

WHAT NOW, WHERE NEXT?

PART F

APPENDICES

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Appendix 1

Quality of Life Survey.

This survey was published in 2007. It attempted to measure the quality of life of adults with disabilities in Ireland. In order to measure this Personal Outcomes Measures were used. There are twenty three measures in all. They represent the ways in which a person might judge a reasonable quality of life.

P

MY SELF

1. I am connected to my family
2. I have intimate relationships
3. I am safe
4. I have the best possible health
5. I exercise my rights
6. I am treated fairly
7. I am free from abuse & neglect
8. I have continuity & security in my life
9. I decide when to share personal information

MYWORLD

10. I choose where & with whom I live
11. I choose where I work

12. I choose my daily routine
13. I have time, space & opportunity for privacy
14. I use my environment
15. I live in integrated environments
16. I interact with other members of the community
17. I perform different social roles
18. I choose services

MY DREAMS

19. I choose my personal goals
20. I realise my personal goals
21. I participate in the life of the community
22. I have friends
23. I am respected

Some of the findings were:

- An average of ten of the twenty-three outcomes were achieved. Those surveyed had a range of disabilities (not just intellectual disability or autism).
- On average those with a physical disability fared best with an average of 13 outcomes while those with a severe or profound intellectual disability on average fared worst with seven outcomes.
- If people were living independently they tended to fare better. The group who did second best were those living at home. The lowest were those living in a campus setting.

This is a very brief look at what is a most interesting survey. We are conscious that selecting parts of a survey may create a biased impression about the situation so we recommend that people look at the complete report. However, what clearly comes across is that we have a long way to go before people with an intellectual disability and autism may regard themselves as having a quality of life equal to many others in society.

Appendix 2

Information to parents

Reproduced with the permission of In Control. If you would like a full version of In Control's Resource Allocation System or to know more about in Control, visit their website : www.in-control.org.uk



Self Assessment Questionnaire 2

(Working Age Adults)

SELF Assessment Questionnaire 2. (Working Age Adults)

1 Looking after myself – my personal needs

This part is about looking after myself – things like washing, dressing and eating, or shopping, cleaning and cooking.

		Point s	Outcomes
A) I need a lot of support to take care of myself. I can get the highest rate of Disability Living Allowance (care component)	<input type="checkbox"/>	3	For me to be, clean, dressed, warm and groomed In a way that I choose and suits me.
B) I need some support to look after myself. I'm OK at home on my own for a little while.	<input type="checkbox"/>	2	For me to be, clean, dressed, warm and groomed In a way that I choose and suits me.
C) Now and then I need support to look after myself. I'm OK on my own in places I know – for quite a long time.	<input type="checkbox"/>	1	For me to keep my independence and to carry on meeting my own personal care needs.
D) I don't often need support to look after myself. I'm OK on my own in most places – for days at a time.	<input type="checkbox"/>	0	

2 Relationships

This part is about friendships and people I know – not just my family.

		Points	Outcomes
A) I don't really have any relationships outside my family. I need support to make relationships – and keep them	<input type="checkbox"/>	3	For me to form a friendship or relationship outside of family or people paid to be with me.
B) I have one or two relationships – but not enough for me. I need support to make relationships – and keep them.	<input type="checkbox"/>	2	For me to form more friendships or relationships outside of family or people paid to be with me
C) I've got a lot of relationships – the right number for me. I need a bit of support to keep them.	<input type="checkbox"/>	1	To keep in touch with people who are important to me.
D) I've got a lot of relationships. I don't need support to keep them.	<input type="checkbox"/>	0	

3 Being part of the local community

This part is about doing things in my community – like using local shops, the library, going to the cinema, clubs, community centre, church or other place of worship, helping neighbours, or being involved in local organisations.

Maybe I can get a **Small Sparks** grant to start a little community project. This can be fun and I might make new friends. I'll ask the Council if they do **Small Sparks**.

		Points	Outcomes
A) I don't do much in my community. I need support to do more.	<input type="checkbox"/>	3	To do things in and be part of my community
B) Sometimes – not often – I do things in my community. I need support to do more.	<input type="checkbox"/>	2	To do more things in and contribute more to my community.
C) I do lots of things in my community. I need support to do them.	<input type="checkbox"/>	1	To remain active in my community
D) I do lots of things in my community. I don't really need support – just now and then.	<input type="checkbox"/>	0	

4 Work, leisure and learning

This part is about having a job, learning new things and enjoying life.

		Points	Outcomes
A) I don't have many chances to work, or learn new things, or enjoy life. I need support to do these more.	<input type="checkbox"/>	3	To work and have a Job, to gain new skills.
B) I have a few chances to work, learn new things, and enjoy life. I need support to do these more.	<input type="checkbox"/>	2	To have more chances to work and take part in ongoing learning.
C) I am busy – with a job or learning new things – and I enjoy my spare time. I need support to keep these going.	<input type="checkbox"/>	1	To carry on working and learning
D) I am busy and enjoy my spare time. I have the support I need to keep these going – from family, friends or workmates.	<input type="checkbox"/>	0	

5 Making Decisions

This part is about who decides important things in my life – things like where I live, who supports me, who looks after my money.

		Points	Outcomes
A) Other people make most decisions about my life. I need support to make more decisions.	<input type="checkbox"/>	3	To take more decisions about things important to me.
B) I decide most day-to-day things. But I don't have as much say in important decisions about my life. I need support.	<input type="checkbox"/>	2	To take the decisions that are important to me.
C) I make all the decisions. I need support and advice to make them.	<input type="checkbox"/>	1	To carry on making decisions with good advice
D) I make all the decisions. I just need a bit of advice.	<input type="checkbox"/>	0	

6 Staying safe from harm

This part is about keeping safe when I'm going out on a bus, or using a gas cooker, or going down stairs. Those are the things that are important for me. But staying safe is about different things for different people.

		Points	Outcomes
A) I need help to stay safe a lot of the time. People worry a lot about my safety.	<input type="checkbox"/>	15	To be safe and free from harm
B) I need help to stay safe some of the time. People worry a bit about my safety.	<input type="checkbox"/>	4	To be safe and free from harm
C) Sometimes I need a bit of help to stay safe. I'm happy and no-one says they're worried.	<input type="checkbox"/>	2	To be safe and free from harm
D) I don't need help to stay safe. I'm happy and no-one says they're worried.	<input type="checkbox"/>	0	

7 Complex needs and risks

This part is about my behaviour – the things I do. Can my behaviour be dangerous for me or other people?

		Points	Outcomes
A) I often do things that could hurt me or other people. People have tried to help me change what I do. But there's still a risk I could hurt myself or other people.	<input type="checkbox"/>	15	To be free from harm and not cause harm to others
B) I often do things that could hurt me or other people. People have helped me change what I do. There's not a big risk I could hurt myself or other people.	<input type="checkbox"/>	10	To be free from harm and not cause harm to others
C) Some things I do are a problem for other people. But there's no real danger to me or other people.	<input type="checkbox"/>	5	To be free from harm and not cause harm to others
D) In the past I've done things that could hurt me or others. Or I've done things that were a problem for other people. But there's no problem now.	<input type="checkbox"/>	3	To be free from harm and not cause harm to others
E) I've never done things that could hurt me or others. People around me support me well.	<input type="checkbox"/>	0	

8(a) Family carer and social support

My family carer

This part is for my family carer. What does supporting me mean for my family carer? What is their life like?

To the family carer:

This part is for you. To answer this question you need to imagine you are caring full-time for your family member – even if you're not; even if your family member has support.

		Points	Outcomes
A) My caring role has a critical impact on my lifestyle - including a significant impact on my health and well-being. I am unwilling or unable to continue in the role as it currently is. (Resuming a greater caring role would have this effect)	<input type="checkbox"/>	15	For my caring role to change so that It no longer has such a detrimental impact on my life.
B) My caring role has a substantial impact on my lifestyle. Playing this role has led to high levels of stress and some health problems.(Resuming a greater caring role would have this effect)	<input type="checkbox"/>	10	For my caring role to change so that It no longer has such a detrimental impact on my life.
C) I have some difficulty and stress in carrying out my day-to-day caring tasks. There is some impact on my lifestyle and playing this role leads to minor stress. (Resuming a greater caring role would have this effect)	<input type="checkbox"/>	7	For me to feel supported to carry on in my caring role.
D) I am able and willing to continue in my current caring role. My caring responsibilities have only a small impact on my daily life.(I would like to play a greater caring role than I currently do, and have some time to provide support)	<input type="checkbox"/>	5	For me to feel supported to carry on in my caring role.
E) I am able and willing to continue in my current caring role. My caring responsibilities have no negative impact on my daily life (I would like to play a far greater caring role than I currently do, and have time to provide support)	<input type="checkbox"/>	0	

8(b) Family carer and social support

	A	X	B	
1	I am able to get nearly all the help I need from my family and friends	1	I currently need no paid support	0
2	I am able to get most of the help I need from family and friends	2	I have or need some occasional paid help	2
3	I am able to get only some of the help I need from family and friends	3	I have or need ongoing regular help	3
4	I can get little or no help at all from family or friends	4	I have lots of paid support Full time day care Respite I currently have 24 paid support	4

	B1	B2	B3	B4
A1	0	2	3	4
A2	0	4	6	8
A3	0	6	9	12
A4	0	8	12	16

Appendix 3

HIQA is a Government Agency who is responsible for driving improvements in the quality and safety of healthcare on behalf of users. They develop standards, monitor compliance with standards and carry out investigations where there are reasonable grounds to do so.

HIQA Standards

1. Each individual exercises choice and control over his/her life and over his/her contribution to his/her community.
2. The privacy and dignity of each individual is respected and promoted.
3. Each individual's daily life is structured in accordance with his/her preferences.
4. Each individual is supported to develop and maintain personal relationships and links with the community in accordance with his/her wishes.
5. Each individual receives sensitive and personalised support in accordance with his/her wishes and aspirations from an adequate number of staff who are selected in accordance with best recruitment practice and who possess the appropriate personal qualities, experience, qualifications, competencies and skills.
6. Each individual is safeguarded and protected from abuse.
7. Each individual exercises control over personal finances and is protected from financial abuse and exploitation.
8. Each individual has a personal plan to maximise his/her personal development in accordance with his/her wishes.
9. The health needs of each individual are assessed and met.
10. Each individual has access to information, provided in a format appropriate to his/her communication needs, to inform his/her decision making.
11. The right of each individual to make decisions is respected and his/her informed consent is obtained in accordance with legislation and current best practice guidelines.
12. Each individual is facilitated and supported to exercise his/her civil and political rights, in accordance with his/her wishes.
13. Each individual's admission and discharge is determined on the basis of fair and transparent criteria and his/her placement is based on a written agreement with the registered provider.

14. The complaints of each individual are listened to and acted upon in a timely and effective manner.
15. The residential service is homely and accessible and promotes the privacy and dignity of each individual.
16. The health and safety of each individual, staff and visitors to the residential service are promoted and protected, while safeguarding each individual's right to a good quality of life.
17. The residential service is governed and managed in a manner that supports the creation and continuous improvement of a person-centred service that meets the needs of each individual and achieves outcomes for him/her consistent with his/her plans and aspirations.
18. There is a written statement of purpose and function that accurately describes the service that is provided and the manner in which it is provided.
19. Each individual is supported by appropriate record-keeping policies and procedures

To see the Standards and the Criteria go to www.npsa.ie

Appendix 4

The Health Research Board is a government agency which supports and funds health research.

According to their website: "The HRB's Strategic Business Plan 2010-2014 recognises the importance of establishing a co-ordinated approach so as to achieve the highest quality health research and developing the right skills, conditions and capacity in the Irish health system, in order to accelerate the translation of research discoveries into real benefits for people."

Their mission is "to improve people's health, patient care and health service delivery by:

- leading and supporting excellent research by outstanding people within a coherent health research system;
- generating knowledge and promoting its application in policy and practice; and, in doing so, play a key role in health system innovation and economic development."

Their goals are "Over the five years of this plan, we will focus on four strategic goals to achieve our vision and execute our mission:

- Driving the development of excellent clinical research, including applied biomedical research, within a coherent health research system.
- Building capacity to conduct high-quality population health sciences research and health services research.
- Working with key partners to develop and manage high-quality national health information systems.
- Generating and synthesising evidence, and promoting the application of knowledge to support decision-making by policymakers and relevant practitioners."