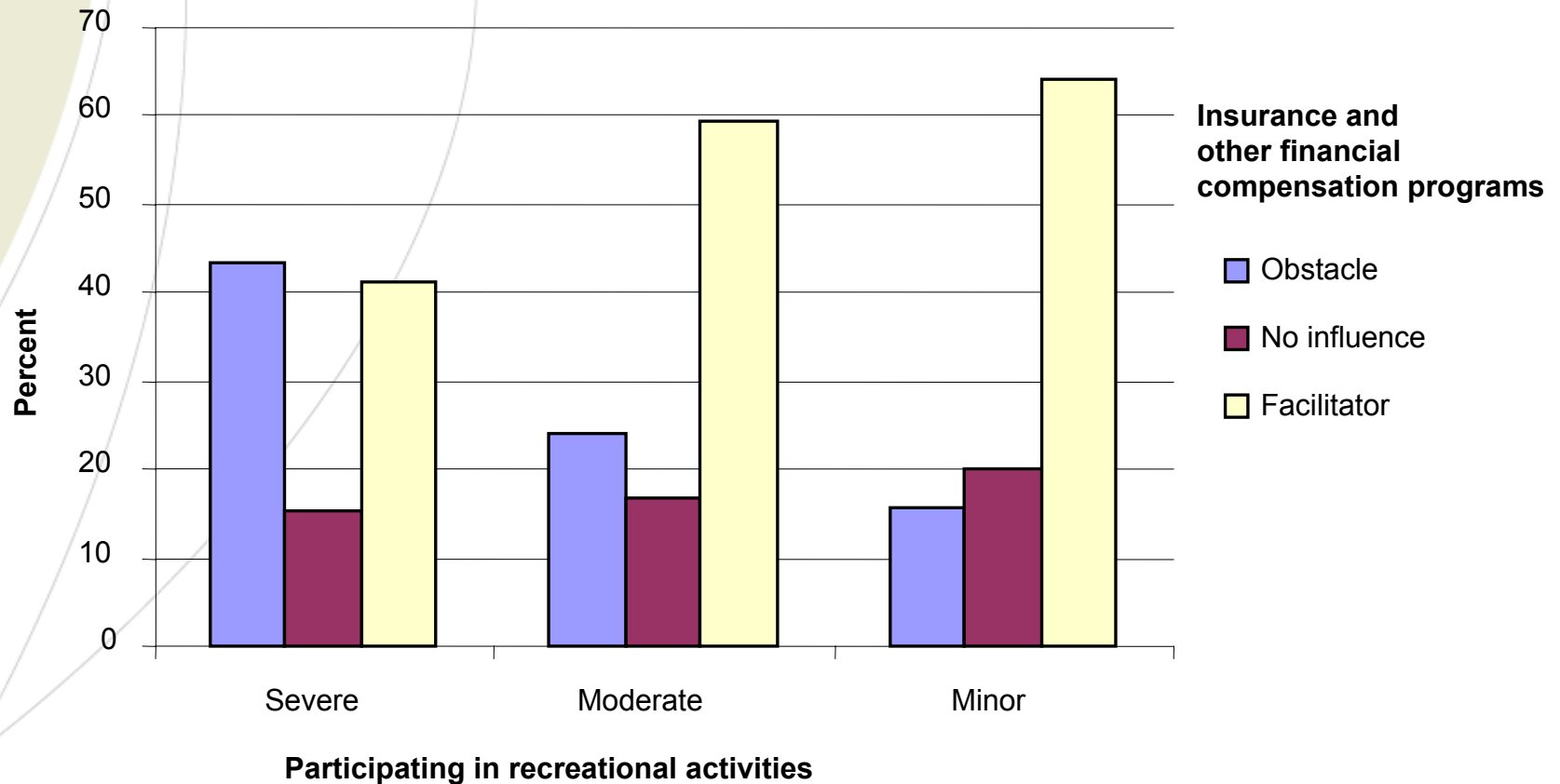
Shopping and accessing services in your community and assistive devices



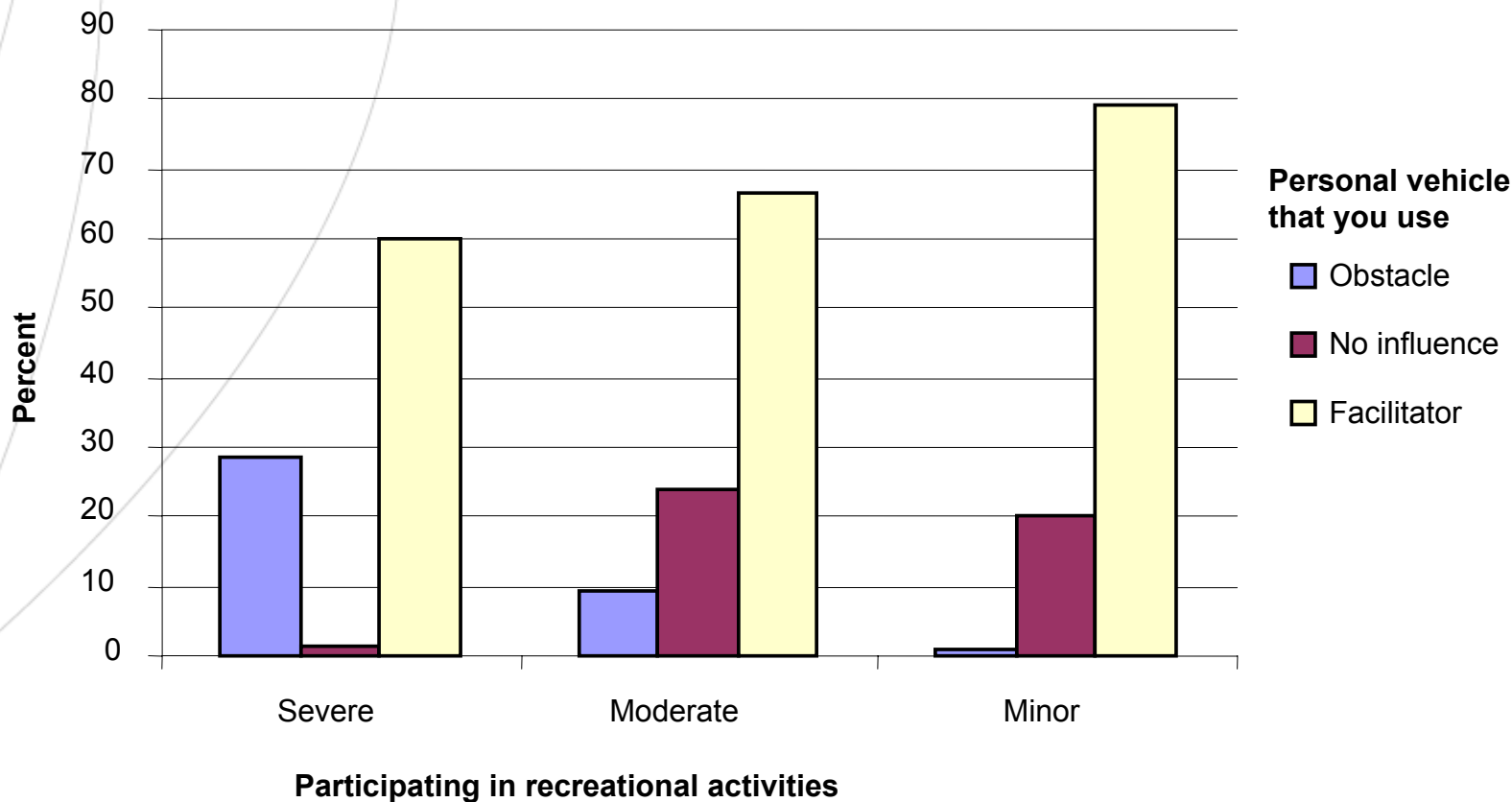
Participating in recreational activities and personal income



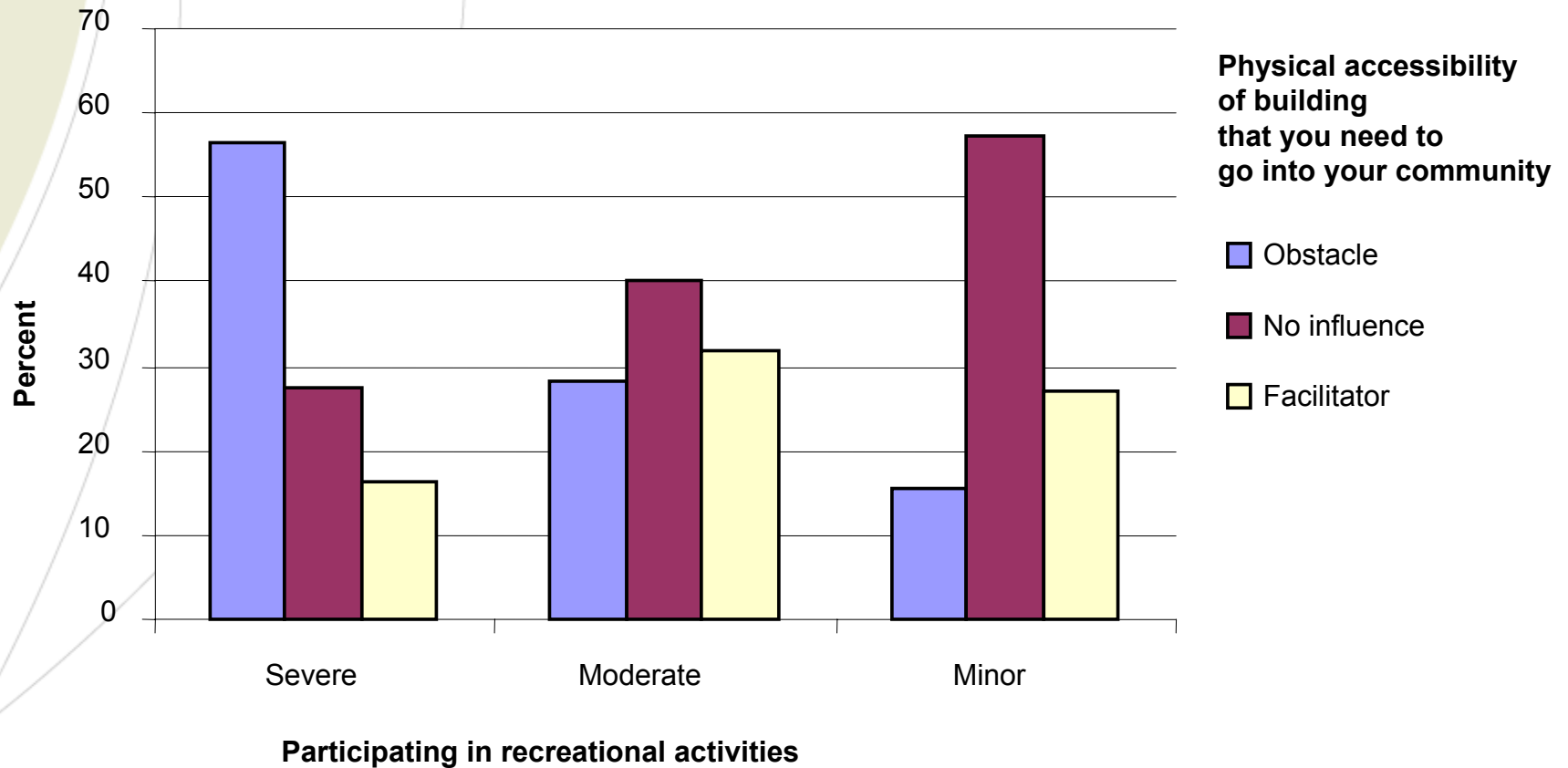
Participating in recreational activities and insurance and other financial compensation programs



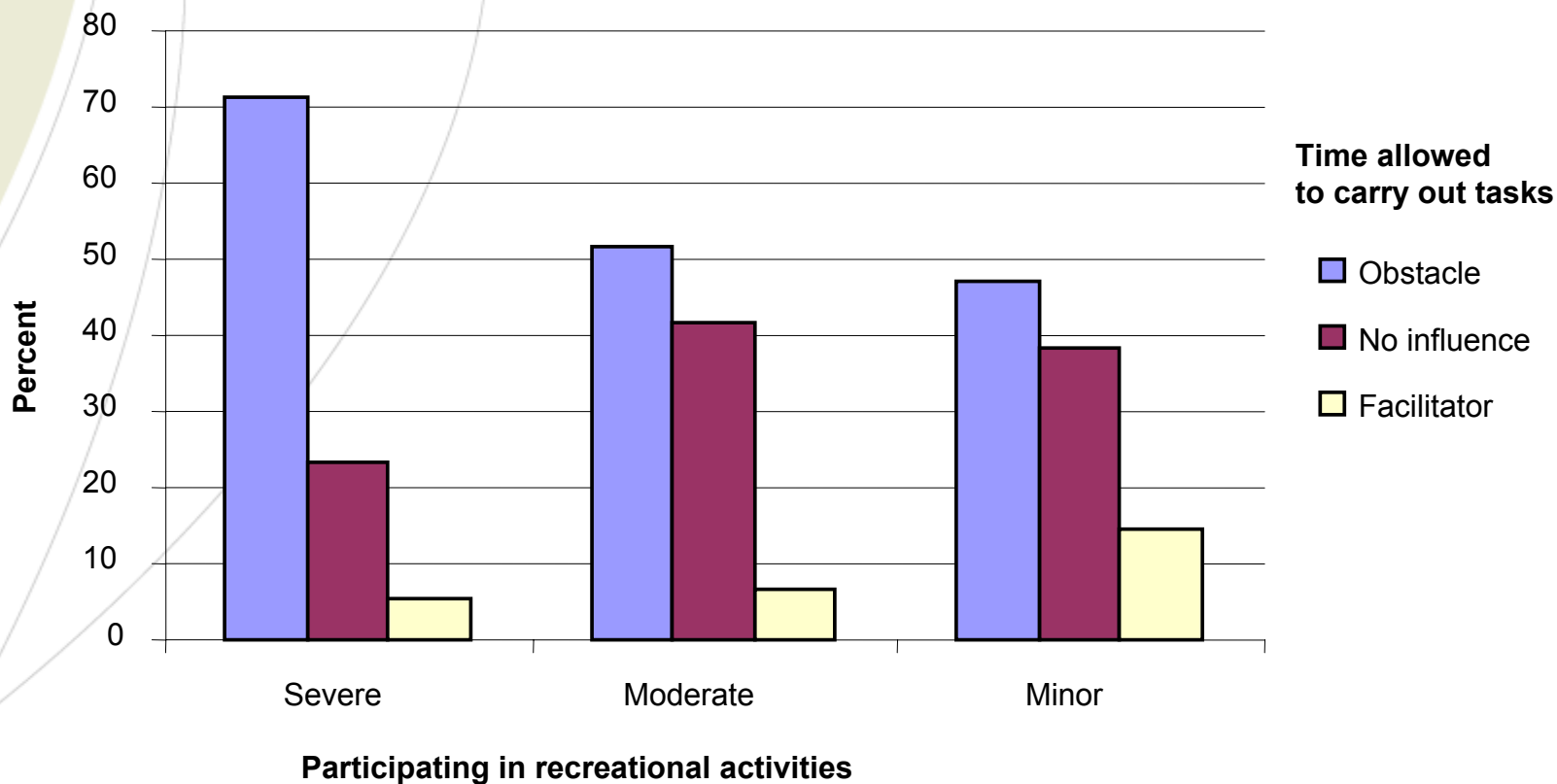
Participating in recreational activities and personal vehicle that you use



Participating in recreational activities and physical accessibility of building where you need to go into your community



Participating in recreational activities and time allowed to carry out tasks



Conclusion

- Actual canadian disability population surveys (PALS, QALS) don't document in a conceptually sound and complete way socially defined participation or life situations and their E.F. determinants. The responsibility weight is still mainly on the individual
- Lack of sound indicators for measuring impact of social policies and contextual change on the outcome of the personal factors/EF interaction
- Short forms of Life-H and MQE tools revealed to be useful to do so and indicate us ways for monitoring EF change on exercise of human rights and quality of perceived social participation
- Need of parallel development of subjective and objective participation indicators including EF influence

References

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