Guidelines on Person Centred Planning in the Provision of Services for People with Disabilities in Ireland

NATIONAL DISABILITY AUTHORITY
ÚDARÁS NÁISIÚNTA MÍCHUMAIS

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Foreword

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
NWTDT	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

Contents.

1 Introduction.

Background to and purpose of this document.

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' (see, for example, Part II, sections 8-(2)-(c, d and f) and 10 (1)).

In the course of nationwide consultation on its work programmes, 2002, person centred planning in the provision of services for people with disabilities in Ireland was identified as one of the areas requiring the NDA's attention.

Supporting good practice in person centred planning will help the government to deliver on its commitment to provide quality services for people with disabilities (see Quality and Fairness – A Health System for You, Department of Health and Children, 2001 and the National Disability Strategy, 2004). The new draft National Standards for Disability Services (which the NDA submitted to the Department of Health and Children, October 2004) make explicit reference to person centred planning as a key reference point for the development and delivery of services for people with disabilities.

In order to be effective, it is important that person centred planning be adopted thoughtfully, carefully and in a way that is tailored to the individual at the centre of the planning effort.

Specific objectives.

The specific objectives of the document are to:

1. explain the term 'person centred planning' and clarify the purpose and application of person centred planning;
2. set out key principles underlying person-centred approaches and principles of effective person centred planning;
3. set out key elements of a person centred plan;
4. make practical recommendations for effective person centred planning including monitoring (or tracking) progress on putting plans into action.

Scope and application of this document.

Person centred planning is a way of helping people or the parents/families of very young people or people with high dependencies, think about what is important to them, how they want to live and what support they want.

A person centred plan can be helpful in guiding the design and delivery of highly individualised, dynamic support arrangements which are unique to each individual's needs and preferences.

This document, on person centred planning **in the provision of services to people with disabilities,** should prove useful to service providers in setting out the values and principles which underlie person centred planning and the essential elements of its overall approach, required context and associated methodologies.

It is mainly intended to provide information and support to services supporting the development and/or realisation of person centred plans, though it is also intended to provide information for people with disabilities and their parents, families, friends, spouses and advocates which will help them understand what is meant by person centred planning.

Some introductory notes on terms used in this document.

Person centredness is defined in the draft National Standards for Disability Services as 'seeking to put the person first' (NDA and Department of Health and Children, 2004). Person centredness is generally seen as essential to the provision of good quality services for people with disabilities in Ireland (see, for example: Frequently Asked Questions (FAQs), draft National Standards for Disability Services, April 2003).

The draft National Standards for Disability Services define a **person centred service** as one which is "provided, organised and designed around what is important to the service user from his or her perspective." (the draft National Standards for Disability Services, September, 2004). They require that **all planning for the provision of services to people with disabilities should be person centred.**

At the heart of a person centred approach to planning lies an appreciation of the person as a unique individual, requiring that all planning is based on supporting each individual lead his or her life as and how he or she wishes. In practical terms, this means that **all** planning around the design, development and delivery of all services for people with disabilities should be both based on and actively involve the individuals availing of these services and each of those individuals' unique characteristics, capabilities, needs and wishes (that is: conducted in a person centred way).

Person centred plans should be viewed by service providers as a useful means of driving person centredness and person centred service provision, that is: as a means for bringing this about. Nevertheless, it is important that service providers recognise and bear in mind the fact that a person centred plan is not a plan for person centred service provision (a 'service plan' as such) but is, rather, a personal, overall life plan for an individual.

Ideally, the process of person centred planning should begin before an individual makes contact with any particular support service. Services constitute just one aspect of a person's life. The matter of services should, accordingly, be addressed only when a person has developed a clear overall perspective on the life they want in general.

The scope of person centred planning will, normally, extend far beyond services.

Most will, however, set out a number of requirements for services or feature some more general wishes which may have implications for them.

2 So what is 'person centred planning'? Definition and brief history.

'Person centred planning' may be defined as a way of discovering:

- how a person wants to live their life and
- what is required to make that possible.

The overall aim of person centred planning is "good planning leading to positive changes in people's lives and services" (Ritchie et al, 2003).

Person centred planning is not so much a new technique for planning as a new approach to - or new type of - planning that is underpinned by a very exacting set of values and beliefs that is very different to the current norm. It is planning that takes as its primary focus **a person** - as opposed to a disability or a service or some other particular issue. It is 'whole person' oriented as opposed to disability-management focused. It is about citizenship, inclusion in family, community and the mainstream of life and self-determination and can, therefore, require some very fundamental changes in thinking and the established balances of power, the implications of which are potentially enormous and far reaching.

It is important to understand that person centred planning is **not**:

- **assessment** – whether of services or service user needs (see the UK Department of Health's 'Valuing People: a new strategy for learning disability for the 21st century'). As Ritchie et al (2003) observe, person centred planning takes as its starting point the individual as opposed to the service and how the individual might be made to fit into the service system. It also goes beyond services, indicating more general action by and for the individual.
- **service planning or Individual Program Planning for service users**. Traditional Individual Program Planning (IPP) is characterised by a synchronised and standardised approach to addressing identified needs. Person centred planning requires a flexible and responsive approach to meeting **an individual person's** needs and changing circumstances, guided by the principles of good practice rather than a standard procedure (Sanderson, 2000).

Person centred planning, service planning or individual program planning and assessment may, legitimately, exist alongside each other and have implications for each other, however. For example:

- the requirement for developing a person centred plan or for updating an existing person centred plan may be identified as part of needs assessment;
- a person centred plan may identify the need to develop or adjust an individual educational or care plan to better suit an individual's requirements, wishes and preferences around support and/or his or her overall vision for his or her life.

Originating with Wolfsenberger, person centred planning has its roots in the normalisation and independent living movements. It is grounded in a social model of disability and a strengths based approach. Person centred planning was developed because people with disabilities often find it difficult to get the kinds of basic services, opportunities and experiences most people take for granted – and even when they do, they frequently find they are required to somehow fit into someone else's idea of what that service, opportunity or experience should be like and how they should act, think or feel in relation to it (see Howell et al, 2004 and Routledge and Gitsham, 2004; see also John O'Brien, 2004).

Person centred planning seeks to:

- craft a vision for a person's life as part of their local community

  and/or the broader mainstream of life and
- describe the actions needed to move it in that direction.

It accomplishes this through:

1. discovering and responding effectively to the various aspirations, capacities and concerns of individuals with disabilities;
2. understanding and addressing the core issues for individuals – exploring where the person is now, how they would like their life to change and what bringing about that change might entail;
3. identifying and exploring choices available to the individual;
4. mobilising and involving individuals' entire social network as well as resources from the system of statutory services in responding to what is expressed and helping to bring about whatever changes are desired;
5. making arrangements to follow up on plans on a regular basis in order to go through them, review progress on putting them into action and update them;
6. discovering a way to record, on an on-going basis:
    - what has been learned about what is important **to** an individual and what is important for them;
    - what **balance** has been worked out between what is important to the person and what is important for **them** where there is a conflict between the the two;
    - what others are expected to know about what is important to and for the person and/or what others are expected to do to help the person get what is important to and for them;
    - what needs to stay the same and what needs to change - and who will do what (by when) in acting on these;
    - what is, in fact, staying the same and what is changing following the development of a person centred plan - and whether this is making a real difference to the person's life in either case.

The earliest proceduralised forms of person centred planning are associated with Karen Green-Mc.Gowan and Mary Kovaks who ran day-long planning sessions for people with disabilities. By 1980, Beth Mount was running training courses in 'personal futures planning' (sometimes referred to as PFP) and by the end of the eighties several alternative formal methodologies (sometimes referred to as 'planning styles') had evolved. These included, for example: 'getting to know you', 'individual design sessions', and '24-hour planning'. The history and path of evolution of these methodologies is charted in O'Brien and O'Brien (2000) and Shaddock (2000).

Person centred plans may be developed either within services or entirely independently of them. In either case, it is the person or family who is to be the focus of the person centred plan that should decide whether to develop one in the first place – and how … and whether to pursue it once it is developed.

A person can, of course, develop his or her own plan and take the lead in getting it implemented. Sometimes, parents, family, spouses, friends, advocates or others will do so on their behalf (for example: where it is not possible for a plan to be guided entirely by an individual due to extreme difficulties with insight, awareness and cognition). Plans may also be developed by one or more individuals acting independently on behalf of an individual and/or his or her family – and/or by service staff specially trained for this (for example: a legal guardian or a specially trained keyworker and expert on brain injury). In Ireland, in practice, at present, person centred plans tend to be developed within services, though some parents and families have begun to develop plans independently.

In practice, the development and implementation of plans usually requires the co-operation of quite a range of individuals, services and the broader community network, if they are to be really effective.

The person at the centre of the planning endeavour is commonly referred to as the **'focus person'**.

Where this person is being supported in the process of drawing up a plan and putting it into action, the individual supporting and guiding the planning effort is called a '**plan facilitator**'. The primary role of the plan facilitator is to 'help someone work out what they want and then help them work out how to attain/achieve it' (after Ritchie et al, 2003). Facilitators may also work as agents of plan realisation, liasing with relevant support or other service providers.

Whether specialist service staff, parents, family members, spouses, friends, advocates or someone acting independently on behalf of an individual and/or his or her family, it is extremely important that a plan facilitator is suited to the task in terms of their values, talents, capacities and skill-base. They should, normally, be formally trained and experienced in person centred planning philosophy, methodology, tools and techniques. They should also be familiar with any significant aspects of the focus person's background that are likely to impact on the person centred planning process.

It is particularly important that diversity and individuality across focus persons should be acknowledged and accommodated, in compliance with equality legislation. In effect, this would mean that in the case of cultural and linguistic minorities, for example, a plan facilitator ought to possess or seek to acquire adequate knowledge/experience of the cultural identity and communication styles of the individual or family that is to be at the

centre of the planning process - and that they make specific provisions to facilitate these. (The Intercultural Press has produced a number of cultural guides which may be found to be useful starting points in this regard, Anna Mindness' books on Irish deaf culture, identity and communication styles and Irish Sign Language (Mindness, 1999 and 2003) being just one example. See also the Equality Authority's website: <http://www.equality.ie>.)

It is essential that a plan facilitator operate entirely independently of any potentially vested interest in the process. Where a plan is being facilitated within a service, the autonomy of the plan facilitator in his or her role as plan facilitator must be adequately assured. It is also imperative that a plan facilitator should adopt, encourage and project an equal partnership approach to working with the person or family at the centre of the planning process.

Where (for whatever reason) an individual is not happy to work with a particular facilitator, another should be found.

The term '**circle** or **network of support**' for plan development and realisation is used to refer to everyone a person might like (or need) to involve in developing and/or working out their plan:- family, spouses, friends, advocates, specialist and non-specialist service providers and local community groups, etc.. The initial and continuing involvement of any particular individual, group or organisation in any part of the planning process should be in accordance with the wishes of the person at the centre of the planning endeavour - and that particular individual, group or organisation.

The person responsible for driving the overall process is sometimes referred to as the '**pcp champion**'. Where a group of people decide to work together to drive the process, this group is sometimes referred to as a '**guiding coalition**'.

Clearly, some individuals may fulfil more than one role. For example: somebody who draws up their own person centred plan and champions the overall person centred process themselves, would be both focus person and pcp champion. Similarly, somebody who supports the development of a person centred plan and also works as an agent of its realisation would be both plan facilitator and pcp champion.

Every effort should be made to ensure that everyone involved is given whatever support they need to play their particular part(s).

This includes developing an adequate system of communication that is fully accessible to all parties likely to be involved in the person centred planning process. It may also mean engaging in some preliminary groundwork on empowerment, relationship-building and advocacy.

The role of the individual's parents, siblings, family and close friends in person centred planning is generally acknowledged as hugely significant for the planning process (see, for example: Shelton et al, 1987 and Turnbull et al, 2000). The main concern of person centred planning is, of course, the focus person - and that person's wishes must be upheld. Even so, planning must also take due consideration of the views of these key individuals in the person's life, particularly in developing person centred plans for young people or people with high dependencies. Where an individual does not want a family member to be directly involved in his or her person centred planning process, this issue can be explored but should not be forced. It must be acknowledged that parents and family members can be a valuable source of information in developing plans and a great help in getting plans put into action. Regardless of whether they have been directly involved in the planning process, parents and family are frequently impacted by plans (sometimes directly, sometimes indirectly). The matter of consulting parents and family members on those parts of a plan that are likely to impact on them should be addressed as part of the planning process and the views of parents and family members on those issues should be sought, acknowledged and explored.

Where the individual and his or her parents and family or service providers or service providers and parents and family hold very different views on a particular issue, every effort must be made to fully understand the reasons for these differences of opinion and to explore how they might be satisfactorily addressed. Should conflicting views prove irreconcilable, the views of the focus person should be taken as paramount.

3 Key principles.

The six key principles underpinning person centred planning are:

1. Person centred planning is planning from an individual's perspective on his or her life: The individual around whom planning is conducted and his or her wishes are taken as the single most important point of reference for the entire planning venture (after Mansell & Beadle-Brown, 2004).

2. Person centred planning entails a creative approach to planning which asks 'what might this mean?' and 'what is possible?' rather than assuming common understandings and limiting itself to what is available: Person centred planning aims to 'unpack' and understand what people desire and connect what is discovered with practical ways of making things happen for them (despite apparent difficulties) - exploring

what is possible for them rather than simply what is available to them (Frizzell, 2000).

3. Person centred planning takes into consideration all the resources available to the person – it does not limit itself to what is available within specialist services: A person centred approach to planning seeks to identify the full range of resources available to the individual. It actively explores the individual's own resources and what is or might be made available in the broader community, including all non-specialised services (the draft National Standards for Disability Services – FAQs, April, 2003; the draft National Standards for Disability Services, September, 2004). It is very much focused on cultivating a shared commitment to action which has a bias towards inclusion, supporting the individual "in moving from dependence to independence and ultimately to interdependence within his or her own community". (The Joint Working Group of the Disability Federation of Ireland, National Federation of Voluntary Bodies, Not for Profit Business Organisations – for the Department of Health and Children and the National Disability Drafting Group).

4. Person centred planning requires serious and genuine commitment and co-operation of all participants in the process: It may take some quite considerable time and effort to develop plans that are meaningful for the focus person let alone begin to realise these plans. Both the quality of plans developed and their final effects on the life of the focus person depend hugely on all participants (family, friends, service providers, etc.) realising this from the outset and being prepared and committed to see the planning process through to fruition.

5. Person centred planning is an art – not a science: It is best viewed as an organic, evolving process which emphasises:

- taking time to really get to know people and build relationships and rapport over time;
- encouraging open and flexible attitudes in all participants in the planning process;
- listening carefully, acknowledging and exploring various and, in particular, opposing perspectives;
- responding creatively, practically and reasonably to what is heard.

6. The development of a plan is not the objective of person centred planning: making real, positive differences to someone's life is.

4 Why person centred planning? Is it better than other forms of planning?

There is a growing body of international evidence to suggest the beneficial effects of person centred planning for people with disabilities, for example: person centred planning can alert people to choices available to them and support them in moving towards their preferred options (Cash and Jefferies, Gloucestershire Partnerships Trust). In Ireland there is growing evidence that person centred planning has a very beneficial impact.

It should be understood that person centred planning is no panacea, however:- it is no guarantee of a better life, in and of itself… and many positive changes for people will be achieved without using person centred planning at all (Ritchie et al, 2003).

Much of the effectiveness of person centred planning would seem to rest in the way it is conducted (Connolly, 2001, Radcliffe & Hegarty, 2001 and The Circles Network, 2004) and the more general person centredness of the overall context in which it is pursued (Sanderson, 2000 and Ritchie et al, 2003).

Although it would seem that well developed person centred plans that are acted upon, can make considerable difference to individuals' lives, it is important to bear in mind that there currently exist few good quality, systematic evaluations of person-centred planning. Exceptions include, for example: a study completed by the UK Department of Health (2005 - unpublished) which indicates beneficial effects. Clearly, there is a real need for ongoing research in the area.

It is important to note that a person centred plan may not be needed or wanted by everyone.

A person with a disability may, however, find person centred planning particularly useful in providing him or her (and his or her closest family and friends) with:

- a chance to take stock of his or her overall life – and quality of life;
- an occasion to explore his or her: strengths, capacities and achievements so far in life; current needs and wishes for the future; the full range of possibilities open to him or her at present;
- a forum within which to make choices as to what is most important;
- an opportunity to set out a number of important things to be achieved in the near future (sometimes referred to as 'goals') and to come up with strategies and action-plans around these goals which specify what steps need to be taken to achieve them, how, when and by whom;
- a source of encouragement to advocate for and pursue the provision of services and choices which would greatly improve their life.

Person centred planning may be viewed and used as a life-long process and support. It can also be used as an occasional or one-time-only undertaking, if that is what a person wants. It has, for example, been found to be particularly useful in times of change or transition in a person's life (see, for example, Miner and Bates, 1997).

5 How to get started on person centred planning: creating a context that will facilitate developing and/or responding to person centred plans.

The following steps should prove a useful guide for those planning for or helping others in getting started on creating a context that will facilitate developing and/or responding to person centred plans:

1. establishing a framework;
2. clarifying roles and responsibilities (especially in regard to leading the person centred planning process both at a general and individual level) and identifying any training and support that will be required.
3. identifying plan-facilitators and ensuring that they are adequately trained, experienced and supported.
4. establishing mechanisms for ongoing communication, plan management and the monitoring, evaluation, review and development of the person centred planning process.

Step 1: Establishing a framework.

The work of establishing a framework to support person centred planning consists of:

1. Encouraging people with disabilities and all around them to develop a positive view of themselves, their lives and their futures.
2. Empowering people with disabilities and their parents/family to take control of their lives.
3. Working towards facilitating people with disabilities and their parents/family, friends, etc., having or knowing how to create an opportunity to say how they want to live their lives and what sorts of help, opportunities and development of local capacities they feel would make a positive contribution towards achieving this.
4. Working towards specialist disability services building a person centred culture and sustaining it.

This means developing a greater general willingness and capacity to seek out, be informed by and respond to the overall vision, life plan or simple wishes and preferences of each individual with disabilities availing of their services and their parents, families and friends (this may include, for example: (a) developing a written policy on person centredness and strategies for transforming this vision into a reality; (b) adequately preparing and facilitating staff to support people with disabilities to think about their life, how they feel about it, how they might like to have it progress – and to articulate this, communicate it effectively; (c) adequately preparing and supporting staff to really listen to, hear, understand, acknowledge and respond to what is communicated; (d) adding a formal person centred planning support service or outsourcing service to its existing range of services; (e) working in partnership with family led organisations to explore family mentoring and other ways of supporting families to develop person centred plans themselves and lead the process of putting them into action).

It also means fostering a culture of feedback - looking carefully and systematically at the differences between what individuals are saying they want and how things are currently done – by providing a means by which person centred plans can inform, support and act as a benchmark of the responsiveness of the service as a whole.

It means developing practical person centred thinking skills in order to be able to bring about change required in practice and culture (for example: the way teams work, staff are supervised and resources are used); developing an openness and willingness to change where necessary; and integrating service users into all aspects of the design, development, test, delivery and ongoing evaluation and continual improvement of services.

(This is the essence of a person centred approach.)

It should be noted that establishing a sustainable person centred culture within organisations normally requires engagement in some degree of organisational review and change. There will be a number of significant challenges for management and staff in moving from a traditional, service-based, 'caring' approach to service provision - to an approach that is based on supporting people with disabilities in getting on with their lives, developing relationships and being part of their community. Clearly, then, this process must include extensive consultation. It will, normally, also require the development and delivery of a comprehensive training programme to support the implementation of proposed developments.

5. Working more generally on developing an overall climate that is supportive of people with disabilities becoming fully part of, benefiting from and making contributions to their local communities. This includes capacity building in mainstream public and

private services and developing de-segregating linkages and communications across mainstream and specialist services (after O'Brien and Towell, 2003, based on UK practice, Ritchie et al, 2003 and Irish best practice).

The scale of this task should not be underestimated and may take some time. Target dates should be set for keypoints in framework development and progress reviewed at regular intervals.

Initially, it is likely to involve:

- identifying people who are likely to be in favour of the idea and soliciting their support;
- running some information and basic training sessions for **everyone** likely to be directly involved, impacted or called upon for support;
- identifying ways of collecting information on the changes which need to be made to support person centred planning;
- establishing a project group to work out some practical strategies for promoting and doing person centred planning in a particular context or setting.

For further information, see, for example: Sanderson and Kilbane 'Person centred planning: a resource guide', 1999; the National Federation of Voluntary Bodies' 'Building Blocks to best practices in people centred services' – Walls, 2002; the New South Wales 'client-centred, solution-focused, competencies-based' model of person-centred service planning and provision; the UK's 'best value review of learning services for adults - a framework for applying person centred principles'; e.g. Barbara Mc.Intosh's 'Person centred planning: Making it work in the UK', 2001; The National Disability Authority's 'Ask Me Guidelines for effective consultation with people with disabilities'.

O'Brien and O'Brien's 'A little book about Person Centred Planning', Ritchie et al's 'People, Plans and Practicalities: achieving change through person centred planning' and on implementation, Cole et al (2000) and the U.K's North West Training and Development Team (NWTDT)'s publication 'Planning with people – developing a framework' - or most basic training courses would be good starting points.

Step 2: Clarifying roles and responsibilities (especially in regard to leading the person centred planning process both at a general and individual level) and identifying any training and support that will be required.

The appropriate levels of involvement and degrees of engagement of individual elements of the focus person's network at various stages of plan development and realisation must be carefully worked out. This may present a challenge to existing assumptions, understandings and balances of power.

Every effort should be made to ensure that the role and responsibilities of every individual, group and organisation participating in the person centred planning process is clearly understood and agreed by them and adequately supported.

The question of who will take the lead in driving the person centred planning process at both general framework and individual plan level (and the training and support they will require to do so) is hugely important. It is likely to require considerable reflection, consultation and negotiation across all potential stakeholders. It is not a decision for service providers to make alone, amongst themselves. People with disabilities, their parents/families, friends and advocates must be actively involved.

All service providers will need to be reasonably familiar with the concepts of person centredness and person centred planning - and the likely implications of person centred planning for the services they provide. Service providers should be prepared to offer to take the lead in instigating, driving and supporting the process – but only if this is what their service user and/or his or her family wish. A person with a disability and/or his or her parents/family may wish to lead the process themselves. Where this is the case, service providers should be prepared to offer them support in this.

Whoever is driving the process will need to develop a very clear understanding of the key principles and processes of person centred planning – and at least some methodologies for developing plans and strategies for putting them into action.

The calibre and commitment of each participant in the process will constitute a key factor in determining its final, overall success.

Step 3: Identifying plan-facilitators and ensuring that they are adequately trained, experienced and supported

in accordance with the recommendations of earlier sections of this document on plan facilitators.

Step 4: Establishing mechanisms for ongoing communication, plan management and the monitoring, evaluation, review and development of the person centred planning process.

At individual plan level this entails careful consideration of and agreement on issues of:

- ownership, confidentiality and copyright, storage of and access to plans - the wishes of the focus person should be followed on the questions of, for example: who should hold the plan, whether it may be copied, if it is to be kept by someone other than the individual whose plan it is, who may access it, when and how and how the information contained in the plan should (and should not) be used;
- maintaining and updating plans over time and changes in circumstances, etc.;
- the best way of keeping everyone informed and up to date on the progression of plans, problems encountered in implementing plans or changes to plans (so as to ensure their successful and expedient implementation);
- the best way of managing relevant information exchange at times of transition (what will new service providers need to know, what else will an individual want them to know, how is this information to be conveyed, etc.);
- whether it will be necessary to re-configure the various individuals and groups involved in the ongoing development and implementation of plans at times of transition and, if so, the best way to go about the re-configuring (this is a particularly important issue where an individual has, for example, asked a service provider to help them manage their plan and drive its implementation but will soon be having little or no further contact with that service).

At a more general level, it is important to establish a routine process of monitoring, evaluating, reviewing and developing the way person centred planning is being done, so as to ensure it is having a positive effect on lives and services.

The principal challenges.

The principal challenges in implementing person centred planning are:

- **The need for everyone to develop a new perspective on people with disabilities.** There is a very real need for everyone to examine the assumptions and values which underpin our views and the way we act towards and interact with each other. "We [should be] moving away from emphasising my needs toward building upon my capacities … from providing services to me in some facility toward building bridges with me to communities and neighbourhood associations … from programming me and other people with disabilities toward empowering us and our families to acquire the support we want … from focusing on my deficits to focusing on my competence … from specialised disability organisations so that we can develop and sustain relationships with people who will depend upon people like me and upon whom people like me can depend" (Kilroy, 1987). One particular advantage of person centred planning is that when it is done well, it can create or enhance a sense of purpose and empowerment for a person with a disability and generate obvious practical evidence to challenge persistent limiting and erroneous views and expectations. See Duffy, 2004 and Howell et al (2004).
- **The need for a new general perspective on services.** Person centred planning is about helping people to live the way they want, rather than just fitting them into or making them work with what is available (after Mansell and Beadle-Brown, 2004 and the East Sussex County Council, April, 2004). It is about people's engaging fully in the mainstream of life as and how they themselves wish. It, therefore, includes but should not be limited to availing of whatever services are available to an individual. "The more we see the job of services as helping people to lead their own lives, the more person centred planning is likely to keep its shape as a process in the person's world; and the more person centred planning will contribute to people's freedom and connectedness" (Ritchie et al, 2003). Clarity of all participants in the planning process on this is critical – as are the proper mindset, attitude and organisational culture of service providers.
- **Resistance to change.** Those who want to, can find many ways to avoid engaging the tension between current standardised reality and a desirable individualised personal future. They can compare the best (or even worst) present to worse past conditions instead of comparing it to desirable future capacities. They can dismiss the image of a desirable future as unrealistic. They can say that they would like to help but that powerful political, socio-economic or other outside forces forbid them. They can stay busy with activities that allow no time to listen and learn from focus people. (after Thaler, Kinsella, 2000 and J & CL O'Brien).

- **The need for a new understanding of planning service provision.** Although it can be shown that the founding ethos of many services for people with disabilities in Ireland is firmly based on many of the key principles of person-centred planning, it can also be shown that, over time, most of these services gradually moved away from an individualised approach to service provision to one grounded on more general principles of service provision based on commonalities across individuals and their disabilities - and for the common good. New forms of Individual Program Planning (IPP) evolved, requiring that staff behave in a somewhat customisable but, effectively, largely synchronised and standardised way towards all service users. Now, person centred planning requires that staff adopt a flexible and responsive approach to meeting people's changing needs and circumstances, guided by general principles of good practice rather than standard procedures (Sanderson, 2000). Acceptance of the need for a more progressive, individualised approach to working with service users is vital – as is adopting a partnership approach to developing the practical strategies, policies, procedures and working arrangements needed to make this possible. An extensive consultation process may be required within services on person centred planning.
- **The requirement for a collaborative approach across a range of individuals, services and the broader community network.** Person-centred planning offers a forum in which the required work of adapting to and assisting people with disabilities may be specified – and possible implementation paths proposed. (This includes assigning responsibility for leading and driving the overall process and ensuring that various strategies agreed on are implemented). Where a collaborative approach to planning is adopted, both requirements specifications and implementation proposals can be more readily and thoroughly explored and, therefore, more readily agreed and acted upon.
- **Risks and learning curves.** It is important to acknowledge that the practice of person centred planning is characteristically tempered by the fallibility of human judgement, the potential impingement of factors outside the control of the process on its success and the possibility that there will be setbacks along the way, the fact that it will be necessary to allow some time for learning and adjustment and that it is unlikely that everyone will get everything right first time.

6 The Plan itself: how to go about drawing it up and set about the task of putting it into action.

The Plan

A person centred plan may include a description of the individual, past and present. It should normally, however, include a description of a vision of a more positive future for the individual (short, medium and/or long term) together with a goal-based action plan for the attainment of this more positive future.

Typical components of a good person centred plan are (after, for example, Smull, 1996, Howell et al, 2004, Helen Sanderson Associates, 2005 and Irish practitioners) a description of:

1. the person at the centre of the planning process indicating - at a minimum - their capacities, strengths, capabilities, what people like and admire about them and what is important to them;
2. what is and is not working well in the person's life at present – what the person would like to change;
3. what the person wants for the future – and how they would like to be supported in moving towards this future;
4. the specific changes required to attain the future the person desires, how these changes are to be made, by whom and when (to include: general strategies, specific activities, particular services, required support intensities and personal commitments by the focus person and others, refinement and assignment of SMART (Specific, Measurable, Attainable, Relevant, Time-anchored) action points and memoranda of agreement);
5. how the plan will be reviewed and kept live (to include: communication strategies on plan progression, a plan and progress review date and strategies for capturing ongoing learning throughout the process).

Howell et al (2004) also point out that each person centred plan should be:

- entirely unique to the individual whose individual life it is meant to reflect;
- true to the hopes and dreams of that person, tackling the difficult goals that are meaningful to that person and supporting action without forcing that person into predetermined courses of action.

A person centred plan should be drawn up in such a way that it can genuinely:

1. help move a person's life in the direction they want;
2. build a person's place in the community and mainstream of life;
3. help the community to welcome, appreciate and value them.

Person centred plans may take many forms. They may be paper-based (e.g. a workbook, scrapbook or storyboard), may take the form of a video or other form of artwork or may be worked out through roleplay, etc. – as the focus person wishes. For ideas on flexible usage of more structured options, see, for example: Jonikas and Cook, 2004.

It is important to appreciate that plans may need to be reviewed and adjusted from time to time, so as to reflect changes in people and circumstances over time (see, for example: Fleming, 2001).

How to go about drawing up a person centred plan.

Key Activities.

The actual process of drawing up a person centred plan consists of a number of key activities, namely: (1) familiarisation; (2) decision-making and action-planning; (3) developing a strategy around progressive realisation and review; (4) recording the plan and ongoing learning about both the person at the centre of the planning process and the process itself.

1. Familiarisation: with everyone and everything that is important to the individual at the centre of the planning action and that needs to be addressed as part of their person centred planning process.

A formal planning meeting may be arranged - in which case, the individual or family at the centre of the planning process decide(s) whom to invite to the meeting. Inviting people who may have an important role in or something to say about important aspects of a person's or family's life can be useful as they may have useful insights or suggestions to offer on particular issues. The agenda for the meeting may be set by the focus person or his or her family or by the plan facilitator. Alternatively, it may be allowed to evolve naturally from the group.

It is important to note that some people may not want a formal meeting, however.

Where an individual does want a formal planning meeting, formal person centred planning methodologies referred to earlier (MAPs (Making Action Plans), PATH (Planning Alternative Tomorrows with Hope), ELP (Essential Lifestyle Planning), etc.) can be helpful in providing orientation, structure, direction and movement to the meeting and ensuring that a good range of potentially significant issues for the individual and ways of addressing them are explored. When using formal methodologies and procedures, care must be taken to ensure the appropriateness and/or adaptation of the method or procedure to the individual and the setting. A general guide to the appropriateness of a number of sample methodologies to varying situations and circumstances is provided in the Appendix to this document.

Some generally useful strategies for effective familiarisation to help ensure the development of a good person centred plan, include (after Doyle and Straws, 1976):

- Getting some basic groundwork done: this means e.g.: building relationships, establishing a rapport, getting to know prospective participants in the planning process and how they are most comfortable and/or may be encouraged or supported in communicating their views;
- taking time to properly organise planning activities;
- taking time at the start of planning activities, to put everyone at ease and agree some ground rules;
- making sure that as planning activities progress, everyone present stays fully involved with the process and is given an opportunity to express their views;
- making sure that all views are heard, acknowledged and explored.

2. Decision-making and action-planning: on where priorities lie, which options to pursue, who is going to take action on the important issues - what actions and when.

A useful strategy for decision making and action-planning to help ensure the development of a good person centred plan, is (after Doyle and Straws, 1976) to work, in a general way, **from the beginning,** towards reaching some definite conclusions by the end of the planning action.

This may mean having to take quite some time to get a clear understanding of particular items an individual may identify in his or her plan. For example: expressing the wish to ‘get married some day’ may actually mean wanting to get married; it might also mean wanting to be treated more like an adult or wanting to lead a more independent life or wanting to live in a regular house as opposed to a larger residence.

It may also mean having to take quite some time (and a creative approach) to find a way

forward on areas which pose significant challenges and/or key areas of concern for those participating in the planning process - so as to be able to come to an agreement on all matters on which opinions differ.

One example of an area which could pose significant challenges is resources. ('We think it good practice to make clear what resources are on the table as people begin to plan' (O'Brien and O'Brien, 2000). It is worth noting that Irish practitioners find it helpful to review, clarify and confirm resources available at **all** stages of the planning process. It has also been the experience amongst Irish service providers that it is good practice to maintain a bank of knowledge of general and community resources to help inform the planning process.)

Key areas of concern for those participating in the planning process may warrant some exploration. Service providers' concerns may, for example, be found to be basically insurance-related – in which case, taking out independent insurance may serve to allay the fears of a service provider. Parents' concerns may stem from a protective attitude or from not realising the extent of the capability displayed by their child outside of their home environment - in which case, showing a parent a video of their child displaying a degree of capability unknown to the parent may suffice to allay any fears they may have.

It can happen that somebody can see a planning meeting as an opportunity to discuss issues not related to the planning work at hand. Particularly where the individual at the centre of the planning effort does not want to discuss these matters, it is important that they are not allowed to distract from the main issues or cause distress to the focus individual or others in attendance. The fact that these matters have been raised and are important to the individual who has raised them should be acknowledged and noted – and another time set to discuss them (after Quality through individual planning – St. Michael's House, 2001).

3. Developing a strategy around progressive realisation and review: agreeing a date and time to look at progress and problems, how difficulties might be addressed and what else may be tried - and whether the person at the centre of the planning process has changed his or her mind on anything since the last discussion of their plan.

It is extremely important that arrangements are made **at the time of developing the plan,** for following-up on it to find out whether, how quickly, how easily and how well it is becoming a reality and whether it is bringing about real change for the better in the life of the individual - or whether it needs to be revised. Decisions should be made on dates, times and ways of tracking progress **before drawing planning activities to a close.**

4. Recording the plan and ongoing learning about both the person at the centre of the planning process and the process itself: It is important that some form of record

be made of all the important issues that emerge at each stage of the planning process. This should be done in a way that makes sense first-and-foremost to the individual at the centre of the planning endeavour – but also to all those who will be impacted by it (including service providers who wish to use particular parts of the plan to help design more person-centred services and/or deliver them in a more person centred way).

Key Considerations.

Three key considerations in drawing up a person centred plan are: ethics, resources and potential pitfalls.

1. Ethical considerations.

Throughout the plan development process, due consideration should be given to the following ethical issues.

- The wishes of service users in relation to the initiation, ongoing development and realisation of person centred plans should be sought and followed.
- Freedom of choice and the informed initial and ongoing consent (freely given and in no way forced or coerced) of the focus person and his or her family to embarking on and continuing to engage with the process (due consideration being given to the individual's capacity and need for support in this regard).
- The professional conduct of the plan facilitator in regard to relationship building and the intimate knowledge of the focus person and his or her family which is at the core of the process.
- Respectful treatment of all participants in the process and acknowledgement and exploration of all views expressed – nobody participating in the process should be allowed to take over the process and nobody should be made to feel that their opinions are not being heard or understood.
- The unintrusive elicitation and the sensitive and strictly confidential treatment of all information exchanged. There should be no question of any information exchanged being communicated or used in any way without the prior knowledge and agreement (again, based on informed consent, freely given) of those who were parties to the exchange. That said, it is possible that, in the course of person centred planning, information emerges which suggests that an individual is in some way at risk. In this case, a plan facilitator or pcp champion or guiding coalition has a duty to report any 'notifiable issues' such as allegations of a health, safety, neglect or abuse risk or financial impropriety

and/or professional misconduct. Plan facilitators will need to explain to all participants in the person centred planning process, this sole necessary limitation of promises of confidentiality given - and their duty to disclose certain types of information in order that the safety, interests and wellbeing of the focus person and/or an other individual(s) indicated may be assured. (For guidelines regarding children, see the Department of Health and Children's Children First National Guidelines (1999), the Protections for Persons Reporting Child Abuse Act (1998) and the Child Care Act (1991). Regarding adults, see policies and procedures set out by the relevant Health Service Executive).

- Adopting a responsible attitude and seeking to strike a balance between choices in theory and real options given practical possibilities or constraints when negotiating both goals and strategies for putting the overall plan into action. There is, for example, an ethical issue around raising expectations beyond what is attainable within given resources. Although every effort should be made to use given resources as creatively as possible and marshal additional resources where needed, it is not always possible to succeed in this effort. In addition: due consideration must be given to what is realistic for the individual from a personal health and safety perspective. It must be accepted, however, that individuals may not always want to settle for a compromise solution - and an individual's dreams or ambitions, etc., should never be unreasonably compromised.
- The ongoing commitment of all participants in the process to developing a good plan and putting it into action.

2. Resources.

Resources/supports for person centred plan realisation fall into two main categories: social and service. Social resources include family members, allies or friends committed to their understanding of the focus person's well-being and networks of other contacts (community, occupational, etc.). Service resources include available public funding, person centred planning facilitators, consultants, a broad range of specialist and general services and service elements and delivery systems (some more accessible than others).

Information from person centred planning practitioners in the UK suggests that 'initially, the costs of person centred planning can be higher than conventional planning' (Mc.Intosh, 2001). Information from Irish practitioners, however, suggests that good person centred plans do not always require extra resources – though they do require the good management and effective use of existing resources. Cole et al (2000) suggest re-organising resources to achieve more flexible support, focusing resources on individuals, creating more ordinary community opportunities and natural supports for people and ensuring that organisations work together, collaboratively and creatively.

For planning which results in a requirement for additional resources, Cole et al (2000) suggest a number of strategies for increasing the amount of support available for implementing plans. These have been echoed by Irish practitioners. They include, for example: the recognition of less obvious social resources and the creative allocation of service resources across individuals' social networks e.g. training and supporting service providers to recognise, build up and mobilise people's community networks and identify and foster individuals' natural supports.

3. Potential pitfalls to avoid in drawing up a person centred plan.

Three serious potential pitfalls to avoid in person centred planning are:

1. **Sacrificing principles to process:** 'It must be understood that person centred planning is an evolution not so much of planning 'technology' but of power and control shifts' (Kathy Brown, Paradigm UK). 'Formalised and systematised approaches may be very helpful in particular settings but the right philosophy, an open mind, an open heart and a blank sheet of paper is still the best way of doing person centred planning' (Jack Pearpoint).
2. **Failure to listen well, accurately or adequately reflect the real life of the individual at the centre of the planning endeavour in the plan, learn from the planning process and/or do anything about what's learned:** It should be noted that there is considerable evidence to suggest that individual plans of various kinds (person centred plans included) frequently fail to reflect the real lives of the individuals they purport to reflect and support. See, for example, Shaddock and Bramston, 1991, who identified absence of significant players (including the focus person), specification of goals and action plans in a manner that resists attainment assessment, disregard for (setting of) review date, etc., as factors which can undermine the planning process.
3. **Rhetoric versus action:** It is essential that services not just adopt the language and rhetoric of person centred planning - but that they make a bona fide effort to undertake the hard work required for learning, developing and delivering new ways of supporting people.

Plans need an outcome: how to go about making a person centred plan a reality.

Having completed the essential groundwork of developing a good plan and clearly defining strategies and responsibilities for putting the plan into action, the final key to making a person centred plan a reality is:

1. gathering together the resources/supports identified in the course of planning as necessary for putting the plan into action;
2. moving quickly and in a properly organised, well managed, committed and sustained way, to put them into effect (see, for example: Dunlap and Fox, 1996 and Osgood, 2003).

It should be understood that simply asking people or services to act or change in particular ways – by particular dates, will not be enough. Usually some negotiation of action or changes is needed - and this may take some time, sustained effort and creative thinking. PCP champions or guiding coalitions will need to be prepared to argue the case for action or change in very practical terms e.g. 'SWOT' (the strengths, weakness, opportunities and threats of things as are - or if left as are - **versus** what is proposed) and a costs/benefits analysis of actions or changes required.

Regular review meetings on plan progression can provide the encouragement required to sustain effort, the opportunity to figure out what is and is not working well (and why) and a forum in which to discuss some alternatives to plan implementation strategies which have not been found to be working as effectively as hoped.

7 Monitoring and evaluation.

What is monitoring and evaluation - and why is it necessary?

In the context of person centred planning, monitoring and evaluation essentially means seeking to establish whether person centred planning is being done well and having a positive impact on people's lives.

The term 'monitoring' refers to the initial, inquiry stage in this process and the term 'evaluation' refers to the subsequent careful consideration given to what is found in the inquiry stage and attempt to draw some conclusions from that.

It is generally considered important that at least some monitoring and evaluation be carried out from time to time in relation to person centred planning, in order to establish whether, where and in what ways it is and is not working, so that what is working well can be further developed and what is not working well can be redressed. What is discovered can be used to, for example, better direct service providers' investments, future programme development and future planning efforts – and everyone's efforts across individuals' circle or network of support.

Who should monitor and evaluate?

Usually those involved in a person centred planning venture will carry out some form of monitoring and evaluation exercise. This is referred to as '**internal monitoring and evaluation'.**

Certainly, the individual at the centre of the process should ask themselves whether they are happy with the process, the plan and the working out of the plan. If they are not, they should let everyone know this.

Family, friends and advocates will usually like to know whether the work is being of help to the individual and might want to look at some aspects of person centred planning they feel is not working well or is causing problems for them.

Plan facilitators ought to be interested in finding out whether the way they are supporting the development and working out of plans is helping or whether it might need to be changed or whether plans are being properly followed up.

Service providers should be anxious to learn all they can about how they can make their services more person centred. It is vital that services seek to learn from plans how services need to change - and that they feed this information into their strategic plans.

The broader community should seek to establish whether they are being sufficiently supportive of some particular person centred planning undertaking and learn more about how they might use person centred planning to be more supportive of other people with disabilities in their community; they may also want to find out whether person centred planning might be useful to other members of the community.

Sometimes individuals or organisations entirely external to the planning process may need to find out whether plans have been developed for particular individuals and, if so, how well they are being worked out. This is referred to as **'external monitoring and evaluation'.**

Both types of monitoring and evaluation are important and valid.

Regular external monitoring and evaluation are recommended for gaining an objective perspective on process, plans and outcomes.

It should be noted that capacity to monitor and evaluate will vary considerably across individuals and groups. It is important that the plan facilitator check whether support will be needed by anybody in this regard and arrange that support will be made available where required. (This is particularly important in regard to the person at the centre of the person centred planning process.)

What to monitor and evaluate.

Returning to the definition of person centred planning given at the beginning of this document, the prime objective underpinning any monitoring and evaluation exercise in relation to person centred planning must, clearly, be to establish whether its overall aim of good planning leading to positive changes in people's lives and services (after Ritchie et al, 2003) is being achieved.

To this end, there are two key aspects of person centred planning which require monitoring and evaluation: (1) Plans (because they are the stated means through which person centred planning hopes to achieve this aim); (2) Programmes, processes and supporting structures (because these are the means of generating good, workable person centred plans - and putting them into action).

Each should be evaluated in terms of both objective effectiveness and how it has been experienced.

The quality of a plan can be evaluated in terms of, for example: (1) how well it reflects the individual it is supposed to be about - and their life, vision, needs and desires; (2) how clear, individual and workable it is.

Programmes, processes and supporting structures can be examined in terms of whether, for example:

- all those involved are satisfied with both the planning process and the plans it generates;
- plans are drawn up in such a way that they readily lead to action;
- people are making a real effort to help make the plan a reality;
- there is evidence of a tangible link between person centred plans of people with disabilities and the planning, development and delivery of services for these people;
- services become noticeably more person centred (service providers listen better to people

availing of their services and make genuine efforts to meet their expressed needs);

- services truly contribute to making real, tangible, positive differences to the lives of those availing of them - and not just for the future: today;
- there is a wider spiralling of positive change across all agencies, organisations and services in the broader community such that every individual can find himself or herself in a position to readily engage in and contribute to the mainstream of life to the fullest extent they wish;
- **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.**

This last point is the best measure of the success of person centred planning.

How to monitor and evaluate.

The way in which person centred planning is to be monitored and evaluated should be decided before person centred planning begins. The necessary resources should also be estimated and provided for at this stage and a general process and basic set of indicators agreed. Ways of dealing with any problems that may come up in the course of monitoring and evaluating should be put in place before monitoring and evaluation begin.

A useful starting point for looking at the whole area of monitoring and evaluation in relation to person centred planning might be the UK's NWTDT's 'Framework for reviewing planning', self-assessment of person centred policies and procedures using 'The Agency Self-Assessment of Person-Centred Policies and Procedures Instrument', the UK's Valuing People Support Team's 'How good is our person centred planning framework?' and, of course, seeking to obtain the views of individuals who have been through the person centred planning process, using, for example: the NDA's 'Ask Me Guidelines for effective consultation with people with disabilities'.

An annual review of the overall person centred planning framework can be useful.

In all monitoring and evaluation exercises, it is important to bear in mind the fact that sometimes, less obvious considerations can prove as or more significant than their more obvious counterparts (see, for example: Smale (1996) and Kinsella (2004)). For example: some obvious indicators of person centred planning activity within services would be levels of plan development, the quality of plans developed and the extent to which plans are progressed – but an equally obvious simple count of numbers of plans developed or goals set might not necessarily give an accurate impression of person centred planning activity within a particular service as no account would be taken of the fact that some service

users might not want a plan and others may want to develop theirs slowly, over time.

The opinion of everyone participating in the person centred planning process should be taken into account, where possible. All information gathering and all information gathered should be treated sensitively and confidentially.

In monitoring and evaluating the development, quality and progression of any particular person's plan at any time, it is important to remember that the goals and priorities of an individual can change quite dramatically over time – it is possible that a plan has not been progressed because the person whose plan it is, is, for example, having second thoughts on some particular goals that maybe were a priority for him or her a while ago but are not now.

If monitoring and evaluation exercises are to have practical effects on services provided for people with disabilities, the results of these exercises must be fed back into service planning in a way that takes account of all the practical considerations of person centred planning described earlier - and all of its challenges which must be addressed. Services should adopt an approach to monitoring and evaluation that is sensitive enough to capture the subtleties of each individual plan yet robust enough to manage and aggregate this information in a way that will be helpful to planning for developing the service.

Finally, it is a good idea to monitor and evaluate the way you go about doing your monitoring and evaluation from time to time, to make sure you are doing it properly and well (again, the Irish Evaluation Network refers).

Bibliography

Brost, M, Johnson, TZ and Deprey, RK (1982) **Getting to know you: one approach to service planning and assessment for people with learning difficulties**, Madison, WI: Wisconsin Coalition for Advocacy.

Cole M, Mc.Intosh, B and Whittaker A (2000) **'We want our voices heard' – developing new lifestyles with disabled people**, Community care into practice series, UK: Joseph Rowntree Foundation.

Connolly, C (2001) **Person centred planning and the identification of educational needs for adults with learning disabilities**, Thesis submitted in partial fulfilment of the requirements for the degree of Master of Science in Developmental Disabilities, Centre for the Study of Developmental Disabilities, Faculty of Interdisciplinary and Postgraduate Studies, University College, Dublin.

Department of Health and Children (1999) **Children First National Guidelines**, Dublin: Stationery Office.

Doyle, M and Straws, D (1976) **How to make meetings work**, Chicago: Playboy Press.

Duffy, S (2004) **Keys to citizenship**, UK: Paradigm.

Dunlap, G and Fox, L (1996) Early intervention and serious problem behaviours: a comprehensive approach, in LK Koegel, RL Koegel, G Dunlap, eds., **Positive behavioural support: including people with difficult behaviour in the community**, Baltimore: Paul H Brokes Publishing Co..

Fisk, M and Phillips, D (2000) **Being there: provider and user perspectives on floating support**, UK: Insight.

Fleming, E (2001) **Now that I am older nothing has changed. Is service provision appropriate to the aging person with a disability?**, B.A. in social care, Dublin Institute of Technology.

Forest, M and Lusthaus, E (1989) Promoting educational equality for all students: circles and maps, in S Stainback et al, eds., **Educating all students in the mainstream of regular education**, USA: Paul H Brookes Publishing Co..

Fortune, J et al (2004) Individual budgets according to individual needs: The Wyoming DOORS system, in RJ Stancliffe and KC Lakin, eds., **Costs and outcomes: community services for people with intellectual disabilities**, USA: Paul H Brookes.

Frizzell, E AM (2000) **Quality of life as a foundation for person centred planning in social and vocational rehabilitation services for adults with learning disabilities**, Dissertation submitted in fulfilment of the requirements for the degree of Master of Science in Disability Management, University College, Dublin.

Holburn, S and Vietze, PM (1998) "Has person-centred planning become the alchemy of developmental disabilities? A response to O'Brien, O'Brien and Mount", **Mental Retardation**, December.

Howell, A et al (2004) **Developing a common framework for the introduction of person centred planning in sheltered workshops** – first draft report from the working group.

Irish Evaluation Network (2004) **Proceedings of inaugural annual conference**, Dublin City University.

Jonikas, JA (2004) and Cook, JA, **This is your life! Creating your self-directed lifeplan**, USA: UIC NRTC Self determination series.

Kilroy, R (1987) "Changing the character of corporate America: diversity lessons from the disability movement" in Neuville, TJ, **Unfinished business: the diversity promise - perspectives on moving beyond diversity awareness training**.

Kinsella, P (2000) **What are the barriers in relation to person centred planning?**, UK: Joseph Rowntree Foundation.

Kinsella, P, (2004) **Individual service design – a training and practice guide**, UK: Paradigm - UK.

Mansell, J and Beadle-Brown, J, (2004) "Person centred planning or person centred action? Policy and practice in intellectual disability services & Person centred planning or person centred action? A response to the commentaries", **Journal of applied research in intellectual disabilities**, 17 (1) March.

Mc.Intosh, B (2001) '**Person centred planning: Making it work in the UK**', Topic Papers, No. 6, UK: The Foundation for People with Learning Disabilities.

Mindness, A (1999) **Reading between the signs**, USA: Intercultural Press.

Mindness, A (2003) **Reading between the signs – workbook**, USA: Intercultural Press.

Miner, C and Bates, PE (1997) **Person centred transition planning**, The Council for Exceptional Children.

Mount, B (1992) **Person centred planning: finding directions for change – a source book of values, ideals and methods to encourage person-centred development**, New York: Graphic Futures.

The National Disability Authority and The Department of Health and Children (2002) **Ask Me Guidelines for effective consultation with people with disabilities**, Ireland: NDA.

The National Disability Authority and The Department of Health and Children (2004) **Draft National Standards for Disability Services**.

O'Brien, J (2004) "If person-centred planning did not exist, 'Valuing People' would require its invention", **Journal of applied research in intellectual disabilities**, 17 (1) March.

O'Brien, J and O'Brien, CL, eds., (2000) **A little book about person centred planning**, Canada: Inclusion Press.

O'Brien, J and Towell, D (2003) **Building local capacity for person centred approaches, notes on workshop experiences**.

Osgood, T (2003) '**Never mind the quality, feel the width!' – person centred planning implementation and developmental disability services … a polemic of unease**.

Radcliffe, R and Hegarty, J R (2001) **An audit approach to evaluating individual planning, British journal of developmental disabilities**, 47 (93), pp. 87-97.

Ritchie, P et al (2003) **People, plans and practicalities – achieving change through person centred planning**, Scotland: SHS, Scotland.

Routledge, M and Gitsham, N (2004) "Putting person centred planning in its proper place, 'Valuing People' Update", **Learning Disability Review**, 9 (3) July.

Sanderson, H (2000) **Person centred planning – key features and approaches**, UK: Joseph Rowntree Foundation.

Sanderson, H and Kilbane, J (1999) **Person centred planning - a resource guide**, UK: NWTDT.

Sanderson, H et al (2002) **People, plans and possibilities: exploring person centred planning**, Scotland: SHS.

Shaddock, A (2000) **Person-directed planning: where is it going and is it a good place to go?**, Paper presented at the 8th National Joint Conference of the National Council on Intellectual Disability and the Australian Society for the Study of Intellectual Disability, October 22-25, Fremantle, Western Australia.

Shaddock, A and Bramston, P (1991) "Individual service plans: the policy-practice gap", **Australian and New Zealand Journal of Developmental Disabilities**, 17 (1) pp. 73-80.

Shelton, T et al (1987) **Family-centred care for children with special health care needs**, USA: Washington, D.C.'s Association for the Care of Children's Health.

Smale, G (1996) **Managing change through innovation**, London: HMSO.

Smull, M (1996) **Person centred planning: should we do it with everyone?**, Maryland: Support Development Associates.

Turnbull, A et al (2000) “Evolution of family-professional partnership models: Collective empowerment as the model for the early 21st century”, in JP Shonkoff & SL Meisels, eds., **The handbook of early childhood intervention**, second edition, New York: Cambridge University Press.

Walls, M (2002) ‘**Building Blocks to best practices in people centred services**’, Ireland: National Federation of Voluntary Bodies.

Yates, J (1980) **Program design sessions: OOP (optional operating procedure)**, USA: Carver.

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:

- **Plain English (Jargon Free);**
- **Easy-to-Read Summary;**
- **Large Print;**
- **Audio Tape;**
- **Braille.**

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