

Person Centred Planning for People in Ireland who have Disabilities

Plain English Version.

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June, 2005.

A Message from the Director of the National Disability Authority

The National Disability Authority (NDA) was established in June 2000 as an independent statutory body. One of the functions of the NDA, as outlined in the NDA Act (1999), is ‘to support the achievement of good standards and quality in the provision of programmes and services provided or to be provided to people with disabilities’ (Part II, sections 8 (2) c, d and f and 10 (1)). We believe that person centred planning can help to achieve this objective.

Person centred planning is a way of discovering how a person wants to live their life and what is required to make that possible. Person centred planning has its roots in the normalization and independent living movements. It is grounded in a social model of disability and a strengths-based approach.

The NDA believes that person centred planning is needed because it is time to move on:

- from focusing solely on a person’s disability and trying to ‘manage disabilities’ and ‘help’ or ‘fix’ people, to appreciating people as people and allowing and supporting them live their lives as they wish;
- from taking charge and taking over people’s lives, to allowing freedom of expression and movement and supporting people as they want.

Person centred planning has the potential to be an instrument of real change, by bringing about a greater degree of choice and better standard of living for people with disabilities in Ireland. Actually achieving this potential, depends greatly on the way person centred planning is done, however.

This is why the NDA has undertaken research on good practice in person centred planning.

Our guideline document outlines the key principles, key considerations and potential pitfalls in adopting the approach. It sets out a number of recommendations on how to go about drawing up a person centred plan and creating a context that will support its realisation. It also provides some guidance on monitoring and evaluation.

The NDA believes that the best measure of the success of person centred planning is that the individual at the centre of the planning process begins to experience a real change for the better in his or her life as a result of their plan being put into action.

I hope that these guidelines will be found to be a useful source of information on person centred planning for people with disabilities and their families, service providers, policy makers, funders and all other potential stakeholders. I truly hope that they will be found to be a practical support for developing good plans and putting them into action, thereby helping to bring about genuine and lasting improvements in the lives of people with disabilities and in the services and supports they receive.



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List of Abbreviations used in this document.

CNEASTA	The Irish Council for Training, Development and Employment for Persons with Disabilities
DFI	Disability Federation of Ireland
ERHA	Eastern Regional Health Authority
FAQs	Frequently Asked Questions
FVB	Federation of Voluntary Bodies
IDS	Irish Deaf Society
MHI	Mental Health Ireland
NAD	National Association for Deaf People
NCBI	National Council for the Blind of Ireland
NDA	National Disability Authority
NFPBA	Not for Profit Business Association
NFVB	National Federation of Voluntary Bodies
NPSA	National Parents and Siblings Alliance
NWTD	North West Training and Development Team
MHI	Mental Health Ireland
PWDI	People with Disabilities in Ireland
UCD (CDS)	University College Dublin, Centre for Disability Studies

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Section 1: Introduction

What is this paper for?

One of our jobs at the National Disability Authority (NDA) is to help get good programmes and services for people who have disabilities.

'Person-centred planning' is one way of making services better for people who have disabilities – see our new draft National Standards for Disability Services.

We wrote this paper to help people carry out person-centred planning well.

We wrote it after talking with people carrying out person-centred planning in Ireland and other places, and to other people representing people who have disabilities.

How will this paper help people carry out person-centred planning well?

Each person-centred plan is different. As a result, the paper can discuss person-centred planning in a general way only.

Nevertheless, we hope our document on person-centred planning will give you a good idea of how to develop a plan well and how to go about putting a plan into action.

Does this paper have anything to do with me?

This paper is for everyone interested in or likely to be involved in person-centred planning. This includes:

- people who have disabilities;
- their families, friends and 'advocates' (people who speak for them on their behalf);
- any person, group or organisation involved in developing or updating a person-centred plan and helping put it into action;
- the providers of specialist and more general services;
- policy-makers and funders.

Section 2: How to carry out person-centred planning well

What does person-centred planning mean?

Person-centred planning is a way of helping people (or the parents or families of very young people or people who need a lot of support) think about:

- what is important to them;
- how they want to live;
- what support they want.

Our new National Standards for Disability Services say that services must be 'person-centred'. This means they must be designed to suit what the people using the services want.

Person-centred planning can help a person and a service provider to find out:

- how you want to live your life; and
- what kinds of support you would need or like to make that possible.

Person-centred planning is different from assessment and individual programme planning.

The point of assessment and individual programme planning is to help you get the most out of the services that are available to you.

The point of person-centred planning is better lives and better services (services helping you to lead your own life the way you want).

Person-centred planning is about:

- **your** wishes for your **life**;
- what might be possible for you – even though it might take some time to work out;
- every area of your life (whether personal or part of your local community or the broader mainstream of life) - certainly **not just services**.

Person-centred planning tries to figure out a good future for you by:

- 1 finding out what is good and not so good in your life now;
- 2 working out what to do about what is not so good;
- 3 understanding and doing something about the things that are most important to you;
- 4 finding out and doing something about your hopes and dreams for the future, developing your abilities and gifts and dealing with your concerns;
- 5 looking at all the choices available to you now and making more choices available in the future;
- 6 bringing people together to get everyone (not just services) involved in making things better for you.

A record is then made of all of this and arrangements are made to get everyone together regularly to review progress.

Once you develop a person-centred plan, you can keep it for life and go back to it from time to time to see how it's working out or to bring it up to date.

However, person-centred planning can be carried out just once. You might find it helpful in, for example, a time of big change in your life.

There are special ways of carrying out person-centred planning that can help make sure you end up with a good plan. These include, for example, the techniques known as: 'Making Action Plans for normalisation' (or MAPs), 'Planning Alternative Tomorrows with Hope' (PATH) and 'Essential Lifestyle Planning' (ELP).

You can develop a person-centred plan on your own or with the support of your family or service providers. Usually, lots of people will need to work together to put a plan into action (for example, family, friends, advocates, services and some members of your local community).

You (or your family, if you are very young or highly dependent) should be the one who decides whether to develop a plan.

The people taking part in person-centred planning usually include the following.

- **You, the person the planning is supposed to be all about.** The person the plan is for is sometimes called the 'focus person'.
- Someone who is trained to help you draw up a person-centred plan. This person is sometimes called the "**plan facilitator**". They can help you work out what you want and how to get it or do it. This person may be part of a service or have nothing to do with services. If you're not happy to work with a particular facilitator, you can ask for

someone else.

- **Your “circle or network of support”**. This means everyone you might like to involve in developing your plan and putting it into action. This includes family, friends, advocates, service providers and local community groups.
- A person or group of people who will help make sure your plan is put into action. They can be called a **“person-centred planning champion”** or a **“guidance coalition”**.

Only those you want to involve should be involved.

It's important to listen to everyone's ideas, parents and family members, in particular. However, your ideas are the most important.

If you don't want your parents or family to be involved in the plan at all, they don't have to be. But, you should let them know about anything in your plan that might affect them.

Two important things to remember about person-centred planning

- 1 Person-centred planning isn't just about developing plans. The whole point of developing a plan is that a plan can be useful in helping to make your life better.
- 2 Person-centred planning isn't easy. People won't get it right all the time.

How to start person-centred planning

To carry out person-centred planning well, service providers have to know four things.

- 1 How to prepare for it.
- 2 What the plan should be like.
- 3 How to develop a plan.
- 4 How to go about putting it into action and make sure it leads to better services and better lives.

This is why we've set out this part of the paper under four headings.

- 1 How services should get ready for person-centred planning.** The information under this heading describes what you can expect from services relating to person-centred planning.
- 2 So what's the plan?** The information under this heading describes what a plan should be like.
- 3 How to develop a person-centred plan.** The information under this heading describes what developing a plan should be like.
- 4 How to put plans into action and make sure they lead to better services and better lives.** The information under this heading describes what happens after the plan is put together.

1 How services should get ready for person-centred planning

Service providers will need to learn about person centeredness and person centred planning. They will also need to think about how person-centred planning is likely to affect the services they provide.

The person in charge of making sure plans are developed and put into action will also need to learn about the special ways of carrying out person-centred planning we talked about earlier.

All service providers should talk with their service users about person-centred planning.

If you've already talked with someone in another service about person-centred planning and don't want to talk about it again, say so.

If you have any questions, ask them.

Service providers will ask you if you already have a person-centred plan. If you do, you should tell them.

They will probably ask if you developed it recently. If you did, they will ask you if it says anything about their particular services. You should tell them if it does but you don't have to show them the plan itself, if you don't want to. If you show it to them, they might ask if they can make a copy of it or keep it for you there. It's your plan so it's up to you. It's okay to say no to either question.

If they will be keeping your plan for you, they should tell you where exactly you can find it when you want to. If you're not happy with what they say, you can ask them to keep it somewhere else or change your mind about them keeping it. They should also tell you how they intend to use your plan. If you're not happy with what they say, you can tell them you don't want them to use it in that way.

If your person-centred plan was developed a year ago or more, a service provider will probably ask you if you would like to bring it up to date. You can say yes or no. If you say yes, a service provider will:

- tell you who helps with person-centred planning in the service and
- ask you if you would like that person to help you, or if you would like someone else to.

If you would like someone else, it's okay to say this.

If you don't have a person-centred plan, your service provider will probably ask you if you would like one. You can say no if you don't want one. If you say yes, a service provider will

ask you if you want help. You can say yes or no. If you say yes, a service provider will:

- tell you who helps with person-centred planning in that service;
- ask you if you would like that person to help you, or if you would like someone else to.

If you would like someone else, it's okay to say this.

2 So what's the plan?

Your plan can be done up as a workbook, a video, a painting (whatever you like).

It should describe you (as you were in the past, as you are now and as you would like to be in the future).

It should show some definite things you want to do or get or change (these things are sometimes called goals). It should also show how to go about these things and who can help.

Everything you want to include should be included.

You can change your mind about what you have in your plan at any time.

3 How to develop a person-centred plan

Your plan facilitator should spend some time talking with you about the different ways you can develop your person-centred plan.

They might suggest inviting people to a formal meeting to talk about your plan. However, you don't have to have a big meeting if you don't want to. You and your plan facilitator could arrange to talk to people one by one, or you could just work out your plan with your plan facilitator and let them take things from there.

If you like the idea of having a meeting, your plan facilitator will talk with you about:

- how to arrange it;
- who you might invite;
- what you would like to talk about.

You should be the one who finally decides who is invited. You should also be the one

who decides what is to be discussed.

Your plan facilitator will know about ways of running the meeting that will help in developing a good plan. They should:

- 1 spend some time before the meeting getting to know everyone who is invited;
- 2 help you (and anybody else coming to the meeting) to come up with good ideas to bring to the meeting and ways of sharing these ideas with everyone else;
- 3 help you get the meeting started, if you want them to;
- 4 make sure that everyone stays interested and involved in the meeting, and that a fair amount of time is given to everyone's ideas;
- 5 back you up if someone starts to talk about something you do not want talked about at the meeting;
- 6 make sure that everyone knows and remembers that what you have to say on anything talked about is what really matters;
- 7 make sure also that they do not tell anyone else what has been discussed without your permission

(Sometimes a plan facilitator will be told something which suggests an individual is in some way at risk, though. For example: in relation to health, safety, neglect or abuse. In this case they will have to tell somebody.

They should make this clear to everyone from the start.);

- 8 help to work out which of the things talked about in the meeting are the most important;
- 9 make sure everyone fully understands the really important things;
- 10 help to work out what has to be done about the really important things (this may take some time and effort when people have different points of view on the important things);
- 11 help people to agree who is going to get these things done, and when;
- 12 come up with ideas on when and how to take stock of how well things are going;
- 13 help to record the main points of the meeting so everyone will remember all the important parts of your plan;
- 14 remind people to arrange a date to meet again soon, to talk about how things are going on putting the plan into action.

Whatever way you go about doing it, a person-centred plan should be developed in such

a way that it can genuinely:

- help move your life in the direction **you** want;
- build your place in the community and mainstream of life; help the community to welcome, appreciate and value you.

4 How to put plans into action and make sure they lead to better services and better lives

Putting plans into action can take a lot of time and work.

Sometimes things don't go as well or as quickly as you might like. If this is how you feel about your plan, you should say this at the next meeting. If you are really pleased at how things are going, you should say that, too.

Everyone else who is working on your plan will have their own views.

- Your family, friends and advocates will want to know whether your plan is being of any real help to you.
- Service providers should be eager to ask you to help them work out how to make their services better.
- People from your local community might ask you to help them work out how to make it easier for people who have disabilities to be more involved in all sorts of community activities.
- Someone from our organisation (or some other similar organisation) might want to ask you what you think of person-centred planning, and whether you think it's making a difference to your life and the services you use.

Your plan should be specially and specifically about **you**.

It should be easy to understand and easy to put into action.

If you change your mind about anything in the plan, remember that it is important to let people know as quickly as possible. Do not wait for the next meeting. Tell the plan facilitator and they will help you let everyone know.

You will be able to tell that person-centred planning is working for you when you begin to experience a real change for the better in your life as a result of your plan being put into action.

You can tell it is not working as it should if you are not experiencing real changes for the better.

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Appendix: A general guide to the appropriateness of some sample methodologies to varying situations and circumstances.

The first four approaches from the community of practice concerned about normalisation teaching tradition:

24-Hour Planning (Karen Green and Mary Kovaks):

- Mixed fora.
- Focuses service development on careful individual plans that specify the exact settings and supports a person would need to engage in functional and meaningful activity.
- Seeks to establish detailed and technically-specific, weekly, daily and parts-of-day plans.
- Seeks to balance participation in the planning process so that professional voices do not drown out the contributions of those who know and love a person.

Personal Futures Planning (Beth Mount and John O'Brien):

- Forum: the individual in the first instance - but a group of people is enlisted to develop ideas on how to make the individual's dream a reality by building on opportunities and overcoming obstacles.
- Focuses on key areas of the individual's life, history, places they frequent, relationships, preferences, dreams and hopes.
- Group members commit themselves to particular actions and set timeframes for these.
- Useful in information gathering, describing present and future and deciding on what is good for and working in favour of the focus person.
- Strong emphasis on profiling.
- For a useful overview, see Mount, 1992.

Individual Design Session (Yates 1980):

- Focuses on reviewing personal history and comparing and contrasting experiences with other populations, groups and individuals.

- Useful in guiding service providers towards a deeper understanding of the focus person's experience and thus building empathy.
- Rooted in PASS.

Getting to know you (Brost, Johnson and Deprey, 1982):

- Seeks to establish definition of service system capacities required to provide individualised supports.
- Blends normalisation teaching perspective on gathering information and understanding people's needs with an approach to individual needs assessment, the development of general service plans and case management.

Early developments.

MAPS - Making Action Plans for normalisation – formerly known as the Mc.Gill action planning system (Forest and Lusthaus, 1989):

- Forum: individual and group of people who know, work with and like them.
- Focuses on an individual's history, dreams, nightmares and ideas, the things that best describe the individual and his or her gifts, strengths and talents.
- Seeks to establish consensus opinion on where a person needs to go - and what everyone involved needs to do to improve a person's life; then develop an action plan for getting there.
- Useful in historical and current profiling and planning.
- Has its origin in the 24-hour planning approach.
- Historically highly procedural with specified steps. In practice, now evolving towards a more flexible approach based on general good mapping practice.

Continued development.

Personal Histories (Sandra Landis and Jack Pealer, Residential Inc, Ohio):

Draws directly from normalisation teaching community of practice.

PATH - Planning Alternative Tomorrows with Hope:

- Forum: a committed group of people.
- Focuses on where the person is now and strengths of his or her support system – to be maintained. Clarifies dreams and works up an action plan.
- Seeks to establish strategies for achieving valued futures when sustained and co-ordinated action is required.
- Useful in establishing direction and goals for the person - and action plans to achieve goals identified.
- 8-step problem-solving approach.

ELP - Essential Lifestyle Planning (Michael Smull and Susan Burke Harrison, supporting people with severe reputations in the community):

- Very detailed planning style.
- Seeks to establish what is important to the person, what supports are available and getting a lifestyle that works for the focus person NOW.
- Useful in information gathering, planning a service around a person to suit them and their needs and day-to-day action plan specification.
- Good starting-point.
- Useful in supporting transitions.
- For an overview see NWTDT book.

Circles:

- Clarifies circles of support for the focus person.
- Generally viewed as a pre-planning tool.

Alternative Formats.

Please note that this document is also available in the following formats:

- Easy-to-Read Summary;
- Large Print;
- Audio Tape;
- Braille.

Further information.

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