

**Research on current practice to inform the
development of a national framework for
person-centred planning in disability services**



**Údarás Náisiúnta Míchumais
National Disability Authority**



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Table of Contents

1. Executive Summary	5
1.1. Background.....	5
1.2. The case studies	5
1.3. The key informant interviews	6
1.4. Supports and Barriers	6
1.5. Areas for improvement	9
1.6. Key findings in relation to good practice	10
2. Introduction.....	13
3. Background Information.....	15
3.1. Case Studies	15
3.2. Ethics.....	18
3.3. Key Informant Interviews.....	21
4. The Case Studies	23
4.1. Emily.....	24
4.2. Aoife	29
4.3. Tom.....	34
4.4. Katherine	39
4.5. Jenny	45
4.6. James.....	50
4.7. Niamh	55
4.8. Michael	61
4.9. Jack.....	67
4.10. Ciara	73
5. Findings from the key informant interviews	78
5.1. Emerging Themes.....	79
5.2. Environment.....	79
5.3. Culture and Ethos.....	80
5.4. Learning and Development.....	83
5.5. Plan Facilitation and Goal Setting	85
5.6. Evaluation.....	90

6. Key findings in relation to supports, barriers and good practice in person-centred planning	92
6.1 Key supports and barriers	92
6.2 Areas for improvement	96
6.3. Findings in relation to good practice	97
7. References	101
Appendices.....	102
Appendix 1 - Information provided in the call for expressions of interest – Case study research	103
Appendix 2 - Survey Monkey profile questions – Expressions of interest.....	106
Appendix 3 - Topic frameworks	110

I. Executive Summary

I.1. Background

The New Directions Working Group has identified the need for a national framework to support the implementation of a consistent approach to person-centred planning in disability services. The framework is being developed under the HSE Transforming Lives programme.

For people receiving disability support services, and particularly those in full-time residential services or in day support programmes, person-centred planning is a key process to focus delivery of services and supports with the individual. It underpins the New Directions model of personal support services for people with a disability.

This research project is one of three strands of research being carried out; the other two are a literature review and an analysis of what HIQA inspection reports say about person-centred planning in residential services.

This strand focuses on person-centred planning (PCP) systems and models in current use in Irish disability services, in order to inform the development of the new framework for person-centred planning. This piece of research also providing valuable information for key stakeholders in relation to the types of supports required to achieve good practice, and the key barriers and challenges faced in the development and implementation of person-centred plans.

There are two main elements to this project – the case studies and the key informant interviews.

I.2. The case studies

Ten case studies were undertaken to look at current practice in person-centred planning. For each case study, the research team set out to conduct semi-structured interviews with:

- the person who is the focus of the person-centred plan
- their keyworker or plan facilitator
- a family member or member of the circle of support
- the Person in Charge(PIC) or service manager

People with physical disabilities, sensory disabilities, intellectual disabilities, autism and acquired brain injury were included in the project. Individuals who communicate in different ways were supported to participate and to express their opinions. The research team analysed the data for key themes and sub-themes in relation to the PCP process, for evidence of the supports and barriers experienced, and for examples of good practice.

In particular, participants commented on the importance of the quality of relationships between the person who owns the plan, the plan facilitators and those supporting the implementation of the plan.

They highlighted the importance of motivated and resourceful facilitators and staff members. They emphasised the importance of organisational culture; organisational values, expectations, willingness to change and the influence of good management and leadership on the PCP process.

A number of consistent examples of good practice were highlighted across the ten case studies. These are outlined later in this executive summary and will be important to inform the development of the national framework.

1.3. The key informant interviews

Interviews were conducted with four key informants from HIQA and the HSE's Quality Improvement Division/ Social Care Division-Quality Improvement Programme. The key informant interviewees drew on their experience of person-centred planning (PCP) across a range of different residential settings, service providers and geographical locations. This included congregated settings and smaller community houses. The interviewees noted that in their experience, there is extensive variation in practice across the country and expressed the view that the quality of person-centred plans tends to be poor. In particular they highlighted the effects of poor living environments, negative organisational cultures, low staff morale, poor governance and leadership, and inadequately managed resources on the PCP process. The interviewees expressed concerns in relation to staff education and skill mix, and the quality of the systems developed for facilitating plans, goal setting, and evaluating outcomes.

1.4. Supports and Barriers

The key supports and barriers to person-centred planning which emerged consistently in both the case study interviews and the key informant interviews were identified. These were grouped into those at the organisational and at the personal level.

1.4.1. Key Supports at organisational level:

1.4.1.1. Organisational culture and ethos

- Organisational cultures including values espoused; respect for individuality, dignity, empowerment, choice, independence, community participation, active citizenship
- An enabling culture and ethos where the focus is on achieving quality of life outcomes for each person
- High expectations of individuals and a respect for the talents and lived experiences of each person
- Strong, confident leadership
- Proactive management; open, willing to listen, ambitious, encouraging and eager to problem solve
- Leaders are intolerant of poor practice
- Leaders and systems support the effective management of resources

1.4.1.2. The Regulations and Standards

- Within residential services, HIQA inspections and the Regulations; more focus on person-centred planning, awareness of the need for quality plans, more formal systems, improved standards of practice

1.4.1.3. Systems of review

- A system is in place for reviewing plans on a regular basis

1.4.1.4. Access to information technology and assistive technology

- Access to assistive technologies
- Access to everyday IT supports (internet and broadband, digital camera, video camera, laptop, colour printer, symbols database, PowerPoint, projector)
- The provision of accessible information

1.4.1.5. Staff skills

- Creative, resourceful and motivated facilitators and staff teams
- Opportunities for learning and development in relation to person-centred planning for staff and managers

1.4.2. Key Barriers at organisational level:

1.4.2.1. Lack of understanding of person centredness and person-centred planning

- A lack of understanding within the organisation of person-centredness and what person-centred planning means

1.4.2.2. Fear and resistance to change

- A lack of flexibility, fear and resistance to change - this can come from management, staff teams or individual staff members, clinicians or the community
- Industrial relations and Human Resource issues; in particular around roles, rosters and performance management

1.4.2.3. The skills of leaders and managers

- Some managers and service providers may not have the capacity (understanding, motivation, expertise) to make the necessary changes required to deliver high quality person-centred plans
- Organisations and managers that are too focussed on HIQA Regulations, to the detriment of other aspects of service delivery, including person-centred planning. Some Regulations seem 'over-protective' and work against providers establishing a culture of positive risk-taking as staff become more risk aware and sometimes risk averse

1.4.2.4. Systems and structures

- There can be over-reliance on paperwork and templates. The focus can then be on the system and administration rather than on the person. There is a risk that more time is spent on paperwork than with the person
- Financial systems, policies and budgetary constraints can restrict the amount of control and choice individuals have

1.4.2.5. Lack of funding and resources

- Lack of funding at the organisational level (for example staffing, resources, equipment) can impact on the quality of the plans produced
- Limited personal finances and budgets can also restrict person-centred planning (for example opportunities for holidays and to attend events)

1.4.2.6. Access to multi-disciplinary team (MDT) supports

- There can be very limited access to MDT supports which can impact on a number of aspects of the PCP process including assessments of need, staff learning and development, making the PCP process accessible.

1.4.3. Key Supports at a personal level:

1.4.3.1. Relationships

- Quality relationships between the person who owns the plan, the plan facilitators and those responsible for supporting the implementation of the plan
- Time and space for the individual to develop relationships and an understanding of the process
- Opportunities for one-to-one time between the person who owns the plan and the plan facilitator

1.4.3.2. Communication

- Good communication between the person who own the plan, staff in day and residential services, management, family members and external stakeholders

1.4.3.3. Family involvement

- The support and involvement of family members; attendance at meetings, phone contact, practical support to work on goals, advocating for the individual, sharing information and ideas

1.4.3.4. Learning and development

- Opportunities for learning and development in relation to person-centred planning for people using services and their families

1.4.3.5. Stimulating environment

- A pleasant, stimulating environment

1.4.4. Key Barriers at a personal level:

1.4.4.1. Poor environments

- Poor environments impose restrictions such as lack of opportunities for community participation and the development of circles of support which limited chances for meaningful engagement in activities. Poor environments also reduce motivation towards person-centred planning

1.4.4.2. Fear and resistance to change

- Fear or a resistance to change from the person who owns the plan
- Lack of motivation from the person who owns the plan - for a variety of reasons such as lack of trust, lack of understanding of the system, previous experience, low expectation of self or the system, mental health difficulties
- Families may present barriers, particularly in relation to risk taking, new experiences or independence

1.4.4.3. Transport

- A lack of accessible public transport, particularly in rural areas. Difficulties travelling beyond short distances, travelling at night and travelling independently.

1.5. Areas for improvement

Participants consistently identified a number of areas where improvements could be made in order to improve the PCP process:

- The systems of governance across the disability sector need to be reviewed - organisational planning, performance management, leadership, communication
- The link between person-centred plans and service development should be more obvious
- There needs to be more thorough evaluation of the PCP process and plans; there is a need for more formal systems of process and outcome measurement
- There is very limited use of software or business systems to record or evaluate PCP information – services are heavily reliant on paper systems
- There needs to be more learning and development opportunities for people using services, their family members and members of the community
- Any learning and development opportunities provided through internal supports or external facilitators should be fully evaluated
- There is limited access to external advocacy services and supports
- There is a need to create awareness and establish relationships with community services and supports
- Community members and supporters from outside the service should be included in circles of support

- The provision of accessible transport needs to be addressed to enable people with disabilities to contribute fully to their communities.

1.6. Key findings in relation to good practice

Across the ten case studies, a number of principles and elements of good practice were consistently observed. These include:

1.6.1. Principles

- Each person is respected as an adult
- Each person is regarded as an individual with their own personhood, sense of self, skills and talents
- There are high expectations of each person, of the PCP process and of the outcomes that can be achieved
- Everyone is considered to have the capacity to make choices and decisions about their plan
- Each person is viewed as having a role to play in their local community.

1.6.2. Organisational structures and practices

- The PCP process emphasises the person's needs, wants and dreams
- There is a PCP policy in place across the service, which is evidence based
- Individual plans can influence service development and the allocation of resources
- Leadership: senior management teams are aware of person-centred plans as they relate to the individual, have an understanding of the supports required and barriers that exist in their service areas, are open to discussion and debate and strive to achieve good practice standards across the service
- There are arrangements in place for performance management, supervision and/or appraisal for staff and managers; staff are accountable for their work, feel valued and supported
- Good practice is recognised and championed
- Organisations engage in positive risk taking and have risk assessment and management policies in operation
- There is a transparent process for reviewing progress and evaluating outcomes
- Internal audits are conducted on a regular basis and address person-centred plans, goal setting and outcomes
- There is a mechanism for issues and complaints to be channelled 'up the line' to the senior management team.

1.6.3. Involving the person who owns the plan and their supporters

- The person who owns the plan is the lead facilitator wherever possible
- The person who owns the plan is involved in all aspects of the process
- The plan facilitator knows the person well or takes time to get to know the person, understands how they communicate, is observant and attentive, is organised and motivated, knows how to gather and record evidence, can reflect on their practice, is willing to learn and to be an advocate for the individual
- Plans are developed with the individual. Where the individual cannot communicate their choices and/or where decisions are made on their behalf, they are based on the consensus of the different people who engage with them on a regular basis, and not just on the perspective of one facilitator
- Staff, family members and those involved in circles of support have a clear understanding of what person-centredness means and are aware of their specific role in the PCP process.

1.6.4. Developing the plan

- Person-centred planning is a continuing process and not an annual event. Information is gathered with the person throughout the year and there are opportunities for constant review, reflection and evaluation to ensure the plan meets the needs and wishes of the individual
- The process is accessible to the person who owns the plan and takes into account their communication and literacy needs. Where necessary, a Total Communication approach is used which includes objects, photos, pictures, symbols, video and assistive technologies appropriate to the individual needs of the person. The person who owns the plan holds the main copy of the plan in a format which is accessible to them. The service provider will have a copy of the plan
- The individual and their supporters can access the expertise and advice of members of the MDT team if they need to. They can also access specialist supports if they wish
- Person-centred plans focus on the personal goals and aspirations of the individual. While a person-centred plan will be informed by a person's medical, clinical and care needs, they should not be the focus of a person-centred plan. In some exceptional cases where the individual is facing significant physical or mental health difficulties, goals related to health and well-being may be appropriate for a period of time
- Activities of daily living do not constitute goals. Again in exceptional circumstances more basic goals may be appropriate for a period of time but there should be clear evidence of progression for the individual as time goes on
- Achievements and outcomes are recognised and celebrated.

1.6.5. Implementing the plan

- There is an action plan which consists of a set of SMART goals
- Long-term goals are broken down into a series of smaller steps
- Those responsible for supporting the person to achieve their goals are clearly identified.
- There is a defined timeframe for achieving the goals
- Where difficulties arise in the implementation of the plan, the issues are addressed initially at the local level. If barriers persist, information is fed up the organisation and the advice and support of management sought
- A step by step approach is taken in relation to risk-taking. This approach encourages and enables the individual to gradually build the skills necessary to partake in different tasks, activities and experiences. Management support the positive risk-taking. Family members are given the necessary time and supports to contribute their ideas and to allay any concerns they might have.

2. Introduction

This research project focuses on person-centred planning (PCP) systems and models in current use in Irish disability services, in order to inform the development of a new national framework for person-centred planning. It is intended that this framework will build on the 'Guidelines on Person-Centred Planning in the Provision of Services for People with Disabilities in Ireland', published by the NDA in 2005. The framework is being developed under the HSE Transforming Lives programme.

A series of Working Groups have been convened to advance the implementation of the Transforming Lives programme. For people receiving disability support services, and particularly those in full-time residential services or in day support programmes, person-centred planning is a key process to focus delivery of services and supports with the individual. It underpins the New Directions model of personal support services for people with a disability.

There are two main elements to this project:

- Ten case studies looking at person-centred plans which illustrate good practice and positive outcomes for individuals
- Interviews with key informants including HIQA and the HSE's Quality Improvement Division/ Social Care Division - Quality Improvement Programme¹, to get perspectives on how person-centred planning is operating in practice in Ireland.

The NDA Guidelines² define person-centred planning as a way of discovering:

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

A number of different terms are used in disability services to refer to different types of plans. There is a requirement in the standards and regulations for residential services for each person to have a 'personal plan'. For the purpose of this report, the term 'personal plan' is used to refer to documents and folders which contain a range of different types of information, for example communication passport, care plan, assessment of need and person-centred plan.

¹ The HSE Quality Improvement Division/ Social Care Division - Quality Improvement Programme work with residential services for adults with ID to advise and support the enhancement of structures and processes to improve the delivery of quality and safe person-centred outcomes and services

² The National Disability Authority guidelines on Person-centred Planning (2005) (<http://nda.ie/Good-practice/Guidelines/Guidelines-on-Person-Centered-Planning/Guidelines-on-Person-Centred-Planning-format-versions/main.pdf>)

The term 'person-centred plan' is used specifically to refer to a document which focuses on the individual's goals and aspirations, and the process involved in achieving these. 'Person-centred plans' are the focus of this element of the research.

The New Directions Working Group has identified the need for a national framework to support the implementation of a consistent approach to person-centred planning in disability services. It is expected that an agreed national framework for person-centred planning will support disability services to consistently achieve good practice, and therefore support the achievement of positive outcomes for people who use those services. This piece of research will inform the development of the framework whilst also providing valuable information for key stakeholders in relation to the types of supports required to achieve good practice, and the key barriers and challenges faced in the development and implementation of person-centred plans.

This research project is one of three strands of research being carried out; the other two are a literature review and an analysis of what HIQA inspection reports say about person-centred planning in residential services.

Ten people with disabilities and their supporters took part in the case study research. People with physical disabilities, sensory disabilities, intellectual disabilities, autism and acquired brain injury were included. The participants engaged enthusiastically, sharing their plans, views and ideas. Individuals who communicate in different ways were supported to participate in the interviews and to express their opinions. Four key informants participated in the project – two from HIQA and two from the HSE.

Section two of this report provides information on the research methodology employed in the different elements of the project. Section three comprises of a description of each case study. In Section four, the main findings from the key informant interviews are outlined and the key themes identified.

In Section five, the main supports and barriers to person-centred planning, as identified by the case study participants and key informant interviewees, are outlined. The areas highlighted for improvement are also summarised. The report concludes with a summary of the key recommendations from the case studies in relation to good practice in person-centred planning.

3. Background Information

The research team set out to ensure that the highest quality standards were maintained and best practice was followed throughout the research process.

3.1. Case Studies

3.1.1. Recruitment process

A convenience sampling method was employed to recruit participants for the case study interviews. The HSE sent a call for expressions of interest to organisations that had previously responded to a HSE benchmarking survey, confirming that they had PCP in place and that they were willing to share learning. Expressions of interest were sought from individuals willing to share their person-centred plans as examples of good practice. The expressions of interest request specified that potential participants should have experienced positive outcomes arising from person-centred planning and have completed a review process.

An information sheet (appendix 1) was prepared and circulated to this agreed list of service providers. At the initial stage, individuals and providers were asked simply to provide a profile of the individual and their plan (no names were required). The profiles were submitted through Survey Monkey (See appendix 2). In total 23 profiles were submitted from eleven different service providers, from which ten were chosen. All those who submitted profiles were contacted and advised if their profile had been chosen or not.

3.1.2. Case study selection

The PCP Working Group set out a range of variables which were considered in the selection of the ten case studies. These included gender, urban and rural settings, age, type of provider, type of service, type of disability, and the PCP tools and processes used.

Tables 2.1, 2.2, 2.3, 2.4, 2.5, 2.6 below give a breakdown of the participant profiles.

Table 2.1 Gender

Gender	Female	Male
Number of participants	6	4

Table 2.2 Urban and Rural settings

Setting	Urban	Rural
Number of participants	6	4

Table 2.3 Age

Age	Under 25 years	26-50 years	Over 50 years
Number of participants	3	5	2

Table 2.4 Type of Provider

Type of Provider	Voluntary – ID & Autism	Voluntary – Physical & Sensory	For Profit	HSE
Number of participants	5	2	1	2

Table 2.5 Type of Service

(Some participants are included in more than one category as they receive both residential and day support services)

Type of Service	Residential (10 + residents)	Residential (5 to 9 residents)	Residential (1 to 4 residents)	Day support service	Clinical Team support
Participants (P) Total Number = 10	1	4	1	8	1

Table 2.6 Type of Disability

(As identified by service providers in the profiles submitted during the recruitment process)

Type of Disability	Complex Physical Disability	Physical Disability	Sensory Disability	Mild to Moderate Intellectual Disability	Severe Intellectual Disability	Autism or Asperger's syndrome	Acquired Brain Injury
P1		*		*			
P2				*			
P3							*
P4			*		*		
P5			*		*		
P6						*	
P7		*	*				
P8						*	
P9				*			
P10	*			*			

Although some providers identified in the initial profiles that they used a specific PCP tool or approach, it became apparent during the interviews that every provider was in fact using a combination of different tools and approaches, along with internally designed templates and guides.

3.1.3. Interviews

For each case study, the research team set out to conduct semi-structured interviews with:

- the person who is the focus of the person-centred plan
- their key-worker or plan facilitator
- a family member or member of the circle of support
- the person in charge (PIC) or service manager

The research team liaised with each participant and service provider to select the most appropriate date, time and venue for the interviews. All participants were sent an email confirming the date, time and venue for their interview.

At least one family member participated in six of the ten interviews. One individual did not want their family member to participate, whilst in other cases family members were unavailable to attend the interview. In all cases, family members who had expressed an interest in participating but could not attend, were offered the option of a phone interview. None of the families took up this offer. In one service, the service manager was unavailable to participate.

Participants were asked if they would prefer to be interviewed on their own, with one supporter, or as a group. All chose group interviews.

A topic framework and interview schedule were developed (See appendix 3), in consultation with the PCP Working Group. The research team also utilised new learning from the literature review and the analysis of HIQA reports to inform the development of the topic framework and interview questions.

The research questions focused on:

- the development process of person-centred plans
- the implementation of person-centred plans
- service level issues such as organisational culture (i.e. mission, strategy, espoused values and beliefs, taken-for-granted norms and assumptions, quality of leadership, relationships, learning)
- systems in place (i.e. structures, processes, pathways, staffing, recruitment, planning, resources) in the service provider which may influence the person-centred planning process.

One researcher conducted all the interviews to ensure consistency. Open ended questions were used where possible. A range of communication supports and conversational strategies were employed to ensure maximum engagement with participants. The researcher provided Total Communication supports³ where necessary and appropriate. Where participants were willing to share their person-centred plan with the researcher, they were given the opportunity to lead the discussion and talk about the elements of the plan that were important to them. The visual/accessible nature of some plans provided a joint focus for conversation.

3.1.4. Data collection and analysis

The data, which was organised manually, consists of written notes, audio recordings and memory based analysis. All case studies and participants were given a code. The confidentiality of all participants was protected and identities will remain anonymous. Service Providers, participating in the case study research, are not identified in this report. Data was stored securely for the duration of the project. All notes will be destroyed once the project is fully completed, with the approval of the NDA and the Working Group.

The researcher analysed the data to establish common themes and patterns, to explore evidence of the barriers and supports experienced, and to identify examples of good practice. The analysed data was reviewed by a second researcher to reduce subjectivity and provide additional insight.

The research team were mindful that the purpose of the research is to help develop a national framework to support the implementation of a consistent, good practice approach to person-centred planning in disability services. The findings in relation to current practices in person-centred planning in Ireland will inform which elements of the person-centred planning framework may need particular focus, emphasis, or an additional level of detail.

3.2. Ethics

Ethical approval was sought for all ten case study interviews. Providers were asked to identify at the expression of interest stage, if they had a Research Ethics Committee in place in their organisation.

³ “Total communication is a process that ensures that all forms of verbal and non-verbal communication are recognised, valued and actively promoted within an individual’s environment...The tools of total communication are gesture, body language, signing, facial expression, objects of reference, photographs, drawings, symbols, written words, vocalisation, intonation, verbalisation and access to modern technology. It is focussed on individuals and an awareness of and ability to use whatever is right for an individual - inclusive of all” (Royal College of Speech and Language Therapists (2016) Position paper – Inclusive Communication and the Role of Speech and Language Therapy).

Research Ethics applications were sent to committees in three different providers. All granted approval for the project. In the absence of Research Ethics Committees, ethical approval was obtained as follows:

- through a Strategic Management Group (one organisation)
- through the Board of Directors (one organisation)
- through Senior Management (four organisations)

External oversight in relation to the ethical procedures in this study was provided by Dr. Suzanne Guerin from the School of Psychology at University College Dublin.

3.2.1. Stage 1 consent – Expressions of interest

Easy to Read and Plain English introductory leaflets and consent forms were prepared and distributed with the call for expressions of interest (appendix 4). These were designed to support individuals to give informed consent for their profiles to be forwarded to the NDA.

A staff member, familiar to the individual, provided the introductory information on the project for the person to consider. The introductory leaflet included a contact number for a staff member in the NDA. This provided potential participants with an independent contact if they had any questions. A question was added to the Survey Monkey form to remind service providers to gain consent before profiles were submitted to the NDA.

The research team worked with a small consultation group of people with disabilities to develop these consent materials.

3.2.2. Stage 2 consent – Case study interviews

The consultation group also developed consent materials and visual supports for the case study interviews (appendix 5), and reviewed the language of the interview questions. Once the ten profiles were selected, the second set of consent materials were distributed to potential participants. The consent information ensured that participants:

- understood what the project is about
- understood key information about the interview
- understood who was to be involved in the interview process
- were aware that they had a choice to participate or not
- understood that they could change their mind at any time
- understood that they could leave the interview at any time
- understood how the data was stored and used

Each service provider was asked to identify one staff member to support participants to engage with the consent process and materials. Again, participants were given a contact number for the researcher and for a member of staff in the NDA, so they could request further information or ask questions. Participants were given as much time as necessary to decide if they wanted to take part or not.

Two participants were unable to give consent in a formal manner. Their family members and supporters felt these individuals would like to take part in the process, and had valuable experience to contribute to the project. They provided proxy consent formally, completing the consent checklists alongside the individuals concerned. The supporters made the researcher aware of the different modes of communication used by the participant to indicate distress or unease. Consent was considered an ongoing process. The researcher met with these individuals and engaged with them in relation to their plan. The individuals sat in on the interviews for as long as they wished and their responses to the discussion were observed and noted. It was agreed at the outset that if the individual became uncomfortable or upset in any way, the interview would be terminated. Supporters provided information on their behalf and continually attempted to include and engage the individual in the discussion.

In the case of the remaining eight participants, the research team liaised with an identified staff member prior to each interview to ascertain the communication, behavioural and medical support needs of the participant. Again consent was considered an ongoing process. The key points in the consent checklist were reviewed with participants on the day of the interview. Participants chose which information they wanted to share with the researcher, had control over their person-centred plan throughout the interview and decided which questions they were willing to answer.

All participants were given the opportunity to take a break and/or leave the room at any stage during the interviews.

3.2.3. Management of risk

The research team were aware of the possible risks of inconvenience and disclosure. The team took a number of steps to reduce these risks.

The research team tried to reduce the risks of inconvenience to participants by offering flexible dates and times for the interviews, and by allowing participants to determine the venues. Participants also had the option to stop the interview at any stage.

Service providers and participants were asked to put forward plans which they felt were of a high quality and showed positive outcomes. However, the research team acknowledged that there was a possibility of distress occurring for the participant during the interview process. This was due to the personal nature of the interview and the questions being asked. Participants were advised that if they disclosed any information during the interview, which made the research team concerned that people were unsafe, then the team would have to tell someone who could help the participant. The researcher asked the service providers to identify a support person who could be called upon if the individual experienced anxiety or distress during the interview. The researcher also committed to make every effort to direct the participant to the most appropriate source of support either internally or externally

The researcher also sought the name of a person responsible for safeguarding in the service provider prior to interviews.

3.3. Key Informant Interviews

3.3.1. Recruitment process

The PCP Working Group engaged bilaterally with key stakeholders. Two organisations were approached to participate in the key informant interviews – HIQA and the HSE. The HSE Quality Improvement Division/ Social Care Division- Quality Improvement Programme nominated participants to take part in this research. HIQA have an overview of residential services for people with disabilities in relation to inspections, and the HSE programme has an overview of HSE residential services and supporting quality improvements in residential services. Each organisation nominated two members of staff to take part in the interviews. All four consented to participate.

3.3.2. Interviews

The semi-structured interviews were conducted at a date, time and venue of the interviewee's choosing. In all four cases, the individual interviews were conducted in the workplace of the interviewee, over a time period of approximately ninety minutes.

The research questions in this element of the process focused on gathering information from the four interviewees on current practice in disability residential services. For example:

- current areas of good practice
- gaps in current practice
- positive risk taking in the context of person-centred planning
- the scope of person-centred plans
- common areas of misunderstanding in relation to person-centred planning
- areas that are identified as key challenges
- practices identified in the sector that support people to achieve goals or outcomes.

3.3.3. Data collection and analysis

The data, which was organised manually, consists of written notes and memory based analysis. All participants were given a code and their identities will remain anonymous.

Using Thematic Analysis, the research team identified the key themes and sub-themes in the data.

Research on current practice to inform the development of a national framework for person-centred planning in disability services

Data from the four interviews was stored securely for the duration of the project. All notes will be destroyed once the project is fully completed, with the approval of the NDA and the Working Group.

4. The Case Studies

This section provides a description of each of the ten case studies undertaken as part of this project. The specific findings in relation to each person-centred plan, and the practices and processes involved in its development and implementation, are outlined. The names of participants have been changed to safeguard their privacy.

Some participants brought their 'personal plans' and 'person-centred plans' to the interviews. A number of different terms are used in disability services to refer to different types of plans. There is a requirement in the standards and regulations for residential services for each person to have a 'personal plan'. For the purpose of this report, the term 'personal plan' is used to refer to documents and folders which contain a range of different types of information, for example communication passport, care plan, assessment of need and person-centred plan. The term 'person-centred plan' is used specifically to refer to a document which focuses on the individual's goals and aspirations, and the process involved in achieving these. 'Person-centred plans' are the focus of this element of the research.

4.1. Emily

Emily is a female over 50 years of age, living in a residential service in an urban setting in the north of the country. She has a mild to moderate intellectual disability.

Emily was accompanied at the interview by her sister and brother-in-law, keyworkers from her day and residential services, a manager from her day service and the service manager.

Emily communicates verbally. She also uses visual supports to get and give information, for example pictures and photographs.

4.1.1. Services and supports

Emily lives in a community residential house with between 5 and 9 individuals, and attends a local day service. She receives both her residential and day services from one service provider. The provider is a small voluntary organisation providing services for people with intellectual disability and autism. The day service is a new service development, and the service manager explained that it provides community based supports in line with New Directions. The interviewees reported daily communication between the residential and day services, and regular contact with Emily's family.

There is a PCP model and policy in place across the organisation which was developed internally by reflecting on existing practice, identifying what was working well, and building on this. There is no specific PCP tool in use, however some members of staff completed the PATHS training programme and this has influenced their practice. There is no quality assurance system in operation in the organisation at this time. The residential service had a HIQA inspection in 2015 and the service manager noted that the feedback on person-centred plans was positive with no changes requested.

4.1.1.1. Culture of the organisation

Overall the consensus of the group was that the culture of the organisation is 'positive' with 'a focus on each individual person'. Communication within the organisation, and between the organisation and families, was noted to be 'very good', 'honest' and 'open'. The Board of Management were described as 'supportive' and 'willing to listen and respond'. The organisation was originally established by a parents and friends association. Person-centred planning is viewed as an ongoing process rather than an annual event and is central to the provision of services and supports. The interviewees described how the organisation is trying to build a culture where staff are clear on their roles and on the importance of person-centredness.

4.1.1.2. Positive risk taking

The service provider is working to establish a culture of positive risk taking. They identified that this is 'a work in progress' and they are keen to promote the values of community inclusion and active citizenship.

4.1.1.3. Facilitators

Emily is supported by facilitators in her day and residential services to develop a person-centred plan. The keyworker in the residential service is the lead facilitator along with Emily. Emily is involved in every aspect of the development of the plan. The facilitators know Emily well and the quality of these relationships was identified as an important factor in the development of a good plan.

4.1.1.4. Learning and Development

The organisation has not provided any formal learning and development for staff in person-centred planning in the past two years. As previously mentioned some staff completed the PATHS training programme and use some of its principles. Emily has some experience of participating in a self-advocacy group, and has completed a number of QQI level three modules relating to personal development. The organisation tries to make information accessible to people using its services by providing Easy to Read information and policies.

There is no formal education offered to families in relation to PCP, however they have had the opportunity to attend open days where topics have included person-centred supports.

4.1.2. The PCP meeting

Emily has a PCP meeting every year which she plans and organises with her keyworker. Emily decides when and where to have the meeting; this is entirely the choice of the individual and the venue could be her home or a local hotel. Emily and her keyworker try to select a date and time which will suit her family to facilitate their involvement. Emily noted the importance of having family at her meeting.

Emily decides who to invite to her meeting; usually this is family, keyworkers from day and residential services, and managers. Members of the Multi-Disciplinary Team (MDT) are invited if they are actively supporting Emily; they are rarely available to attend but they do provide written information if this is required for goal setting or evaluation.

The annual meeting is a 'special event' with tea and treats. Staff note that the process is 'improving every year'. Emily explained that the PCP meeting is 'something to look forward to'.

Achievements and outcomes are recognised and celebrated with photos, pictures and mementoes used to support Emily to recall and share information; these represent activities, events, family occasions, important places, goals and achievements. Emily's brother in law helps to gather the photographs.

4.1.2.1. Family involvement

Emily has regular contact with her family, visiting them often. Family members described how they attend Emily's PCP meeting every year. They noted however that they don't have to wait for an annual meeting to get information or to put their ideas forward. They explained that the 'door is always open' and they can approach staff, the PIC or the service manager if they have any concerns or questions.

The family expressed the view that they have a key role to play in supporting Emily to achieve her goals. They described Emily as ‘an independent liver’ who sets her own agenda and they are ‘happy to fit in to her schedule’.

The family feel well supported by the service provider and commented particularly on the supports they received during times of transition and family bereavements.

4.1.3. The content of the plan

Information is gathered prior to the PCP meeting and throughout the year. There is a PCP template in use in the organisation to record relevant information. Staff keep a written copy of the plan, information on goals, and progression notes in an individual PCP folder. Emily has her own copy of the PCP plan in an accessible format with photos, Easy to Read goals, her personal timetable and communication passport. Emily keeps this in her locker. It is very evident that Emily is familiar with all aspects of the plan and the goals set.

Emily is encouraged to aim high, to share her dreams and wishes, and to focus on new experiences and events. She has the opportunity to reflect on current practice and to think about ‘what I want to do’. There is evidence in her plan of outcomes and previous accomplishments in both written and photographic forms. Emily explained that her plan is also a way to maintain current routines that are important to her:

“I know what I want. Sometimes I want nothing changed. I don’t like change. That is important too.”

The plan addresses:

- big life issues; employment, supports to maintain a job (Emily works in a Chemist one day a week)
- everyday choices and activities; knitting, cooking, exercise, daily schedule, religious and spiritual needs
- building independence and skills; educational and career opportunities such as computer skills training
- community participation and social roles; using community facilities, working in the local community, relationships
- treats and occasional outings; trip to Lourdes, meal at a Chinese restaurant.

Emily explained that she ‘likes to pick her own goals’. Her supporters talked about the importance of ‘ownership of the plan’ and individual autonomy and choice.

The person-centred plan contains an action plan and those responsible for supporting Emily to achieve her goals are identified here. The action plans include short and long term goals which are discussed and agreed with Emily.

4.1.3.1. Positive risk taking

A positive risk taking approach was noted in relation to Emily taking up employment. Supporters had worked together to identify and overcome barriers including medical risk.

4.1.3.2. Community participation

Emily participates in her local community and uses many of the facilities in the local town and surrounding area. Emily works locally and is in contact with the public as part of her job. As a result she is well known and engages regularly with members of the community. The new day service is trying to further develop opportunities for inclusion and participation, and is located in a community building with a number of other stakeholders.

At the moment, members of the local community do not form part of Emily's circle of support. Most of the supports required by Emily to achieve her goals are provided from within the service, with the exception of education and lifelong learning supports. These are provided by the local Education and Training Board, for example accredited and non-accredited courses.

4.1.4. Reviewing the plan

There are formal monthly reviews of Emily's plan with the key information and outcomes shared with the relevant people. These meetings usually take place in the residential service and involve Emily and her keyworker. Family members can input into these reviews if appropriate.

Usually reviews are scheduled by the keyworker, however Emily or her family members can request a review of the plan at any stage.

If the process is not going well and goals are not being achieved, this is raised with the service manager. The interviewees described how they 'work together' at a local level to identify and overcome any obstacles. The service manager can channel any major issues to the Board where they will be addressed. It was noted that where money or other resources are a major barrier to an individual achieving their goals, they are almost always found. There is a formal complaints procedure in the organisation which people using the service, their families and staff can use if they are unhappy with any aspect of the service. Emily understood that she could make a complaint at any time but explained that she would usually go directly to the service manager whom she knows well and trusts.

A paper record is kept from each review meeting. At present the organisation is not collecting soft data on person-centred plans and there is no audit system or outcome measurement tool in place. Regular staff appraisals provide an opportunity to review roles, performance and progress in relation to person-centred planning.

4.1.5. Key supports

The following were highlighted as crucial to good practice:

- Person-centred planning is an ongoing process and forms part of daily routines and structures
- The plan is based on the wants and needs of the individual
- There is a clear PCP process which people using the service can understand
- There is good communication between all those involved and this includes accessible information
- The person who owns the plan is given the opportunity to give regular feedback and has one to one time with keyworkers and managers in a quiet environment
- The family are involved, have a chance to input their views, and are kept up to date with progress
- There are sufficient staff resources to implement the plan.

4.1.6. Challenges and barriers

The group reported that they had encountered very few challenges and barriers.

Those highlighted include:

- Lack of accessible transport; one individual living in Emily's house is a wheelchair user. If they choose to go out together, transport can be difficult
- HIQA/the Regulations/Health and Safety; there is a sense that some Regulations seem 'over-protective' and can impose 'additional restraints'. This can work against providers establishing a culture of positive risk taking as staff become more risk aware and sometimes risk averse
- Lack of ongoing opportunities for learning and development for staff.

4.2. Aoife

Aoife is a female between the ages of 26 and 50, living in a residential service in an urban setting in the north east of the country. She has a physical disability and a moderate intellectual disability.

Aoife attended the interview with one of her keyworkers, the Person in Charge (PIC) of her residential service, and the manager from her day service. Her family was not available to attend.

Aoife uses single words, body language, facial expressions, gestures and vocalisations to communicate. She can engage with visual information such as photos and videos. Pictures and photos are used to support her understanding and expression.

4.2.1. Services and supports

Aoife lives on a campus setting, in a house with between 5 and 9 individuals, and attends a local day service. She receives both her residential and day service supports from one provider. There is a PCP policy in place across the two services, which was developed locally. There is no specific PCP tool in use with the current model developed internally and influenced by different tools and approaches.

4.2.1.1. Culture of the organisation

Those supporting Aoife highlighted the 'huge' work undertaken across the services in the past two years to develop a person-centred planning system. They acknowledged that they are working towards a good practice model, moving from a medical model with goals centred around health and care, to a more aspirational and social model based on the choices and skills of each individual. The focus in the residential service in the recent past has been on Registration and HIQA inspections. Now that the Registration process is complete, there is a desire to maintain and further improve standards and practices. The culture of the organisation was described by the interviewees as 'changing' and 'more positive'. However, it was noted by the managers that the culture of the organisation can still be more 'business-centred' than 'person-centred'.

4.2.1.2. Facilitators

Aoife is supported by facilitators in her day and residential services to develop a person-centred plan. The facilitators are usually the named keyworkers and tend to come from a nursing background. In the day service, a nurse and a healthcare assistant are assigned to each individual. The facilitators know Aoife well and understand how she indicates her preferences, dislikes and choices. The residential service leads on the development of the person-centred plan, however there is a constant exchange of information between the two services.

4.2.1.3. Learning and Development

Aoife has not received any formal education on person-centred planning, decision making or self-advocacy, but has experience of making everyday choices and decisions.

The service provider has delivered a three day training module on person-centred planning to nurses working in the organisation through the Nursing and Midwifery Planning and Development (NMPD), but this has not been extended to healthcare assistants to date. Healthcare assistants receive some informal training through staff meetings but this is ad hoc. The involvement of healthcare assistants in PCP is a recent development.

Families are not currently involved in the learning and development programmes on person-centred planning.

4.2.2. The PCP meeting

Presently, Aoife has a person-centred planning meeting every year. A range of people are invited to participate including her keyworkers, the person in charge from her residential service, the day service manager and family members. Members of the local multi-disciplinary team (MDT), G.P. (if actively involved with Aoife), and senior clinicians in the organisation are also invited but rarely attend. During the interview, Aoife expressed a desire to have more control over the guest list for her meetings and the organisation of invitations.

Aoife's planning meeting usually takes place in her home, however she suggested that she would like to try a new venue next time, for example a local hotel.

Photos, pictures and mementoes are used to support Aoife to recall and share information and achievements, and to select goals for the future. The plan is kept in the office in Aoife's home. Aoife does not have her own accessible copy at present, however she explained that she can remember her goals and talks about them regularly.

4.2.3. The content of the plan

Aoife is clear that the person-centred plan belongs to her and notes that she is the 'boss of the plan'. Aoife decides who to share her plan with and how much information to divulge. She indicated that some of the information is 'private' and should be kept 'secret'.

The plan is developed through a process of ongoing information gathering, trial, reflection and review. The person-centred plan is kept in a 'personal file' along with the tenancy agreement and contract, information on daily routines and activities of daily living, communication and hospital passports, personal care information, personal safety information, risk assessments, emergency contacts and circle of support details.

The residential service is currently reviewing the content of all person-centred plans and personal files. This review will take into account feedback from HIQA following a recent inspection. The review will also look at the need for more accessible versions of the plans and the goals within them.

Aoife's person-centred plan addresses:

- everyday choices; activities, places to go, relationships
- treats and outings; concerts, shopping trips, holidays
- developing independence; accessing an art course at a local college
- social roles;
 - involvement in local charity events such as the Mini-marathon and Christmas shoe box collection (this involves shopping for and filling shoe boxes with gifts then donating these to a local charity)
 - participating in community health initiatives such as mental health week
 - becoming a college student
 - joining a fan club
 - becoming a member of the local library.

There are clearly defined goals, with the steps to achieving these outlined and the names of those responsible recorded. For example, Aoife has a keen interest in music and is a fan of Nathan Carter. One of her goals is to become a member of the Nathan Carter fan club. The steps outlined include using the computer and internet to research information, sending emails/letters to request specific information, investigating the costs, completing the application, becoming a member, accessing information and participating in events such as concerts.

Aoife is aware of the progress being made towards her goals. There is evidence of the goals achieved in the recent past with positive outcomes for Aoife, for example going to a concert, going on a shopping trip to Dublin, completing the mini-marathon.

Presently big life issues (should they arise for Aoife) are attended to outside of the PCP process. The facilitators reported that they are looking to address big life issues as part of the PCP as the system develops and progresses. Examples of big life issues could include decisions about where to live, health, or relationships.

4.2.3.1. Community Participation

Aoife uses the facilities in her local community – pub, shops, library, church, hospital, G.P., hairdresser, restaurants, and engages with members of the community during these activities. At the moment, members of the local community do not form part of her circle of support. The supports required by Aoife to achieve her goals are provided from within the service, with the exception of the art class which is on offer at a local college. Staff from the residential service support Aoife to attend this course.

4.2.4. Reviewing the plan

Aoife's plan is reviewed through regular informal chats with her keyworkers, the Person in Charge in her residential service and the manager in her day service.

There are also less frequent formal meetings with keyworkers and with the Person in Charge.

Grace or those supporting her can request a formal review of her plan at any time. Both the manager from the day service and the residential service identified that they are currently seeking to formalise the process to ensure that concrete evidence of progress towards goals can be gathered. Communication between the day and residential services was identified as an essential component of good practice. Keyworkers and managers link on a regular basis and share information both through informal mechanisms (phone calls, discussions) and more formal systems (written records, templates). Both services work together with Aoife to identify and reflect on goals, and to engage with family.

There is a goal action plan template in use which tends to be updated when a significant piece of progress is made. The manager reviews the goals monthly and an internal audit system is being developed which will include PCP goals. This information is filtered up through the organisation to Senior Management. There is no formal quality assurance or outcome measurement system in place.

Aoife's plan can inform the delivery of services and supports at a local level, for example the allocation of staffing, but it was reported to be difficult to influence the wider organisation. If Aoife or her facilitators are unhappy with any aspect of the PCP process or the progress made, they can take their concerns to a senior clinician or Complaints Officer. There is a complaints policy and procedure in place which Aoife is aware of. Aoife has brought issues of concern to the attention of both the PIC in her residential service and the manager in her day service in the past, for example in relation to equipment or staffing.

4.2.5. Key supports

Aoife and her plan facilitators noted the following key supports as they strive to build good PCP practice:

- Sufficient staff resources— recent increases in staff numbers have made a significant contribution to improving PCP practices and outcomes
- Ongoing learning and development for staff
- Good management support
- Having a keyworker; a staff member in both the day and residential services, who know Aoife well and understand how she communicates. Aoife rejected the idea of an external facilitator for her plan
- Opportunity for regular meetings and one to one time
- Access to technology (computer, internet) so Aoife can be supported by staff to carry out research and work on her goals
- Accessible information; the use of photos and pictures

- HIQA inspections and the Regulations; this has resulted in more focus on person-centred planning, more awareness of the need for good quality plans, more formal systems being developed and implemented and improved standards of practice.

4.2.6. Challenges and barriers

The key challenges and barriers noted include:

- Staff engagement; staff may lack awareness of the benefits of PCP and may have little experience of good practice. Some may be reluctant to become involved in planning or to extend their roles to include work on PCPs
- A lack of ongoing learning and development for staff which can lead to a poor understanding of PCP
- Transport issues – lack of accessible transport can restrict opportunities to go out and about both locally and further afield
- Difficulties with organisational communication and access to funding in the organisation, in particular in relation to financial restrictions; lack of petty cash, individual services cannot manage their own budgets and have limited financial independence, contracts and procurement
- Perceived attitudes of some older parents who seem to prefer a more ‘medical model’ with a focus on care, safety and health rather than the current person-centred model where individual involvement and decision-making is encouraged and enabled. It was noted by the managers that this can be a reflection of the concerns and fears of families in relation to service deficits and budget cuts.

4.3. Tom

Tom is a male between the ages of 26 and 50 years of age, living in a rural setting in the north west of the country. Tom lives at home with his wife and family. He has an acquired brain injury.

Tom was supported at the interview by the Assistant Psychologist in the service. His family were unavailable to attend. Tom communicates verbally but requires some conversational supports to process information and to express his thoughts and ideas.

4.3.1. Services and supports

Tom attends a local community service where a person-centred rehabilitation plan is in place for him and he is supported by a clinical team. Post-hospital discharge, Tom spent a period of time in a transitional living unit before returning home. These supports were delivered by one service provider, a voluntary organisation providing services for people with physical and sensory disabilities.

At the outset Tom was provided with information on the model of service and package of care on offer, including the person-centred nature of the approach and the potential benefits. Tom reported that he understood this and found the information helpful. The person-centred rehabilitation plan was initiated in the transitional living unit and has been developed and adapted as Tom progressed and moved home.

There is a PCP model and policy in place across the organisation. This was developed internally and is influenced by current research in relation to supporting people with acquired brain injury. There is no specific PCP tool in use. The person-centred plans are grounded in evidence based rehabilitative practice.

4.3.1.1. Culture of the organisation

The culture of the organisation was described by Tom and the Assistant Psychologist as 'supportive' with a focus on achieving the best outcomes for individuals through quality rehabilitative supports. The team supports individuals to return to their 'regular' life or to adapt to a 'new' life. There is an 'open door policy' so both staff and people using the service can express their concerns and ideas. The service supports individuals to maintain natural supports and to link to community groups and external support services.

The person-centred rehabilitation plan is an ongoing process rather than a one-off event.

4.3.1.2. Positive risk taking

The service provider encourages positive risk taking and seeks to identify ways to overcome obstacles in a safe and graded manner. This means that individuals are supported to work through situations and tasks, with the level of risk increasing over time. There is a risk assessment policy and procedure in place.

4.3.1.3. Facilitators

Tom is supported by the Assistant Psychologist on the clinical team, who acts as the lead facilitator, to develop and implement his person-centred plan. The Psychologist works alongside the individual, their family, managers, keyworkers, rehabilitation assistants and other clinicians to facilitate the plan. Team work was noted to be a crucial aspect of the process.

Tom highlighted the importance of building strong relationships with facilitators who are ‘understanding’ and can ‘read the cues’:

“They know me well and can spot if I am having a bad day...they are very observant and tuned in....they will say it to me and address the problem before it gets worse”

4.3.1.4. Learning and Development

The organisation does not provide mandatory learning and development for staff on person-centred planning. Clinical staff may receive formal or informal education in relation to PCP through their training, continuing professional development (CPD) or through different aspects of their professional work. The Psychology department can offer learning and development opportunities in relation to PCP to frontline staff if required. Staff are constantly encouraged to reflect on their work and to share information and learning across disciplines.

There is no specific PCP education in place for individuals using the service or for families.

4.3.2. The PCP meeting

Following an initial assessment period at the transitional living unit, which involved Occupational Therapy and Psychological evaluations, Tom had a ‘goal setting meeting’. Feedback was provided to Tom, his family and support team, in relation to the evaluations and recommended ways to move forward. Tom identified that at this point his main goal was ‘to get back to a normal life’. He worked with the team to identify a number of short term goals which the team felt he could work towards and achieve. At the outset, these mainly related to dealing with his health needs (managing fatigue, managing sensory difficulties, attending specific medical and therapeutic appointments and groups) and engaging in activities of daily living. The person responsible for supporting Tom with these goals was clearly identified and his family were involved in both the goal setting and in supporting Tom in practical ways to achieve his goals.

The goals agreed at the meeting were recorded in a plan and a written summary was given to Tom, along with a set of monitoring sheets. Tom expressed the view that setting goals gives him:

“Something to hold on to...a reason to get up and get going every day”

Along with work on his personal goals, Tom also engages with group therapy supports within the service, for example a cognitive group and psychology support group. These offer both clinical, peer and social supports.

4.3.2.1. Family involvement

Tom's family have been involved throughout the process. Practical and emotional supports are available to family members and they are encouraged to communicate regularly with the clinical support team either through face to face contact (meetings and reviews), telephone contact or written communication. They are also involved in discussions in relation to risk assessment and risk taking.

4.3.3. The content of the plan

The plan contains a set of SMART goals⁴. There are long-term goals which are broken down into smaller, more realistic and measurable short-term goals. These may have a series of steps which are outlined on the monitoring sheets. Tom reports that he 'aimed very high initially' but is now taking 'small, steady steps'. He explained that this gives him a better sense of achievement, an emotional boost and a sense of progress. For example, Tom set a goal of learning to cook so he could make meals at home. To begin with he got involved in preparing meals in the transitional living unit, he looked at taking a cookery course and will over time extend his skills to cooking and cleaning up at home.

The monitoring sheets provide a visual record of progress and Tom can tick off the steps achieved as he goes along. Tom received specific support and training in completing the monitoring sheets, which are filled in across the week. This visual record supports individuals who may have memory difficulties to recall and retain information. The system also encourages reflection, ownership of the goals and a sense of responsibility towards achieving them.

The monitoring sheets are read and signed off each week by the facilitator and the support team. Both the individual and the team keep copies in a personal folder or individual file. Tom explained that he would often look back over his personal folder at home to remind himself of the progress he has made and the positive outcomes he has achieved.

Tom's plan addresses:

- life issues; career, living arrangements, medical decisions
- everyday choices; daily routines, group work, hobbies and interests

⁴ SMART stands for Specific, Measurable, Achievable, Realistic or Relevant, and Timely

- building independence; returning to activities of daily living such as cookery or managing medication, educational opportunities
- relationships and social roles; emotional supports, maintaining natural support networks
- milestones towards achieving personal goals; steps in the rehabilitation process.

4.3.3.1. Community participation

Tom participates in his local community and uses the facilities in the local town and surrounding area. The clinical support team encourage those using the service to engage with community groups such as Men's Sheds, Walking Groups and other social supports. They link regularly with HSE staff and services to identify programmes which may be of benefit to those with acquired brain injury, for example occupational therapy groups, psychiatric supports, peer support groups.

Where appropriate, people using the service, are encouraged to seek out lifelong learning opportunities in local colleges and educational centres, and to look at ways to develop hobbies and interests in a social setting.

The service identifies the importance of reducing isolation and connecting people to social networks and supports, which they can maintain into the future.

4.3.4. Reviewing the plan

Along with the weekly monitoring meetings, the team also conducts a formal monthly review of the plan. This can be more frequent if the team feels this is needed or if a review is requested by Tom or his family. The lead facilitator provides very regular information, feedback and updates on progress to other members of the clinical team.

Weekly contact allows Tom and his facilitator to quickly identify any problems and to put measures in place to resolve them. Access to high quality MDT supports assists in the problem solving process. Regular reflection allows goals to be adapted, changed or added as appropriate. The service manager is part of the MDT team. If issues arise for Tom, the manager is aware of these, can try to resolve them locally or can channel information up the line to senior management and can seek additional supports. The lead facilitator noted the support and responsiveness of colleagues within the clinical team and highlighted the value of access to professional supports and expertise.

Tom reported that he can ring up at any time with questions or problems, and described how 'there is a sense that you are never on your own'. He explained that he has learnt to say if something is not working or if he is finding something too difficult, so that he does not get overloaded. Staff respond immediately to these requests and work through the situation with him.

4.3.5. Key supports

Tom and his supporters emphasised the following items as the most significant elements of good practice in person-centred planning:

- “Everything centres around quality relationships with staff you like and can trust”; staff who are passionate and enthusiastic about their job, observant and honest
- Good communication between all those involved
- Teamwork with everyone focused on supporting Tom to achieve positive outcomes
- Family involved and included in the process
- A clear PCP process and SMART goals
- Regular follow up and opportunities for problem solving if difficulties arise
- Access to MDT resources with a wide range of expertise and experience
- Good links to community services and supports.

4.3.6. Challenges and barriers

Tom expressed the view that he had encountered ‘no issues or brick walls’ in working towards the goals in his person-centred plan:

“Everything I need is there...it all works well for me”

4.4. Katherine

Katherine is a female between the ages of 26 and 50, living in a residential service in a rural setting in the midlands. She has a sensory disability and a severe intellectual disability.

Katherine was joined at the interview by her mother, the keyworker from her day service and the manager from her day service.

Katherine communicates non-verbally using body language, movement, facial expression, physical contact, objects and responsive behaviours. Those supporting Katherine need to be highly observant and attentive to recognise Katherine's communication attempts and to understand these. Staff record Katherine's preferences using photographs and video so information can be shared amongst her circle of support. Katherine has a communication passport which outlines how she interacts, the things which motivate her to engage, and the best ways to support her communication.

4.4.1. Services and supports

Katherine attends a day service and lives in a community residential house with five other people. She receives both her day and residential services from one service provider. The provider is a small voluntary organisation delivering services to people with intellectual disabilities and autism. The interviewees describe the organisation as 'close knit' and 'accessible'. There is daily communication between the day and residential services with a 'communication book' used as an information sharing tool. The day service aims to provide a stimulating environment and programme in line with the values of New Directions.

There is a 'well-defined' PCP policy and procedure in place across the organisation, which was developed by an internal committee and approved by the Board of Directors. This policy is reviewed regularly. It was influenced by O'Brien's five service accomplishments⁵ and by the PATH PCP process. The policy includes a flow chart outlining the steps to be taken in the PCP process.

⁵ John O'Brien proposed five areas which are widely agreed to be important in shaping everyone's quality of life:

- Sharing ordinary places
- Making Choices
- Developing abilities
- Being treated with respect and having a valued social role
- Growing in relationships

Implementing Person-Centred Planning - John O'Brien & Connie Lyle O'Brien, Inclusion Press: Toronto, 1998

4.4.1.1. Culture of the organisation

The culture of the organisation was described by staff and Katherine's mother as 'generally very positive'. There is an 'ambitious' attitude to person-centred planning from the top down. Communication within the organisation is good and there is an 'open door' approach, with senior managers very willing to engage in discussion and debate. Katherine's keyworker, manager and mother described how they feel supported and listened to.

4.4.1.2. Positive risk taking

The organisation promotes a culture of positive risk taking and openness to change and new ideas. They set out to support individuals to try new things and extend their skills. There is a risk assessment policy and procedure in place in the organisation.

4.4.1.3. Facilitators

The PCP policy outlines the roles and responsibilities of the facilitator. Where possible the person who owns the plan is the lead facilitator. If this is not feasible then the keyworker acts as the facilitator. This person knows Katherine well and understands how she communicates and expresses her likes and dislikes. The facilitator liaises with others involved in Katherine's life, for example family members, residential staff, clinicians. The service manager emphasised the importance of developing a plan based on the views of the many different people who engage with Katherine on a regular basis, and not solely from the perspective of one individual staff member.

4.4.1.4. Learning and Development

Staff in the organisation receive formal learning and development in relation to person-centred planning. This is provided internally, is delivered mainly by managers and takes place over one day. The programme focuses on the policy, procedures, tools and templates. It aims to develop consistency between the organisational policy and practice on the ground. It was noted that the learning and development programme needs to be constantly refreshed as terminology is ever changing and there are constant developments in relation to good PCP practice.

Where necessary the organisation has sought specialist advice and inputs from external sources to support staff to develop and implement quality person-centred supports, for example from the Anne Sullivan Centre or from the local HSE multi-disciplinary team.

Currently the organisation does not provide specific education on PCP to people using its services or to family members.

4.4.2. The PCP meeting

Katherine has an annual review of her PCP plan. This is a formal meeting which involves her circle of support. It is described as 'a day of celebration' where Katherine is the centre of attention. The meeting takes place in a location where supporters feel Katherine is most comfortable. Invitations are sent in advance of the meeting to facilitate key individuals to attend; this includes family members, staff from

the residential service, and staff from the day service. Members of the MDT team do not attend the PCP meeting; one view was that individual clinicians may over focus on one issue or aspect of Katherine's support needs and this can detract from the holistic nature of the meeting. Members of the MDT can however contribute their recommendations and ideas to the meeting, and usually do this through written reports and/or liaison with keyworkers.

Information for the PCP meeting is gathered throughout the year by offering Katherine new experiences, observing, actively listening to and respecting all communication attempts, responding appropriately, reflecting, introducing changes where required and constantly evaluating practice.

During the PCP meeting, keyworkers use PowerPoint presentations which include photos and videos, along with objects and mementoes, to talk about goals and evidence Katherine's achievements and the positive outcomes resulting from these. Staff work hard to try to make the process as accessible as possible and to facilitate Katherine to participate in the meeting. They identify that this is a challenge due to Katherine's complex support needs, and requires staff to be creative and adopt a Total Communication and sensory approach. Teamwork, co-operation and information sharing are essential elements throughout the process.

4.4.2.1. Family involvement

Katherine has very regular contact with her family and goes home often. Katherine's family understand her extremely well and can interpret her communication and responsive behaviours. Her mother explained that she is keen to carry on the routines that are followed with Katherine in the service, along with providing activities at home, and so it is important that she is kept up to date with progress and developments. The family attend the PCP meeting each year and the review meetings where necessary. They are in weekly contact with the service (face to face or by phone) and feel the PCP process is an open one where they can contribute their ideas and views. The family continually advocate for Katherine and lobby to ensure that her support needs are met. The manager reported that the family have been instrumental in securing resources and supports for Katherine from health, education and disability services in the past.

4.4.3. The content of the plan

The first step in the PCP process involves the completion of an assessment of need. This provides a general overview of the individual, their strengths and support needs. Assessments of need and care plans are kept completely separate to the person-centred plan.

The person-centred plan focuses on achievements in the past year, areas of development, new experiences and activities, and goals for the coming year. There is a long term vision (five years) outlined for the person, along with long term and short term goals. Staff are encouraged to support individuals to develop aspirational goals based on their dreams and wishes.

Katherine's person-centred plan addresses:

- everyday choices; activities and places to go (swimming, bowling), purchasing new items for her bedroom
- new experiences; these are related to previous likes and preferences. Staff look for patterns in responses and Katherine can communicate if she dislikes or is unhappy with something
- developing independence; laundry tasks, taking cup to the sink, use of hand rails to guide movement around the building
- health and well-being; maintaining health is important as Katherine has had significant health problems in the recent past, also includes access to sensory integration and psychological supports
- social roles; volunteering with a local community Fás group.

The goals in the plan are clear and focused. There is evidence of progress and outcomes in relation to previous goals, for example skill development, new life experiences, community participation.

The plan facilitators (usually a keyworker) report that big life issues are addressed as they arise and usually outside of the PCP process. Family are involved and invited to make their views known. One example of a big life issue which arose for Katherine was a move to a different bedroom in her residential house. This constituted a significant life change for Katherine due to her specific communication and sensory disabilities. It was agreed and actioned outside of the PCP process, however following the move, a PCP goal was added which centred on choosing new items for her new room.

The service is using a new PCP template which they have developed to record information. The person-centred plan is kept in the 'daily active file' along with the assessment of need, MDT reports and guidelines, the care plan, communication passport and hospital passport. Managers and keyworkers in the day and residential services work closely together to develop Katherine's person-centred plan, sharing information and ideas.

4.4.3.1. Community Participation

Katherine uses the facilities in her local town. Her complex communication support needs limit her engagement with community members but those supporting her are actively seeking opportunities to facilitate interaction with a wider group of people. At the moment, members of the local community do not form part of Katherine's circle of support. The supports required to achieve her goals are provided from within the service and there is limited engagement with external stakeholders. Katherine's supporters noted that volunteers or leisure buddies may be a route to explore in the future. External advocacy supports would be available to Katherine should she need them at any stage.

4.4.4. Reviewing the plan

Katherine's keyworker completes a monthly report outlining the progress made on the PCP goals and identifying any barriers or specific challenges. This is shared with the centre manager and may be passed on to senior management if necessary.

Katherine's plan is reviewed formally after three months and again after six months by the keyworkers in her day and residential services. These meetings are scheduled by the keyworkers and are an opportunity for reflection. Goals may be amended or adapted if necessary. The centre manager will attend these meetings or will review the minutes of the meetings. Katherine's keyworkers, service manager or family members can request a formal review at any stage in the process if there are significant developments or if concerns arise which cannot be addressed through informal channels.

These meetings are an opportunity for reflection and goals may be amended or adapted if necessary. The centre manager will attend these meetings or will review the minutes of the meetings.

Managers are aware of PCP goals, particularly long term goals. There is an internal audit process in place in the day service, which is carried out by the services officer. Data in relation to PCPs is gathered on specific organisational templates and is collated on an annual basis for the HSE.

Katherine's plan has a direct influence on the routine and structure of the day and residential service. Individual plans inform the daily schedule, rosters and allocation of staff. Where possible, keyworkers are freed up to support individuals to engage in specific activities and new experiences. This allows them to observe responses and to report back to the staff team.

The plan also highlights any resource issues which need to be addressed or raised at a senior management level. The plan identifies any referrals which need to be made to external services and supports. The centre manager or services officer will lobby for external supports on Katherine's behalf if necessary, for example psychological supports from the HSE.

Staff supervision sessions provide an additional opportunity to review progress in relation to PCP supports and plans, and promote the exchange of information, a focus on outcomes and a level of accountability.

4.4.5. Key supports

Katherine's supporters highlighted the following as instrumental in the development of a high quality person-centred plan:

- Connectedness; quality relationships between the person who owns the plan and their circle of support. People who know Katherine well, focus completely on her wants and needs and advocate on her behalf

Research on current practice to inform the development of a national framework for person-centred planning in disability services

- Staff who are willing to engage in constant discussion, question and research, have a desire to reflect on and improve their practice, strive for positive outcomes, and are open to change
- Responsive and creative communication
- Communication and respect between staff and families where they can work together and support each other to achieve the best outcomes for the individual
- A culture where good practice is acknowledged and valued
- A clear and consistent process
- A good environment – physical and social.

4.4.6. Challenges and barriers

The key challenges and barriers noted include:

- Making communication and information relevant and accessible to Katherine
- Generating ideas for new activities, experiences and goals for Katherine
- The provision of ongoing learning and development opportunities for staff
- Resources – financial, staffing
- Lack of tools and resources to support people with sensory disabilities through the PCP process
- Lack of MDT supports, in particular behaviour therapy and sensory supports
- Transport issues – lack of accessible transport.

4.5. Jenny

Jenny is a female over 50 years of age, living in a residential service in a rural setting in the north west of the country. She has a severe intellectual disability and sensory disability.

Jenny participated in the consent and interview process with support from her keyworker and a service manager. Her family were unavailable to attend the interview.

Jenny communicates non-verbally. She uses body language, signs, gestures, physical contact and facial expressions to indicate her needs and preferences. She also engages with pictures and photographs. Jenny relies on staff that know her well and understand how she communicates and makes choices.

4.5.1. Services and supports

Jenny lives in a community residential house with between 5 and 9 individuals, which is run by a large organisation providing services to people with intellectual disabilities and autism. She has lived in this location for over ten years and has been engaging with the local services for more than twenty years. Jenny is retired from day services.

There is a PCP policy in place across the organisation which was developed by reviewing what was working well and not working in different services. The policy was also influenced by the NDA Guidelines on person-centred planning from 2005. Elements of the Essential Lifestyle Planning process, PATH process and MAPS PCP tool have been included and tailored to suit specific services and individuals. In the past Personal Outcome Measures (POMs) from the Council on Quality and Leadership were introduced in the organisation but it was noted that this system was 'too ambitious for the service at the time'. POMs are no longer in use and there is no quality assurance system in operation at the present time. The residential service had a recent HIQA inspection and the service manager reported that the inspector was happy with the current processes in relation to person-centred planning.

The service is a training facility for nurses, and the manager highlighted that this can create a conflict where on one hand a nursing model is strongly advocated, but on the other there is a move away from the medical model.

4.5.1.1. Culture of the organisation

It was noted that the culture of the organisation is 'changing' and there was a sense that it is 'more positive' and 'improving'. Staff are becoming increasingly aware of their role as advocates for the people they support, however there is still some resistance to change. Some members of staff can be reluctant to 'expand' their roles or to take on what they perceive as 'an additional paper exercise'. The organisation is working hard to change attitudes and to ensure staff do not 'slip back into old habits'.

The culture and bureaucracy of a large organisation was noted to be a significant barrier in supporting individuals to achieve their goals. In addition the application of the Regulations was also identified as a potential barrier to inclusion and independence. This is discussed further in the section on supports and barriers.

4.5.1.2. Facilitators

The named nurse in the residential service is generally the lead facilitator for each person-centred plan. Jenny also has a keyworker who is actively involved in the process. This person is a healthcare assistant. Jenny is involved throughout the process with the facilitators taking their lead from her.

4.5.1.3. Learning and Development

The organisation provides a two day programme on person-centred planning for all staff. This programme was developed internally and is delivered by local staff. This learning and development programme is driven by the PCP policy and by the Regulations.

Around ten years ago, the organisation bought in a training programme on person-centred planning from external consultants. From this a 'Train the Trainer' programme was established to upskill key staff.

At present there are no specific learning and development opportunities on person-centred planning offered to families or people using services. This was identified as a significant 'gap'.

4.5.2. The PCP meeting

Jenny has an annual PCP meeting, organised by the lead facilitator and keyworker with input from Jenny. This meeting usually takes place at Jenny's house and involves members of the staff team along with family. Jenny's family are invited to attend and their input at this meeting is very welcome. If the family are unavailable to attend, then copies of the goals and the minutes would be forwarded to them, and they are given the opportunity to make contributions and to ask any questions they might have. Jenny's family live a distance away from her residential service.

Members of the MDT are not usually invited to attend Jenny's PCP meeting unless they are very involved in or responsible for a specific goal. Medical, psychological and therapy reviews are conducted outside of the process. Information from these may inform the PCP meeting but is not central to the meeting. It was noted by the manager that at present 'there does not seem to be a need for MDT involvement in PCP meetings'.

The PCP facilitators use photos and pictures to maximise Jenny's involvement in the information gathering process and the meeting itself. At the information gathering stage, observation of Jenny's reactions and responses to different people, places and activities is essential to ensure a profile of her likes and dislikes can be developed.

There are specific templates in use for collating information and recording meetings. Jenny has her own version of her person-centred plan in a more accessible format, which she keeps in her bedroom; this contains photos and art work. The main plan is kept in the office in the residential house.

4.5.3. The content of the plan

The person-centred plan is viewed as a 'lifestyle plan'. Information is gathered prior to the PCP meeting and throughout the year. This includes key information on Jenny, her choices, likes and dislikes, personality, circle of support, routines, professional reports and guidelines, family inputs, health and well-being, financial circumstances, safety.

The nursing or care plan is developed and kept separate to the person-centred plan. Some of the information from the care plan may be included in the person-centred plan if it is particularly relevant to a specific goal. It was noted that families often request information on the care plan at the PCP meeting, and this information is provided for them at the end of the meeting.

Jenny also has a separate communication profile and safety plan. Activities of daily living and the routines connected to them are identified separately to the PCP plan and do not constitute personal goals.

There are PCP templates in use in the organisation to record relevant information – some developed internally, some taken from the work of Joe Wolfe and Helen Sanderson. The facilitators record information manually in an individual PCP folder.

Jenny's plan addresses:

- big life issues; these issues may arise initially at a review meeting and may require a case conference meeting as well as a PCP meeting, for example a change in living arrangements, medical decisions
- everyday choices and activities; craft work, painting, spending more time with family knitting
- building independence and skills; purchase of an I-pad
- community participation and social roles; using community facilities, knitting blankets for a local charity
- treats and occasional outings; holidays, day trips.

The person-centred plan contains an action plan and lists those responsible for supporting Jenny to achieve her goals. This tends to be the named nurse or keyworker, along with members of the staff team. The plan also highlights achievements and outcomes with pictorial evidence included throughout.

There is a Risk Assessment Policy in place in the organisation with screening procedures and templates.

It was suggested that the organisation is trying to encourage a positive risk taking culture where staff can be creative and can problem solve at a local level. One example given was non-nursing staff giving medication to ensure individuals can go out without needing a nurse on duty.

4.5.3.1. Community participation

Jenny uses local community facilities including shops, post office, cinema, G.P., hairdresser, bowling alley. She has limited interaction with members of the community and at present the local community do not form part of Jenny's circle of support. Jenny is not currently involved in any community groups and there are no volunteers working in the service.

It was suggested during the interview that current policies in relation to the care of vulnerable adults and Garda clearance for volunteers or neighbours, make it very difficult to support naturally occurring relationships between people using services and members of their community. For example, the practices implemented by the organisation in relation to safeguarding mean that a neighbour or community member wishing to accompany a person to an activity or event without a staff member, would need to be Garda vetted. Local people can perceive the process of Garda clearance to be complex and intrusive, and therefore may be reluctant to engage with people with disabilities.

The supports required to achieve Jenny's goals are provided from within the service only at the current time.

4.5.4. Reviewing the plan

There are formal quarterly reviews of Jenny's plan, which are called for and conducted by the lead facilitator and keyworker, with the findings shared with key people. The minutes are recorded manually on an evaluation template which is forwarded to the manager and forms part of an internal provider nominee audit which is conducted bi-annually. The evaluation template highlights any significant issues to the manager to address. The organisation uses a metrics system – 'testyourcare.ie' to input PCP data on a monthly basis.

Generally the residential staff team work together with the manager at a local level to identify and overcome any obstacles. Jenny's plan can influence services and supports at a local level but it was not felt that it would have influence beyond this.

There is a formal complaints procedure in the organisation which people using the service, their families and staff can use if they are unhappy with any aspect of the service. Jenny would require staff or family to advocate on her behalf if she needed to use this.

4.5.5. Key supports

The following were highlighted as crucial to good practice:

- Staff learning and development

Research on current practice to inform the development of a national framework for person-centred planning in disability services

- The willingness of staff to engage with the process
- Adequate resources (staffing, financial) to implement the plan
- Motivation of the person who owns the plan and their family
- Regulations; these provide structure, targets, and help maintain standards
- Accessible communication.

4.5.6. Challenges and barriers

- Lack of resources
- Lack of ongoing learning, development and upskilling for staff; one-off inputs are not sufficient
- Inflexible shift patterns; these restrict where people can go and when
- Time management; paperwork versus time spent with people
- Budgetary constraints; lack of petty cash/ 'comfort fund' – if an individual wants to go to a concert, who pays for the staff ticket? Often residents are relying on the goodwill of staff to use their own funds to pay for items such as tickets as there is no 'house' credit card available.
- Bureaucratic procurement systems; if something is needed in the house, the team need to get three quotes before they make a purchase, so the residents cannot just go out and choose for example a new piece of furniture.
- Lack of accessible transport
- HIQA/the Regulations/Safeguarding policies; these were all noted to be important but they also impose restrictions on people developing relationships outside of the service. These restrictions relate to the need for Garda vetting.

4.6. James

James is a male between the ages of 18 and 25 years of age, living in an urban setting in the north east of the country. He lives at home with his family. James has autism.

James was supported at the interview by keyworkers from his day service, the service manager and his mother. He was happy to share his person-centred plan and to show examples of posters and visuals related to his plan.

James requires verbal and non-verbal communication supports. He benefits from a Total Communication approach with access to visual supports such as photos and symbols.

4.6.1. Services and supports

James attends a day service, provided by a voluntary organisation supporting people with intellectual disabilities and autism. The day service operates under the New Directions policy and focuses on the delivery of person-centred supports. The service embraces the values of independence, choice, control and community inclusion. Some families, including James' family were involved in the establishment of the service and the development of the model of support. This was part of a GENIO project.

There is a clear PCP system and policy in place across the organisation which was developed internally and is reflective of current national policies and legislation. There is no specific PCP tool in use however staff are familiar with a range of different tools and approaches, and try to adapt these to meet the needs of the individual they support.

The service is working on developing positive links with the local community in order to support individuals to achieve their goals.

The organisation has achieved a gold award for Investors in People and operates according to ISO Quality Management System Standards for business.

4.6.1.1. Culture of the organisation

The culture of the organisation was described by the group of interviewees as 'open', 'positive' and 'focused on reflection and improvement'. Communication in the organisation was described as good. Staff are encouraged to approach each individual with 'fresh eyes' and to start from 'a blank canvas' when undertaking person-centred planning. Keyworkers access only a limited amount of information on an individual when they transition into the service. They are encouraged to spend time getting to know the person and to understand their likes and dislikes.

The organisation completes an assessment of need with an individual following their referral to the service. The organisation will not accept referrals if the funding is not forthcoming to provide the necessary supports.

It was recognised by the service manager that to do this would impact on current service users and on the quality of the supports they receive. Many of the individuals attending the day service have complex needs and require one to one supports to achieve their goals.

There is a risk assessment and risk management policy in operation and the organisation promotes positive risk taking and engagement in positive behaviour supports.

4.6.1.2. Facilitators

James is supported by a keyworker in his day service to develop a person-centred plan. The keyworker involves James as much as possible in the information gathering and the goal setting. Staff are described as 'great advocates' for the individuals using the service. They are clear on their roles and responsibilities, and there are strong lines of accountability. It was noted by the interviewees that it is important that the facilitator takes the time to get to know the person well and to understand their system of communication.

4.6.1.3. Learning and Development

The training department provides a two day learning and development programme on person-centred planning to all staff. This programme outlines different PCP tools and approaches and encourages staff to take key principles from these and adapt them to the individual needs of the people they support. The programme also helps staff to identify a hierarchy of needs, to set goals and to build person-centred plans. Staff also have the opportunity to complete an education module on reflective practice.

Some family members have accessed specific PCP training as part of their involvement in the GENIO project. At present the organisation does not provide learning and development opportunities in PCP to people using the service or their family members.

4.6.2. The PCP meeting

James has an annual PCP meeting, however the interviewees emphasised that person-centred planning is an ongoing process which is integrated into daily routines and structures. It involves open and active listening, detailed observations and interpretations of communication and responses in a range of different settings, opportunities for activity sampling and the introduction of new activities and experiences. The facilitator records observations on a specific template.

The PCP process is made accessible to James through the use of photos, symbols, video, posters, art work and mementoes. This supports James to understand information, to recall events and to express his choices. Additional evidence of achievements and goals includes observation sheets and task analyses.

Those invited to the PCP meeting include keyworkers from the day service, family members, and the service manager.

The service has limited MDT supports but it was noted that individual clinicians would be invited to the meeting if they were supporting James to work on a specific goal. General medical and clinical reviews are conducted separate to the PCP process but the findings from these can be considered at the PCP meeting if relevant.

The interviewees reported that goals are constantly being updated and changed to take into account new observations and information in relation to the individual. Goals are not set in stone and can be amended at any point.

4.6.2.1. Family involvement

James lives at home and his family are involved in all aspects of his life. They maintain regular contact with the day service through daily correspondence in a communication book. Copies of daily and weekly timetables are also sent home. James' family attend the annual PCP meeting and review meetings where necessary. His mother explained that she can contact the service at any stage, commenting positively on the 'open door policy'. A formal meeting or telephone call can be arranged to discuss any concerns or to answer specific questions.

James family are totally committed to the model of person-centred supports, and they are happy to support the implementation of different aspects of the plan, for example specific skill development, participation in activities.

4.6.3. The content of the plan

Information is gathered and recorded on a continual basis and the PCP plan is considered to be an ongoing piece of work. All the information gathered is recorded on an observation template, and there is also a specific template provided by the organisation for goal setting.

James' keyworker described how active listening and observation has allowed them to explore his interests and develop goals. One example given was horse riding. James had taken part in horse riding in the past but had decided to stop going. James' keyworker observed subtle changes in his body language each time horse riding was mentioned, that led her to believe that James might like to go again. She approached James with the idea and he agreed.

The action plan contains over-arching goals which are broken down into smaller goals, for example the long term goal may be employment and the short term goals may relate to learning a specific skill, work experience, volunteering, or completing a training programme. Those responsible for supporting James to achieve his goals are identified and there are also clear time frames for reaching the goals.

James' current plan is based on his interests, skills and on promoting independence. It addresses:

- big life issues; respite
- everyday choices and activities; horse riding, going out for lunch
- building independence and skills; cooking, DIY

- community participation and social roles; volunteering, using community facilities
- treats and occasional outings; day trips, one to one outings.

4.6.3.1. Community participation

James uses a range of community facilities in the local town. The interviewees noted the challenges of supporting individuals with autism and complex communication needs to engage in community activities. The service is working hard to identify appropriate opportunities for engagement which are built on the interests of individuals and which promote social roles. These include accredited education programmes in conjunction with the local ETB, volunteering options with local charities and community groups, participation in community events and activities, links with local HSE supports and services, and the recruitment of volunteers to the service. The service is also keen to develop circles of support for James in the future, which extend beyond paid staff and family members.

4.6.4. Reviewing the plan

James' plan is reviewed with his family and keyworkers after two months and again after six months. The keyworker and team leader review progress on a monthly basis. The process is transparent and constant evaluation is encouraged. Keyworkers, managers or members of James' family can call for a formal or informal review of his plan at any point if they feel this is warranted.

Monthly regulatory reports are provided to the Assistant Director. There is an unannounced audit in the organisation approximately every six months. The operational plan for the organisation includes demonstrable outcomes for service users.

Staff supervision and appraisal meetings are opportunities to reflect and review performance in relation to person-centred practice and the outcomes achieved for individuals. Good practice and achievements are recognised and celebrated.

James' person-centred plan influences the allocation of staffing in the service, the daily timetable and the selection of activities. Staff are recruited to the organisation based on individual support needs and personal goals, for example if a staff member needed a specific skill set to support an individual to achieve their goals, then this could be addressed at the recruitment stage.

If any issues arise in relation to the implementation of a plan for an individual, then the service manager will first seek to resolve these locally and within allocated resources. If this is not possible, then the issue will be 'fed up the line' and raised with senior management.

4.6.5. Key supports

The following were highlighted as key to good practice and the development of quality person-centred plans in the service:

- A focus on each person as an individual; a willingness to observe all forms of communication in all situations and to be open to interpretation and understanding. The right approach; 'A service with you at the centre'
- A desire to find and value each person's skills and talents and to use these to support the individual to engage in meaningful activities and set personal goals
- Staff who work well as part of a team, are accountable for their work, are dedicated and responsible, are clear on their roles, are good listeners and observers, embrace the values of New Directions
- Staff and family members who are willing to constantly reflect on their input, influence and impact, are open to change and new ideas, and can accept feedback
- A system which recognises and champions good practice and rewards achievements
- An interest in developing circles of support beyond just staff members and family members
- Flexibility, Innovation and Creativity; from the organisation, families, staff and external stakeholders
- Adequate funding and resources to provide the individual supports which the person might need to achieve their goals
- Good communication and sharing of information between all those involved
- Clear systems for monitoring and the evaluation of outcomes
- The ongoing involvement of and support from family members
- Ongoing learning and development opportunities for all those involved.

4.6.6. Challenges and barriers

- Lack of community opportunities for young people, particularly for people with more complex support needs. It can be hard to implement the principles of New Directions when the community is not ready or does not have the resources to support you, for example educational opportunities, activities for young people, social roles
- A lack of flexibility from external stakeholders and systems; if the person does not 'fit' the current system, e.g. in relation to an employment service, then there is no means to 'adapt' the model
- Lack of funding, in particular staff resources which can affect one to one supports. This was identified as a potential problem but is not an issue for James or his support team at the current time.

4.7. Niamh

Niamh is a female between the ages of 18 and 25 years of age, living in an urban setting in the east of the country. Niamh has a physical disability and a sensory disability. Niamh lives at home with her family.

Niamh was supported at the interview by keyworkers from her day service and the service manager. Niamh communicates verbally and through the use of Irish Sign Language. Her keyworkers provided signing supports during the interview. Niamh's family were not available to participate in the research interview.

4.7.1. Services and supports

Niamh attends a day support service, provided by a voluntary organisation supporting people with physical and sensory disabilities. The day service offers a rehabilitative training (RT) programme with a strong person-centred ethos.

There is a clear PCP system and policy in place across the organisation which was developed internally. The organisation seeks to establish links with external services and agencies in order to facilitate individuals to achieve their goals. There is no specific PCP tool in use however staff are familiar with a range of different tools and approaches.

4.7.1.1. Culture of the organisation

The culture of the organisation promotes the idea that the adult using the service is 'the most important person' in the PCP process. Each adult is presumed to have the capacity to make choices and is supported to make their own decisions.

There is a strong sense of community with different departments and services working together in a flexible manner to deliver 'a holistic approach'.

"The focus is on getting the outcomes that each person wants."

Communication in the organisation was described as 'good', 'open' and 'positive'. Discussion and debate are encouraged and Niamh explained that she 'feels free to talk to whoever I choose about the plan and my goals'. She reports that staff regularly ask 'what my goals are and how things are going'. There is a healthy interest in person-centred planning and in particular in the achievements and outcomes which result from the process.

There is no quality assurance system in operation in the organisation at this current time.

4.7.1.2. Positive risk taking

There is a policy and procedure for risk assessment and risk management in place. This promotes controlled risk taking where independence is encouraged, safety is considered, options are discussed and where teams seek to overcome barriers. The service manager noted the importance of controlled measures and small, steady steps where the person can learn new skills and grow in confidence.

The interviewees expressed the view that if families are anxious or reluctant to allow a person to take risks, they can often be reassured by this approach. Honesty and trust were seen as essential components of relationship building in relation to positive risk taking. Niamh described how she managed the different risks associated with going to college and described how she sought the support of external providers to overcome barriers. The risks were related to things such as independent travel or the potential loss of funding:

“All of it is a risk. The money could go, the roads are dreadful but I just said I am going to do it...you have to take a chance sometimes. I worked with Dublin Bus on the travel and talked about it all.”

4.7.1.3. Facilitators

Niamh is supported by a keyworker in the day service to develop a person-centred plan. The keyworker acts as a co-facilitator as Niamh takes the lead in the development of her plan. The keyworker is allocated during the individual's first week on the programme. Their initial role is to explore with the person, their interests, aspirations and the different options available to them.

Niamh reported that she can change facilitator if she wishes; she would do this in consultation with the service manager.

The interviewees emphasised that the facilitator is not the only person to support the PCP plan. The facilitator helps to draw all the information together but the staff team as a whole support the implementation of the plan. All members of the team are aware of individual goals and understand that they may have an active role to play in supporting the person to achieve these.

4.7.1.4. Learning and Development

New staff joining the team are supported and mentored in the PCP process. The co-ordinator or manager will spend time with them, going through the PCP policy, process and paperwork. Each staff member will be shown examples of person-centred plans, the goals set and the outcomes achieved. They will have a weekly meeting with the co-ordinator or manager where the work they have undertaken in relation to an individual's PCP will be reviewed.

A number of different opportunities are available to the people using the service in relation to learning and development around person-centred planning. The training department provide internal workshops on person-centredness. There is also a planning day on person-centred supports as part of the Rehabilitative Training Programme. Niamh has participated in QQI accredited modules within the service on topics such as personal effectiveness and community access. The interviewees reported that decision making is an aspect of almost every education module on offer in the programme. Niamh has also taken part in a workshop on PCP with Deaf Hear.

The service has recently set up a rights committee which will be involved in shaping policy and procedures, and in engaging with external agencies.

There is a service user council which meets monthly and provides information to the senior management team.

Presently there are no specific educational opportunities offered to families in relation to person-centred planning.

4.7.2. The PCP meeting

At the outset of the programme, Niamh spent time with her keyworker, exploring her interests, looking at ways to enhance her skills, and identifying priority areas for goal setting. Niamh expressed a strong desire to increase her independence and to pursue her academic studies. Her main goal was to go to college and she looked at the possibility of attending college on a part time basis and attending the RT programme for the remainder of the week. Niamh identified that the RT programme could support her to develop important skills in areas such as travel, money management and communication, which would benefit her in the longer term on a full time college course. Niamh also required considerable supports to set up the resources she needs to attend a local college.

Niamh and her facilitator drew up a plan. This plan was shared with her Mother and Aunt at a meeting. This meeting could take place in the day service, at home or in a community venue. Families are included in the PCP process only if the individual wants them involved. Niamh reported that her family were happy to attend the meeting and with the proposed action plan. They were given the opportunity to give their views and to ask questions.

At the early stages, Niamh discussed her plan on a daily basis with her keyworker. A more formal meeting was held weekly. Significant amounts of time were spent in the planning stage whilst they worked to establish contact and relationships with external agencies, for example Dublin Bus, the Primary Care Team, Access Officers, the local college. Each step in the process was clearly identified, the actions agreed and a list drawn up, for example a needs analysis, who to approach for support and in what order, alternative sources of funding, organising meetings, links with the community Occupational Therapist (OT).

One of Niamh's goals was to pursue a QQI level 5 qualification at a local college. Much of the work centred on accessing sources of funding to enable Niamh to recruit supporters; an interpreter, a note taker and a personal assistant were provided through the college. The lack of flexibility in systems and policies, in particular in relation to funding and recruitment, caused considerable frustration and time delays as Niamh worked to achieve her goal. There were a number of 'knock backs' but Niamh and her supporters continued to lobby and put forward her case to both the Department of Education, the local ETB and the HSE.

4.7.3. The content of the plan

Information is gathered and recorded on an ongoing basis. All the information gathered and the work undertaken is recorded in a written format in a PCP booklet and in a personal learning plan.

The PCP booklet is divided into different sections including the minutes of the introductory meeting, a needs analysis, the goal setting process, the supports required to achieve the goals set, progress reports and outcomes.

The interviewees commented that in the past, the focus of plans was on rehabilitation and training. Now they are more holistic and include more personal and social aspects. There is a focus on ensuring that people have a 'good life' beyond the hours of 9 to 4 with community connections, natural supports and circles of support highlighted.

If the person who owns the plan requires additional supports to understand and record information, then alternative systems can be used, for example picture based systems. Alternative and Augmentative forms of Communication (AAC) are also facilitated in the process.

The action plan contains long term goals broken down into a series of smaller short term goals, with those responsible for supporting Niamh identified. There are goals relating to personal development and aspirations, and also goals relating to education and training. Engagement in meaningful activities and the development of social roles are important components of the plan.

Niamh's current plan addresses:

- big life issues; college, career choices, employment
- everyday choices and activities; exercising rights, work experience, activities and social events
- building independence and skills; communication, travel (including addressing risks)
- community participation and social roles; volunteering, advocacy.

The person-centred plan is kept in an individual file in the office at the day service.

4.7.3.1. Community participation

Niamh uses a range of community facilities including public transport. She lives in a small village and the interviewees commented on the limited community links available to Niamh. Niamh is attending the local mainstream college where she has built relationships with staff and other students. Niamh has also established links with the deaf community through Deaf Hear, the Irish Deaf Society and the Deaf Village.

4.7.4. Reviewing the plan

Niamh and her keyworker determine how often the plan is reviewed. Niamh can touch base with her keyworker every morning if she wishes. At present, Niamh's plan is reviewed on a weekly basis through a formal meeting with her keyworker. The keyworker keeps a diary which logs all interactions and progress on specific goals. The keyworker also identifies any issues to be addressed, records links and contacts with external agencies, and notes any changes to goals or new developments.

The co-ordinator in the service looks at the diary on a weekly basis. They will suggest a review of the plan if they feel this is necessary. The staff team on the RT programme meet regularly and any concerns or issues in relation to individual plans or the PCP process can be raised at these meetings. Where possible, any issues that arise are resolved locally by the team. It was noted that the team try to be creative and resourceful in their approach, and to support each other.

If it is not possible to resolve issues locally, then the co-ordinator will bring the information to the Adult Services Manager. The co-ordinator submits monthly reports to senior management which outlines outcomes achieved and any resource issues or barriers experienced in supporting people to achieve their goals. A business plan or case for the allocation of resources can be developed and submitted to senior management if required. Information can also be brought to the attention of the CEO or the board where necessary.

Findings from the keyworker diaries and the monthly reports are collated across the different programmes. A range of different outcomes are measured including the numbers of PCPS completed, the number of reviews completed, the number of individuals accessing further education, the number of individuals in employment, the number of people participating in and achieving GAISCE awards or QQI awards. In addition information is kept on levels of participation in cultural, social and community activities.

4.7.5. Key supports

The following supports were noted as key elements in the development and successful implementation of Niamh's person-centred plan:

- the focus should be on the individual and the person must be treated and respected as an adult
- good communication between the person who owns the plan, the facilitators, the staff team in the centre, family and external stakeholders
- it is important that the person who owns the plan feels confident to speak out and to express their wants and dreams. It is also important that people understand how they communicate and can respond
- partnership and trust; people working together on an equal footing to achieve the goals

Research on current practice to inform the development of a national framework for person-centred planning in disability services

- quality relationships between the person who owns the plan and the facilitator; someone who knows you well, can keep you focused, understands how you communicate and get information, keeps personal information private
- staff who are willing to be flexible, to work differently and to step outside time restraints and rosters
- staff knowledge and expertise
- constant probing and reflection
- family involvement at every stage, if the person wants this
- strong links between the service provider, external agencies, the local community and families.

4.7.6. Challenges and barriers

- Time – availability of staff to engage in the PCP process
- Funding and resources
- Professional knowledge, expertise and the availability of MDT supports – hoists, IT equipment, communication supports, funding sources
- The medical model and resistance to change
- Communication barriers
- Inflexible systems and supports.

4.8. Michael

Michael is a male between the ages of 18 and 25 years of age, living in an urban location in the east of the country. Michael has Asperger's syndrome. Michael lives at home with his family.

Michael participated in the interview along with his Mother and his keyworker. The service manager was interviewed separately as he was unavailable to attend the first interview.

Michael communicates verbally and has good literacy skills.

4.8.1. Services and supports

Michael is attending a training and education centre run by a voluntary body providing supports for people with intellectual disabilities and/or autism. There is a specific focus on the provision of training, with both accredited and non-accredited programmes on offer. Michael attends this service Monday to Friday during the day. The service strives to deliver supports which meet the New Directions policy and there is a particular focus on independence, education and employment.

There is a PCP system and policy in place in the organisation which was developed internally.

4.8.1.1. Culture of the organisation

The culture of the organisation was described by Michael's keyworker and his mother as 'supportive' and 'open'. The interviewees noted that the organisation is 'built around person-centred planning' and so it is inherent in its systems and processes. The PCP process is 'clear' and the service manager explained that 'staff are very aware of and disciplined in their roles and responsibilities in relation to the development and implementation of individual plans'. The rehabilitation officer and psychologist are involved in the development of person-centred plans from the outset.

Communication in the organisation is good and the interviewees talked about a 'two way flow of information'.

The service manager described the referral process to the service and explained that a needs led analysis is completed with each individual before they start to attend the centre. This is the beginning of the PCP process. The centre offers a very specific type of programme, for a defined period of time, to candidates showing potential to progress to education or employment. It is not a permanent day placement and if the team felt the individual would not benefit from the supports on offer, then the referral would be rejected. The needs assessment is a way of ensuring that individuals are participating in programmes that meet their needs and ambitions.

The organisation uses a recognised quality assurance system. It is also a registered provider of QQI accredited training.

4.8.1.2. Positive risk taking

The organisation is working to promote a culture of positive risk taking. There is a risk assessment and management procedure in place in the service. If the issue of risk arises in relation to a specific goal for Michael, then this can be addressed at one of the PCP meetings. The team work to put the necessary measures in place to overcome any barriers which might arise.

4.8.1.3. Facilitators

Michael is the main facilitator of his person-centred plan and he explained 'I own this plan'. The initial PCP meeting is run by the regional psychologist or rehabilitation officer. The psychologist undertakes a needs analysis on a one to one basis with the individual and brings the findings from this process to the initial meeting. The psychologist drives the process at the outset and records all the relevant information throughout the process. The keyworker is involved in supporting Michael with planning and organising.

4.8.1.4. Learning and Development

Staff have ongoing access to learning and development opportunities in relation to person-centred planning through online training, webinars and work related mentoring and supports.

Michael completed an education module in decision making which he feels was very helpful to him in and ties in with the PCP process. His mother explained that she noticed positive changes in Michael following this module as he showed more awareness of his rights and an understanding of the importance of making choices and decisions.

Families are not offered any formal learning in person-centred planning, however they can attend an open day where person-centred supports are discussed and the importance of family involvement and information sharing is explained.

4.8.2. The PCP meeting

The first phase of the process and the first PCP meeting focus on discovery - finding out about the person, their strengths, interests and dreams. The organisation has developed its own templates for recording this information (hard and soft copies are kept). Potential goals are explored with the individual and their family. These are amended and updated throughout the process.

Michael has regular PCP meetings (approximately every three to four months) but there is not one formal annual meeting. He emphasised that he does not particularly like formal meetings and prefers 'if things are kept casual'. Michael also pointed out that some information and issues are private and he would prefer to discuss these one to one rather than bring them to a formal meeting. He noted that he would prefer not to discuss all information with his family or with managers, for example relationships:

"Not everything that is important to talk about is for a meeting...I want to keep some of it to myself...maybe just talk to one person about it or tell my close friends"

Michael can access written information but a range of photos are included in his PCP folder which highlight key events and achievements. The plan is written in the first person and the content focuses on Michael, his experiences, skills, choices and wishes. Again hard and soft copies of the plan are kept.

Michael is supported by the plan facilitators to arrange meetings at times which suit his schedule. Michael also determines the frequency of the meetings. Meetings are attended by Michael, his keyworker, family members, the psychologist or rehabilitation officer and on occasion the service manager. The completed plan is kept in the centre in an accessible location and Michael explained that he 'can look at it anytime'.

4.8.2.1. Family involvement

Michael's mother attends a number of the PCP meetings with Michael. She reported that the service is very accommodating and will try to schedule meetings at times that suit Michael and her. There is regular communication between the family and the centre. Michael's mother explained that she can ask questions, seek clarification, request more information or offer ideas and suggestions. She can contact the centre by phone for support if an issue arises. She can discuss the addition of a new goal or ask for a change to the plan if she feels this is necessary.

The interviewees highlighted the importance of teamwork in relation to person-centred planning.

4.8.3. The content of the plan

Information is gathered and recorded on a continual basis in an 'About Me' book. This contains information on the person, their skills, achievements, hobbies and interests, community participation, education and employment.

There is no medical or health information in the learner's PCP folder. This information is kept in a separate personal file which the service manager, psychologist and rehabilitation officer can access if necessary. Medical, therapeutic and mental health supports are accessed externally and generally kept distinct from the person-centred plan. Goals relating to health and well-being may be included in the plan if they are a key focus for the individual or if they influence other goals or support transitions and progression.

Instructors and keyworkers do not have access to this information except on a 'need to know' basis.

At each PCP meeting, a number of goals (usually 4 or 5) are set for Michael. These are selected by or with the person, in discussion with the family. There are usually long term goals which are broken down into a set of short term goals. Transitional plans and supports may be included in the goals set. There is an individual action plan and goal setting template which form an integral part of the PCP system.

Michael's current plan addresses:

- big life issues; education, employment, preferences for where to live – own apartment
- everyday choices and activities; sampling new activities and places, work experience
- building independence and skills; using public transport, healthy eating, shopping, preparing meals
- community participation and social roles; volunteering, GAISCE awards
- treats and occasional outings; holidays (if appropriate), day trips, GAISCE activity.

Michael commented that having a person-centred plan:

“It keeps you going and gives you something to do...it gets me around...I can learn something new”

For each identified goal, one or more people are assigned to support Michael to implement the plan. This could be Michael himself, his family, keyworker or a specific instructor.

Michael described his plan as 'perfect'.

4.8.3.1. Community participation

Michael uses the facilities in the community where he lives and also in the community local to the day service, including shops, public transport, leisure activities, restaurants, public services. Michael has also volunteered with a local community group as part of the GAISCE awards programme.

Michael's keyworker is trying to identify appropriate opportunities for community participation which draw on his strengths and interests. At present there are no members of the community in Michael's circle of support.

The team in the centre link regularly with external agencies, providers and stakeholders to support individuals to achieve their goals, for example respite services, employment services, local businesses for work experience, HSE clinical services and supports, social and community groups. They are also linked in with the Dublin Volunteer centre.

4.8.4. Reviewing the plan

Michael's plan is reviewed monthly with his keyworker and every three months with his family and other team members. Updated versions of the plan are added to the learner folder and old copies are filed. The schedule for reviews is driven primarily by Michael and his keyworker, however family or other team members can seek a review if they wish.

The service manager has access to all learner folders and person-centred plans. Where issues arise, these are highlighted by the instructors and keyworkers. Any concerns can be brought to the service manager or to the team meetings for discussion and problem solving. Plans can also be reviewed with the psychology team or rehabilitation officer.

All information relating to PCPs is recorded online and can be shared with senior management at any time. There are monthly regional management meetings which are attended by members of the senior management team – any relevant information in relation to PCPs can be raised here also.

The service manager records the monitoring and review process undertaken in relation to person-centred plans, along with the outcomes.

Michael's plan can influence the delivery of service locally, for example the timetable, activities and courses on offer, staff roles, staff recruitment. To date there have not been any issues with financial or staffing resources. The support from Michael's mother is also a key element in the implementation of the plan.

The organisation is currently conducting research on a number of its day service programmes. This is an internal review which will be published and will explore the outcomes achieved for individuals using the services, the programme development and the costs. The research will look at the perspectives of both staff and people using the services.

4.8.5. Key supports

The following were reported as the key factors in Michael's plan working well:

- The person leads the plan and owns the plan
- A good keyworker who knows you well and supports you to be independent
- Staff who know their roles and boundaries and don't create dependency
- Family involvement and support
- Good communication and listening
- Regular meetings and reviews
- A clear goal setting process with long and short term goals, and an action plan
- Organisational supports – staffing, financial supports
- Practical supports to achieve your goals
- A range of educational programmes which allow the person to develop their skills and interests
- Good staff to learner ratios
- Strong links with services in the community.

4.8.6. Challenges and barriers

- Money – personal and organisational budgets – ‘having enough money to do all the things you want to do’
- Lack of employment supports, for example job coaches, and employment opportunities
- Staffing resources could be a potential barrier
- More opportunities for accredited training would be good
- The focus in this centre is on day service provision – no option for supports in the evenings or at weekends. This can be restrictive, particularly in relation to social skills and supports.

4.9. Jack

Jack is a male between the ages of 26 and 50 years of age, living in a residential service in a rural location in the north-west of the country. Jack has a mild intellectual disability and mental health difficulties.

Jack was supported at the interview by his father, plan facilitator, the service manager from his day service and the managing director of the organisation providing his day service. The group chose to be interviewed together.

The day service takes the lead in the development of the person-centred plan.

Jack communicates verbally, articulating his thoughts, views and ideas clearly.

4.9.1. Services and supports

Jack attends a day support service which is provided by a small organisation. The organisation's model of support is person-centred, promoting individual achievements and empowerment. The aim is to deliver services and supports in line with 'New Directions' and 'A Vision for Change'.

There is a PCP system and policy in place in the organisation which was developed internally. The organisation is willing to use external and community resources to support individuals to achieve their goals. The managers described how they are willing to 'push boundaries' to achieve outcomes for those using their services.

Jack lives in a residential setting with 10 or more residents – the residential service is provided by a different organisation.

4.9.1.1. Culture of the organisation

The culture of the organisation is grounded in a person-centred approach. The PCP model is described as 'a two way learning process' and plans are a 'constant work in progress'. There is a focus on quality of life outcomes for people.

Although there is a clear PCP system in operation with specific templates and systems for recording information, the interviewees acknowledged that much of the work is informal and can take place 'over a cup of coffee'.

The service promotes a culture of positive risk taking and has a risk assessment and risk management procedure in place. The issue of risk may arise at referral and is addressed at the initial stages of engagement with the person and their family. The interviewees highlighted the importance of honesty and trust in relation to positive risk taking. The team use the expertise of the staff group and try to be creative in the use of resources when managing risks. They feel it is important to take on board fears and concerns, for example of family members, to assess each situation and to develop a step by step plan which addresses any obstacles to independence. The interviewees expressed the view that support for families is a key component to positive risk taking.

4.9.1.2. Facilitators

Each individual has a facilitator to support them to develop a person-centred plan. Facilitators can come from a range of different professional backgrounds. They are encouraged to start from 'a blank page' with an open attitude and with high expectations of the outcomes that can be achieved. Staff are aware of the need to be accountable for their work.

4.9.1.3. Learning and Development

The organisation does not provide any mandatory formal learning and development opportunities for staff in relation to person-centred planning. Instead they focus on person-centredness at the staff recruitment stage and deliberately seek to recruit people who they believe will work in a person-centred way. They are open and transparent about the values and priorities of the organisation, and look for individuals with key skills such as listening, empathy and creativity. Questions are structured during the interview process to tease out the individual's knowledge and skills in relation to person-centredness.

New staff are given the opportunity to shadow more experienced staff to learn about the PCP process and documentation. Less experienced staff can be coached and mentored by more experienced colleagues.

The organisation also uses external supports to develop staff skills, for example in relation to supervision. External facilitators are employed to provide additional support and mentoring to staff members, separate to their line management supervision. The external facilitators are skilled in working with people with disabilities and mental health difficulties, and with person-centred planning. This process gives staff an opportunity to discuss, review and reflect on their practice with a facilitator who is not engaged in the day to day management of the organisation.

At present the organisation does not provide any formal learning and development opportunities in relation to person-centred planning to families or people using the service.

4.9.2. The PCP meeting

The model of support focuses on a process rather than a one off meeting.

Jack explained that when he initially engaged with the service, he was nervous, shy and was feeling somewhat 'low'. Early stages of intervention focussed on profiling; this can take up to three months. The priority was to get to know Jack in a relaxed environment with 'no pressure'. One philosophy adopted by the organisation is to give people space, time and choice, and to allow them to lead the process wherever possible. The person is recognised and respected as the expert on their own life.

Jack was supported to work at his own pace and to begin a journey of self-discovery. He was allocated a facilitator who met with him almost every day and slowly discovered more about Jack, his interests, skills and aspirations. The interviewees noted that the relationship that develops between the individual and the facilitator is key, as is the support from family.

It was acknowledged that people need time to experience choice making, to understand the PCP process and to consider the potential benefits for them. It was suggested that it can take up to a year for some people to grasp the process of sharing ideas and to feel confident enough to express their true feelings and opinions.

Jack commented that the regular meetings and planning sessions:

“Gave me something to get out of bed for...a place to go”

There is a ‘settling period’ as the relationship develops and the person builds their confidence. Jack explained that he welcomed the regular one to one support and the steady, relaxed pace which made him ‘comfortable’ with the process. He described how he had set goals in the past but the ‘time wasn’t right and I wasn’t ready’.

“Everything else was too rushed...all my life...I took my time...chose the right moments for me and ticked the boxes that were right for me”

“I am hungry for it now and that’s the difference”

Jack gave an insight into the challenges of person-centred planning for individuals with mental health difficulties. He highlighted the fact that at times in your life, your physical or mental well-being is the most important thing and takes priority over other goals and dreams. ‘Getting better’ has to be the main priority along with managing simple everyday activities. At these times the person may not be in a place to develop relationships or to share their ideas. Jack emphasised the importance of one to one time and the model of individual supports:

“I couldn’t do this (PCP) without being happier but I couldn’t even say that I was not happy. The most important thing was to find happiness in myself. I had to concentrate on myself...I needed the doctors and my family to help me”

The process is ‘aspirational but practical’. As the facilitator gets to know the individual, they share ideas around potential goals. Where possible these are of the individual’s own choosing but it was agreed that some people may need gentle prompting and encouragement:

“It is important to get the balance between not pushing someone and that gentle nudge at the right time which can make the difference”

Different options are presented which the individual can take time to consider. The facilitator looks at the person and where they are at that specific moment in time. They try not to focus on the past unless a particular issue needs to be addressed for the individual to move forward. The interviewees explained the importance of ‘respecting no’ if that is the choice of the individual. Jack described how in the past, he might have gone along with suggestions and lacked the confidence to speak up. His father suggested that previously Jack may have suppressed his real emotions or opinions but this process has given him the skills to ‘tell it straight’ and to ‘have a vision’. Now Jack understands that he ‘can chop and change goals’ if he wishes and can ‘speak his mind’.

Jack and his father highlighted the importance of a skilled facilitator who understands the person well and can pick up on small and subtle changes in their mood or behaviour, which may give important clues on their levels of satisfaction with the goals and the process. Where difficulties are noticed early on, they can be discussed and problems solved.

The organisation has developed systems and templates for recording personal information and goals set across the different stages of the process.

4.9.2.1. Family involvement

Family are actively included throughout the process with the agreement of the individual who owns the plan. Jack's father explained that he has been kept informed at all stages of the process. The family are invited to attend meetings and are aware of the goals set with Jack, and the progress he is making towards achieving them. Jack can choose to share information with his family and will often talk over his plans with them. The family can communicate with the service through formal and informal face to face meetings, and through telephone calls.

4.9.3. The content of the plan

Once sufficient information has been gathered, the process of goal setting begins. The organisation uses the Goal Attainment Scale to help identify the priority areas for intervention and support. There are long term goals (get a qualification) and 'super long term goals' (hold down a job), which are broken down into much smaller steps (make a phone call). There is no limit on the number of goals set but individuals are encouraged to prioritise.

The action plan and information on progress towards goals is documented in a development log every week. The implementation strategies are clear and responsibilities are well-defined. Jack can have his own copy of each document if he chooses.

Jack's current plan addresses:

- big life issues; career and employment, move to independent living
- everyday choices and activities; music activities, daily routine
- building independence and skills; literacy classes, money management, personal care
- community participation and social roles; educational opportunities, social groups, establishment of community links
- treats and occasional outings; specific purchases, social events, holidays
- milestones towards achieving personal goals; paying rent, work experience, preparing a CV, interview practice.

4.9.4. Reviewing the plan

Jack's plan is developed through a process of discussion, trial, review and reflection. The interviewees described how they 'learn as they go along'. Even if goals are not achieved or if goals are changed along the way, Jack's facilitator explained that there is 'still value in the work undertaken'. Jack suggested that you can learn from situations that didn't work, and gain something positive even if the outcome was negative. Jack decides how and when his plan is reviewed.

Staff supervision sessions are provided on a monthly basis and offer an opportunity for facilitators to discuss PCPs. These supervision sessions include opportunities for support from a supervisor who is not employed on a day to day basis by the organisation, but has a background in rehabilitation, disability and person-centred approaches.

There are a number of ways in which the process and the work undertaken are monitored and evaluated. Management seek regular feedback from people using the service and from staff on the progress and outcomes. As this is a small organisation, there is regular face to face contact between the individual who owns the plan, staff and management. The service manager will link with facilitators and review the documentation gathered. Any challenges or difficulties will be addressed at a local level to begin with. If a plan is 'stalling' or if additional resources are needed to enable the person to achieve their goals, the service manager will bring this to the attention of the Director, the Board of Directors or the HSE. The interviewees reported that 'generally management will find a way to meet needs'.

The organisation provides information to the HSE on their programmes and on the outcomes achieved for individuals. They also conduct an annual audit which includes PCP goals and outcomes.

When asked about his plan, Jack commented:

"I wouldn't change a thing".

4.9.5. Key supports

The following were reported as the key elements in good person-centred planning:

- The person who owns the plan needs to be motivated and has to want to have control and to make decisions about their life – Jack suggested that some people are not in the right place to engage in the PCP process, particularly if they are experiencing mental health challenges:

"Be who you are. Believe in yourself and what you can do. Never give up."

- A skilled facilitator; patient, honest, real, be present and in the moment with the person, be interested, be at the person's level, accept them for who they are, listen, don't have preconceived outcomes and go with the flow, persevere, accept that you don't have all the answers
- Time; allowing the person to go at their own pace, to think and to make the right choices

- Space to create quality relationships
- Mutual respect and trust
- A desire from all involved to facilitate empowerment
- A clear structure and process
- Family involvement and support; an understanding of the process and the benefits
- Good communication
- Regular opportunities for feedback
- Focus on achievements and progress.

4.9.6. Challenges and barriers

- Person themselves if they lack confidence or motivation. Jack explained that sometimes you can 'put yourself down', 'have self-doubt'
- Poor attitudes and low expectations of the person or the process
- Transport in rural areas can be a significant barrier to people achieving their goals, particularly in the evenings. This can have financial implications as individuals may have to rely on taxis
- Literacy and numeracy skills
- There is a need for education and skill building for families at an early stage in the process
- Resources can sometimes be an issue
- Awareness; the community is not yet thinking about person-centred supports and the role they may have to play in this
- There is a need for service provision outside of day service hours (evenings and weekends) to facilitate social and community supports. At present the service is reliant on the goodwill of staff to enable some individuals to achieve their goals. The organisation has approached the HSE for additional resources to extend their hours and provide more flexibility. This barrier is particularly significant when it comes to supporting people to develop friendships and relationships.

4.10. Ciara

Ciara is a female between the ages of 26 and 50 years of age, living in a residential service in an urban setting in the mid-east of the country. Ciara has a complex physical disability and a mild intellectual disability.

Ciara participated in the interview along with her plan facilitator and the manager from her residential service. Her family were not available to attend. Ciara communicates verbally.

4.10.1 Services and supports

Ciara lives in a residential service with three other residents and attends a day support service. Both the residential and day service are provided by one organisation, a voluntary body providing services to people with intellectual disabilities and autism.

There is a PCP policy in operation in the organisation which was developed internally. There is no quality system or outcome measurement system in use at present.

The current PCP system began prior to the implementation of HIQA inspections. The interviewees reported that the feedback from inspections was positive, which boosted staff morale and reinforced the rationale and the process. Compliance with the Regulations is good and the inspectors were happy with the documentation provided in relation to person-centred plans.

4.10.1.1. Culture of the organisation

The culture of the organisation is described by the plan facilitator and manager as 'encouraging', 'focused on the individual', and 'ambitious'. Those using the service are encouraged to 'have high expectations and to dream'. The interviewees noted that managers are open to ideas and willing to listen. There is a desire for change and resisters are not allowed to block progress or veto the system. There is a sense that 'nothing is off limits' and 'all options can be explored'.

The service promotes positive risk taking and there is a risk management policy in place. The plan facilitator reported that staff feel 'well supported' and that managers 'have their backs'.

4.10.1.2. Facilitators

Ciara is the lead facilitator for her plan. The organisation has employed a team of PCP planners (four in total) for the last two years. The role of the planner is to support individuals to develop and implement their person-centred plan. These facilitators are external to the day and residential services and act as a pair of 'fresh eyes' whose complete focus is on the PCP process.

Ciara expressed the view that this model worked very well for her. The planner took time to get to know her and to support her to communicate her dreams and wishes. The interviewees compared the PCP process prior to the introduction of planners with the current system:

Before:

- Not so well co-ordinated
- Staff had limited time to do a person-centred plan – often the process was rushed
- The responsibility fell mainly on the keyworker
- The focus was on the annual meeting rather than the ongoing process
- Ciara felt she didn't give her own opinions as much or make as many choices
- Ciara felt the system was not particularly transparent.

“Years ago things might have been forgotten about...now it's been told to everyone...not just one person who can help me...everyone knows my goals”

Currently:

- Planner works in a co-ordinated way and has a 'single focus'
- Process feels 'tighter' and 'more controlled'
- The plan comes together more quickly and is more holistic
- The documentation is clearer and more user friendly
- There is an ongoing process – 'you are thinking about goals all the time'
- There is more weight behind the system and people are more committed to it
- There is a sense of shared responsibility
- The evidence and outcomes are more transparent – 'you see the full picture'. The evidence gathered is more robust.

4.10.1.3. Learning and Development

The organisation provides QQI accredited learning and development modules at level 5 in person-centred approaches. This is provided to specific staff groups. Staff also receive ongoing mentoring and support from the team of planners.

Ciara explained that she has completed a QQI level 3 module on self-advocacy. She has participated in advocacy groups and service user representative groups in the organisation and local area. Ciara felt that this knowledge and experience has helped her with the person-centred planning process.

Currently family members are not provided with any specific learning and development opportunities on person-centred planning.

4.10.2. The PCP meeting

Ciara works with her planner to develop a person-centred plan. To begin with, an assessment of need is undertaken with the support of day and residential staff, and clinicians. The planner tries to merge the information from the assessment of need with the information gathered during the PCP process.

Ciara and her planner organise an initial meeting with the keyworkers from residential and day services. Family members are also invited to attend. A date is arranged which suits staffing rosters and Ciara's schedule. Although Ciara receives regular clinical supports from the organisation, individual clinicians are not usually invited to attend the PCP meeting as the focus is on Ciara's dreams and wishes rather than on very specific medical or clinical needs. Clinicians do provide information and support if their input could have a direct impact on short or long term goals.

A formal PCP meeting happens at least once a year but there are regular update meetings in addition to this. The meeting is held at a venue of Ciara's choosing.

Ciara reported that usually she has a number of ideas for goals which she brings to the meeting. The planner, keyworkers and family members may also bring their own ideas. The meeting is a chance to look back at and celebrate achievements, as well as a chance to plan for the future.

Although specific goals are set at the annual meeting, these can be adapted over the course of the year. Ciara explained that sometimes goals are achieved quickly or other more important goals or new opportunities arise and the plan needs to be changed. The interviewees commented on the importance of flexibility.

Long term goals are broken into a series of steps. A timeframe is set and those responsible for supporting Ciara are identified. The interviewees noted that it is important for each member of the circle of support to be clear on their roles.

Each person has a copy of their plan which is accessible and meets their communication and literacy support needs. A copy of the plan is kept on file in both the day and residential services. Ciara can access her files at any time.

4.10.3. The content of the plan

A template has been devised by the staff team which is used to gather and record PCP information. There are seven main areas addressed in the document; it is not necessary to include a goal for each of these areas. The seven areas are daily living, physical and emotional well-being, relationships, work and career, finance and possessions, fun and leisure and formal education.

Ciara's current plan addresses:

- big life issues; buying a car, moving to a different part of the town
- everyday choices and activities; changing model of day service
- building independence and skills; courses, managing money, job support plan
- community participation and social roles; developing and maintaining relationships and natural support networks
- treats and occasional outings; holidays, Spa trips, concerts
- milestones towards achieving personal goals; paying rent, work experience, preparing a CV, interview practice.

The service works to develop relationships with external stakeholders and community groups. There is a desire to include services and supports which are outside the organisation in the PCP process but it was noted that this can be challenging and community resources are limited. Members of the community would be welcome to participate in circles of support if they have developed a meaningful relationship with the individual and if the individual wants them involved.

4.10.4. Reviewing the plan

The interviewees acknowledged that the current system is a relatively new initiative in the organisation. Much of the focus to date has been on establishing the system and the role of the planner. The next step is to explore more formal ways to measure change and identify quality of life outcomes for people. Anecdotal evidence would indicate that there have been significant outcomes for individuals.

Currently the system recommends that the planner meet monthly with the individual and their keyworker to go through the plan and identify progress, issues and next steps. The centre manager also links with the Person in Charge (PIC) or their line manager to provide an update on progress on a quarterly basis. The residential staff team meets every 6 to 8 weeks with the planner to share information.

The senior management team in the organisation reviews data in relation to specific outcomes and interventions such as employment supports, family involvement, person-centred plans, and community involvement. Senior managers develop area team plans. Issues and concerns can be 'moved up the chain' if necessary. There is an internal audit which looks at action plans and the number of goals achieved. Internal recording systems also identify if plans have not been developed, if annual meetings or reviews have not taken place and if goals have not been achieved.

4.10.5. Key supports

The interviewees identified the following elements that worked well during the PCP process and contributed to the development of a quality plan for Ciara:

- A holistic approach where all aspects of a person's life are pulled together in one plan

- An independent planner with a defined role; ‘someone different to work with’, ‘someone to see the bigger picture’, ‘this person is focused on the task and not distracted by everyday tasks’,
- Teamwork; the person who owns the plan, their planner, day and residential staff working together to achieve the goals
- Management attitudes, approach, support and ‘buy-in’
- Staff training
- Good communication and information sharing
- A focus on goals and outcomes
- The involvement of family and friends
- Regular contact with the planner and regular reviews which involve other key people.

4.10.6. Challenges and barriers

- Sometimes health or life issues can get in the way of plans. It is impossible to control everything; Ciara explained that one of her goals was to travel to England but health issues meant this had to be deferred. The goal was changed to a short hotel break in Ireland
- Resources, in particular in relation to staffing and rosters, for example staff annual leave or sick leave can cause a delay with work on setting or achieving goals. Where individuals have complex medical support needs, nursing staff may be needed for outings or trips, and this may impose restrictions. Staff changes can also impact on plans. The team identified that this is rare but delays can occur from time to time
- Resistance to change can sometimes hinder progress and development. A small number of staff were dubious about the idea of an external planner coming into the service
- Transport issues
- Accessibility issues on some public buildings.

5. Findings from the key informant interviews

The case studies in the previous section provide examples of individual practice. This section of this research consists of four key informant interviews, which provide a separate and broader perspective on person-centred planning practices in residential services across the country. There is no overview available of other services as there is no regulation or inspection process in place. It is important to consider the circumstances and contexts from which some of the observations in this section of the report are drawn.

Two of the interviewees are employed by HIQA in the roles of Inspector and Inspector Manager, and two are employed on the HSE Quality Improvement Division/ Social Care Division - Quality Improvement Programme. The HSE interviewees emphasised that they are currently working in large congregated settings, where the medical model dominates and where residents tend to be over fifty years of age. The HIQA interviewees have carried out inspections in a wide range of settings including congregated and campus settings, and smaller community residential houses.

The interviewees have experience of person-centred planning (PCP) across a range of different service providers and geographical locations. All four interviewees drew on their experience in both current and previous roles, including as frontline members of staff in disability services.

The interviewees made a number of key points at the outset of the interviews:

- There are pockets of very good and sometimes excellent practices around the country, but these examples are not recognised or championed sufficiently
- There are very different views in the sector on what ‘person-centredness’ and ‘person-centred planning’ are. In the main, there seems to be a poor understanding of what a person-centred approach actually means in practice
- There is extensive variation in practice across the country
- Overall the quality of person-centred plans tends to be poor

HIQA measures to support person-centred planning

The HIQA interviewees explained that a number of measures have been taken by HIQA which support the person-centred planning process. Additional training has been provided to inspectors to ensure they are clear on expectations in relation to person-centred planning and goal setting.

Initially inspectors may have had little knowledge of person-centred planning and may have focused on the Regulations. One HIQA interviewee noted that since January 2016, poor practice in person-centred planning is highlighted more often, and there is more commentary on PCPs in inspection reports.⁶ The current Quality Assurance (QA) process within the organisation is designed to identify examples of both good and bad practice, with Inspector Managers seeking clarification on specific points and pushing inspectors to triangulate non-compliance.

5.1. Emerging Themes

The broad themes and sub themes which emerged from the interviews are classified under the main headings below:

- Environment
- Culture and Ethos including management and leadership
- Learning and Development
- Plan Facilitation
- Goal Setting
- Evaluation.

5.2. Environment

5.2.1. The physical and social environment

The physical environments in which some people reside are described by the interviewees as ‘dismal’, ‘poor’ and ‘unacceptable’. In some instances residents are living on wards in hospital settings with little personal space and privacy. Their supports are provided mainly by nursing and care staff, sometimes wearing uniforms. Other residents are living in large campus settings in houses with six to ten people. The interviewees expressed concern that the medical model dominates in large settings, however, even when individuals move from these settings to smaller centres, the model can persist. All four interviewees felt that services tend to focus on care rather than on the outcomes achieved with individuals, and they noted that staff can have a poor understanding of ‘what a good life’ means and ‘feel good care equals a good life’.

In many large settings, there is little opportunity for community engagement and participation; some people rarely get the opportunity to leave the main campus.

⁶ One strand of the research to inform the development of a national framework for person-centred planning is an analysis of what HIQA inspection reports say about person-centred planning in residential services.

The goals set for individuals are described as ‘basic’ and ‘limited’, for example going out for coffee, going to mass, visiting the local pub for a pint. However, the interviewees noted that achieving even these apparently simple goals in such circumstances can be difficult. Opportunities for education, employment and the development of social roles are severely restricted.

HIQA recognise that they ‘need to be proportionate’ in such situations and the HIQA interviewees explained that they are ‘looking for positive steps in the right direction with clear signs of progression for people’. The HIQA interviewees outlined that they are required to regulate in campus settings but they are not responsible for decongregation. They felt that the Regulations can be very important in trying to achieve outcomes for people, particularly in relation to engagement and community participation.

5.2.2. Support networks

The interviewees recognised that many older people living in congregated settings have minimal family contact or natural support networks. As contact with the wider community is so limited, there are few opportunities to build relationships, to engage with people beyond the campus, and in turn to develop circles of support. One interviewee explained that they ‘had never seen external supports used to help an individual achieve their personal goals’. Services are described as ‘looking within themselves rather than outside for supports’, with one interviewee expressing the view that services are going backwards in this regard.

5.2.3. Advocacy

Some interviewees reported on a lack of access to independent advocacy services and supports, believing that this exacerbates the issues with person-centred planning in congregated settings. It was noted that self-advocacy platforms tend to be driven by people with mild intellectual disabilities, who are verbal, can express their views and ideas, and often live independently, with families or in small residential settings in their local communities. Some of the interviewees emphasised the importance of hearing the views of people with more complex disabilities who are non-verbal, communicate in different ways and live in congregated settings:

“We cannot presume that individuals involved in advocacy groups and platforms can represent the views or lived experiences of those with more complex disabilities living in congregated settings”

These individuals may have limited life experience and understanding of consultation, and rely heavily on staff to champion their engagement in decision making and service planning.

5.3. Culture and Ethos

The interviewees all agreed that the culture and ethos of an organisation is of paramount importance to the implementation of a high quality person-centred planning process. All expressed concern that the culture can be ‘negative’, and can be ‘pervasive’ across centres and geographical locations.

The focus may not be on the individual or on improving their quality of life; instead there can be an over-emphasis on the needs of the staff and the organisation. It was identified that organisations need to be ‘person-centred from the top down and bottom up’, and need to embrace the values of individuality, dignity, respect, empowerment, choice and independence.

5.3.1. Management and Leadership

It is recognised that management and leadership is directly related to culture and ethos, and there was strong agreement that positive and proactive leadership, focussed on the needs and rights of the individuals using the service, is essential to good person-centred planning.

5.3.1.1. Governance

It was noted that often the required governance systems are not in place to support person-centred planning. All four interviewees felt that clear organisational structures with defined roles and lines of accountability are necessary, but often absent. The HSE interviewees suggested that the focus of some leaders may be solely on compliance with HIQA or on financial management, stating that this can have significant long term consequences for service development.

5.3.1.2. Leadership skills

The interviewees felt that in order for managers and leaders to drive the person-centred planning agenda, they should have good communication skills and be capable of developing strong working relationships with individuals, their families and staff. They must have an open door policy and be willing to listen to the people using the service and to the staff working in the service.

There was agreement that managers need to be willing to tackle culture change and to deal with HR and IR issues in workplaces. They should be intolerant of poor practice and must seek to introduce disciplinary and performance management procedures. Equally they must be willing and able to recognise, value and promote good practice.

5.3.1.3. Staff morale

The HSE interviewees reported that staff morale, particularly in large congregated settings, can be very low. Staff feel under significant pressure in their roles and feel undervalued. There are ongoing issues with high levels of absenteeism and with staff turnover. They report that staff feel ‘battered by HIQA’ and ‘unsupported by the HSE’. There is a reluctance to engage in career development initiatives and it can be difficult to recruit staff to ‘person in charge’ roles, as they are viewed to have ‘too much responsibility’ and to be ‘too much hassle’.

All four interviewees commented on the need to value and support staff, with one individual noting that:

“the way we treat staff is reflected in how they treat and support the residents”

5.3.2. Expectations

The interviewees commented that generally service providers and staff tend to have low expectations of individuals and of person-centred planning processes and outcomes. There can be a lack of recognition of the importance of person-centred planning, a lack of understanding that this can be a key driver for the person's life and 'little understanding of what is important in people's lives'.

Within congregated settings, one interviewee identified that families have low expectations in relation to levels of community engagement, education and employment. Families are familiar with the 'care' model and seldom challenge this.

5.3.3. Readiness to change

All agreed that readiness to change and a flexible approach are essential components in moving services forward and striving for best practice. However, the interviewees explained that they often encounter a lack of understanding of the need for change, a lack of desire for change or a strong resistance to change. It was reported that this can arise from a lack of knowledge and skills, a lack of leadership or a climate of fear. Both managers and staff can lack confidence and can be reluctant to use their own initiative in case 'they do the wrong thing'.

Industrial Relations (IR) and Human Resource (HR) issues dominate in some services, for example in relation to roles, rosters and performance management. This can make it very difficult for providers to change poor practice, particularly where there is union intervention on behalf of the staff. The HIQA interviewees noted that their focus is on compliance with the Regulations. Service providers must make all the necessary changes to comply or face closure; the Regulations can over-ride HR and IR issues and support providers and staff to tackle issues of resistance and reach resolutions.

The HIQA interviewees highlighted that where providers and staff are motivated, creative, and willing to be flexible, significant positive outcomes for individuals were reported.

5.3.4. Positive risk taking

All four interviewees described a lack of positive risk taking across services. Some noted a culture of fear where staff and supporters can be risk averse. This was attributed to a lack of support from management and to the interventions of family members. The interviewees suggested the need for robust risk management policies and procedures within which individuals are protected yet supported by staff and families to make decisions, develop their independence and engage in new and meaningful activities. One of the HIQA interviewees commented that providers are 'becoming more aware of the need to balance rights and risks'.

"HIQA are keen to support this and to ensure they (HIQA) don't become a barrier to positive risk taking"

5.3.5. The influence of HIQA and the Regulations

In some services, managers were reported by all four interviewees to be ‘overly concerned’ with inspections. As a result they have ‘taken their eye off all other issues’. All interviewees reported a ‘sense of panic’ amongst some managers and leaders. This may have been exacerbated by the publication of inspection reports and recent media coverage of disability services. This ‘panic’ leads to ‘knee-jerk reactions’ and ‘firefighting’ rather than proactive management. Both the HIQA interviewees and those from the HSE described a ‘blame culture’ where staff are fearful of making mistakes. Where providers are non-compliant with the Regulations and Standards, often the focus of blame is put on individual staff members rather than the organisation, its culture, processes and policies. This stifles creativity and innovation and reduces the quality of supports provided to people with disabilities.

In other services, the interviewees described ‘a complete lack of urgency’ and a ‘sense of complacency’, even when inspections have highlighted a significant number of areas of non-compliance. There was a sense that some managers do not have the skills or expertise to understand and make the changes required by HIQA. The ‘Person in Charge’ was identified as one of the key supports in the delivery of quality person-centred supports, but it was noted that some do not have the required knowledge or skills to do this, for example an understanding of person-centredness, skills in leadership and performance management, experience of goal setting. There was a strong consensus that inspections and regulation can be used as an ‘excuse’ for poor management practice with leaders complaining that they are ‘too busy with HIQA’ or ‘overrun with paperwork’.

5.3.6. Management of resources

It was acknowledged that many providers are endeavouring to deliver services and supports with limited resources. However it was suggested that in some cases, resources are poorly managed and utilised. One HIQA interviewee identified that providers can spend significant resources in an attempt to meet the basic Regulations, which can leave very little money for PCP related activities.

“There is a lack of connection between the Regulations and person-centred planning. If there are good PCP processes in place then providers will be compliant with many of the Regulations and Standards....there needs to be a move away from putting things in place to please HIQA to focusing on the person...nothing in the Regulations goes against person-centred planning but there is a sense out there that it does”

5.4. Learning and Development

5.4.1. Learning and development for people with disabilities and their families

The interviewees recognised the importance of education and learning for people with disabilities and their families in relation to person-centred planning and decision-making, however, they could provide little evidence of this happening in practice.

5.4.2. Learning and development for staff

The interviewees highlighted that practices vary enormously across providers in relation to staff education in PCP. In some services, staff have no specific opportunities for learning and development in relation to person-centred planning, so they work off their own perspective on what this means. Other providers develop their own internal learning and development programmes or engage external consultants to deliver programmes. These programmes can be influenced by specific PCP approaches and practitioners. One of the HIQA interviewees noted that sometimes staff training and education can be:

“A box ticking exercise which providers believe will please HIQA or help them comply with the Regulations”

All four interviewees agreed that staff learning and development in PCP must deliver attitudinal change and must have a direct effect on the quality of services to residents. In the main, it was felt that staff are well intentioned; they are seeking change and welcome advice and recommendations.

5.4.3. Evaluation of learning and development

The interviewees expressed the opinion that learning and development must be evaluated to ascertain the transfer of knowledge and skills to everyday practice. This is not commonly undertaken and there appears to be little attention paid to outcomes.

Some services have bought in additional PCP learning and development for staff from external consultants. This has significant financial implications, yet the interviewees report that service providers still don't seem to evaluate these programmes to determine if there are any real outcomes for the people using the service. The interviewees expressed the view that these programmes seem to bring little change in PCP practice; one interviewee described how a group of external consultants were brought into a specific service to deliver a module on PCP. She explained that this intervention did not resolve any of the outstanding issues in the centre, which related primarily to culture, ethos and management practices. The interviewees stressed the need for ongoing mentoring and coaching for staff in relation to person-centred planning and in particular around goal setting and outcomes.

One of the HIQA interviewees expressed the view that:

“It would be better if providers got to know their residents rather than bringing in external people. Providers needs to get involved themselves from top down”

5.4.4. Skill mix

All four interviewees spoke about the skill mix in centres and organisations. All agreed that education and qualifications are important and can be an indicator of the type and quality of the service. However, the interviewees felt that the skill mix and staffing ratios can be poor and are not comparable across the country. This may be due to historic practices, recruitment issues in particular geographical areas, or related to funding and the allocation of resources.

The HIQA interviewees explained that they can and should look at the skill mix in a service as part of the inspection process. They also identified that this is often not a feature of the work undertaken by providers when they carry out assessments of need.

The HSE interviewees emphasised the need for clarity on the distinction between roles – nurse, social care worker (SCW), care assistant. They described how some care assistants can be under-utilised due to a lack of flexibility in the system and IR issues around roles and responsibilities. One example of this relates to the administration of medication; some of the interviewees noted that the policies of some service providers state that medication must be given by a nurse, therefore it is not possible for an individual to go out into the community with a care assistant if they need to take a tablet during the day. If there is no nurse available to go out with the person, then the trip must be cancelled.

The role of Social Care Workers arose on a number of occasions during the interviews. One of the HIQA interviewees explained that SCWs should be able to develop quality person-centred plans, expressing the view that this is a core competency of the profession, and should be linked to fitness to practice. The interviewees reported that in some geographical areas there are very few or no SCWs and this has serious implications for service development.

The HSE interviewees also highlighted a lack of qualified and experienced Intellectual Disability Nurses. Nurses working in congregated settings particularly tend to be from either a general or mental health background and can be too focussed on medical issues.

5.5. Plan Facilitation and Goal Setting

The interviewees highlighted a number of key factors in the facilitation of person-centred plans and the development of personal goals. It was recognised that many residents really enjoyed their planning meetings which were a valuable and special occasion for them.

5.5.1. The facilitator

There was strong agreement that the plan facilitator tends to be the keyworker. This person can be from a variety of staff roles. It was recognised that good facilitation demands a person who is:

- clear on their role
- focussed on the task
- knows and understands the person well
- understands person-centredness and the PCP process
- is organised and motivated
- knows how to record evidence

It was accepted that the keyworker role is important to and highly valued by the individuals who own the plans.

The interviewees described the different levels of involvement of people with disabilities in the development of their plans. It was reported that in a handful of situations the person clearly owns their own plan and is the lead facilitator. In such cases the person is involved in all aspects of the development of the plan – from organising their own meeting, deciding who will be invited, choosing the venue, setting goals, having their own copy of the plan etc. When this happens and people are well supported, there can be excellent outcomes. It was recognised that in more progressive services, staff can do ‘amazing things’ to support individuals to achieve their goals.

Where practice is poor, the following observations have been made:

- a meeting can happen without the person attending
- a meeting can happen without the person being aware it is on
- relief staff or new team members are asked to produce PCPs in very short time periods (during night shifts)
- plans are based on the instincts and perspectives of one staff member only
- plans are locked away in offices and nurses’ stations

5.5.2. Involving Families

Where the individual had contact with their family, efforts would usually be made to involve them in some way in the PCP process – for some families this might mean an invitation to attend the meeting, a phone call with a keyworker, or receiving a copy of the plan. Other family members are involved in supporting people in a practical way, on a very regular basis, to work towards their goals, for example supporting an individual to go on holiday or learn a new skill.

The level of family involvement was described as ‘hit and miss’. It was noted that the records may suggest that the family were involved but the evidence might indicate that this was minimal.

One of the HSE interviewees commented that some families can be overly focused on care and on protecting the individual. This can restrict the individual’s independence and affects goal setting.

5.5.3. The use of templates

The interviewees reported that most organisations use templates for person-centred planning, which have either been designed and developed internally, or shared from another service provider. One template tends to be used for everyone and there is little individualisation in evidence; one interviewee suggested that ‘the one size fits all approach’ is indicative of ‘the underlying lack of understanding of what a person-centred approach actually is’.

Whilst it was acknowledged that templates can provide guidance for inexperienced staff members, all four interviewees expressed concern that at times the focus appears to be on the paperwork rather than the outcomes. Specific issues arise where templates are 'borrowed' from other services, and are used in the absence of clear policies on person-centredness and clear directives for staff.

Some providers claim to use specific PCP tools or approaches, however it was noted that this practice is rare. One of the HIQA interviewees explained that they have undertaken around 160 inspections and have only seen a specific tool in use maybe two or three times.

The interviewees accepted that the inspection process may play a part in the over-focus on paperwork, with inspectors paying too much attention to this aspect of the process. HIQA acknowledge they have a role to play here and are trying to 'encourage inspectors to look beyond the documentation to the quality of life outcomes for individuals'.

5.5.4. The content of plans

The content of each person-centred plan varies considerably both within services and from one service to another. Generally they are reported to be 'huge files' with 'everything in' and with 'huge duplication of work'. Some services have distinct care plans or support plans, and person-centred plans, whilst others combine both. The interviewees commented that PICs are afraid to leave anything out of the file in case the HIQA inspector wants to see it and often 'put huge work on themselves trying to please HIQA'. The HIQA interviewees expressed concern that PCPs can be driven by what service providers think HIQA or individual inspectors want, rather than driven by the individual. One example was given of the same template and goals being used for individuals across a service, because one inspector commented that it was good in one location for one person.

It was noted that there is a lack of clarity and understanding of the difference between care plans and person-centred plans. It was suggested by the HSE interviewees that HIQA have added to this confusion as there is a lack of consistency between inspectors in this regard. The HIQA interviewees explained that the PCP process should start with the assessment of need. HIQA do not prescribe what a person-centred plan should look like, but there must be a comprehensive assessment of need and following this a personal plan must be developed. Both health and social needs must be addressed. It was noted that residents are often not involved at all in the assessment of need and so from the outset the process is not person-centred.

5.5.5. Supporting communication and accessible information

There was strong agreement amongst the interviewees that good practice in person-centred planning requires staff to facilitate people who communicate in different ways and to create accessible information. Again there was evidence of wide variation in practice.

In some services there was a reported lack of knowledge and expertise, with unskilled staff members struggling to provide the necessary supports to enable people to experience control, get and give information, and make choices and decisions. There can be a lack of creativity as well as a lack of practical supports such as training programmes, IT equipment, broadband, and visual resources like symbols databases. It was noted that HIQA have begun to identify these resource issues in their inspection reports.

All four interviewees stressed that sometimes staff and HIQA inspectors 'think something is accessible when it is not'. Examples provided include complaints policies, PCP templates, schedules and reports. At times there is no obvious value to the resident yet staff have clearly spend a lot of time and energy creating what they believe is accessible or what they believe an inspector wants to see.

Some PCP measures can be tokenistic with a 'one size fits all' approach to creating accessible materials and supports. For example the same 'Easy to Read template' used for everyone regardless of their skills, or only one section of a document produced in an accessible format.

There can be very limited access to Speech and Language Therapy (SLT) supports; in some settings the focus of the SLT service is on dysphagia rather than communication. Where communication interventions are available, they can be confined to a one-off assessment and staff rarely have the opportunity to work alongside a therapist to build their own skills and capacity. Sometimes assessments are only sought following non-compliance with the Regulations. Reports and guidelines may be present for some individuals but there may be no follow through on the recommendations.

The HSE interviewees reported that staff have identified the particular challenges they face in supporting people with autism and/or severe and profound levels of intellectual disability, who may be non-verbal. The interviewees conceded that staff request communication training on a regular basis but this is not always forthcoming or sufficient to meet their needs.

The interviewees commented on the lack of Alternative and Augmentative Communication supports such as Lámh signs, visual communication systems, I-pads and other devices. Communication passports are often in place for individuals but these can be out of date, kept in filing cabinets and rarely accessed by the person.

Where people have significant communication difficulties, this can be given as a reason for lack of engagement or inclusion in the PCP process. Managers and staff can 'decide' that the person does not have the capacity to contribute to the process.

Examples of the good practice observed include:

- the use of video to record meetings

- the use of easy to read materials which have been created with people using the service
- the inclusion of photos and videos as part of the information gathering process and during the meeting itself (PowerPoint presentations, digital photo frames, photo-albums)
- the use of ASD specific approaches to support communication, and activity sampling
- an increased use of technology
- quality relationships between the individuals and the staff supporting them. The staff know the person well, can interpret their communication and behaviours, and support them to indicate their needs and preferences.

5.5.6. Multi-disciplinary team (MDT) supports

The interviewees reported a significant lack of multi-disciplinary supports in some services, in particular behaviour supports, occupational therapy and speech and language therapy. The interviewees felt there were very limited examples of clinical inputs into PCP training modules, policies, meetings and goal setting, and that this could have a negative impact on the quality of person-centred plans. Clinical supports tend to be put in place in relation to PCP following major non-compliance, and this is often reactive rather than proactive. Often external clinical supports are sought prior to or following a HIQA inspection but these tend to be one-off interventions with minimal team work evident and little follow up or review.

One interviewee noted that the role of the MDT can be undervalued by staff and there can be poor understanding of how a particular professional might support a person to achieve their goals. There is little robust review of professional advice and MDT inputs.

5.5.7. Goal setting

There was a general consensus that there is poor goal setting across the board with little long term planning evident in the content of plans. Although this is particularly common in congregated settings, the interviewees stated that poor practice can also be found in small community houses:

“It is not as simple as small community houses do good PCPs and large institutions do poor PCPs”

The interviewees explained that the vast majority of goals are linked to activities of daily living or healthcare and do not constitute long term personal goals. Plans can be ‘tokenistic’ and there is little evidence that the goals are set from the perspective of the individual. It was suggested that not enough time is spent getting to know and understand the person. In some situations goals are still set based on group needs, or within the resources of the service provider. The goals set rarely deal with bigger life issues such as living arrangement, relationships, financial issues, end of life care.

Where good practice is evident, services deliver on aspirational plans and are outcomes focused. The long term goal is clear and is often broken into smaller goals or learning steps which work towards this, for example if the long term goal is a holiday, the smaller steps may involve researching different locations, budgeting, using IT skills. Good facilitators can link a basic goal to a bigger outcome for the person.

It was noted that where an individual presents with behaviours that challenge, positive behaviour supports and guidelines can drive good PCPs.

5.6. Evaluation

The evaluation of person-centred planning at organisational level arose in all four interviews. The interviewees agreed that there is little evidence of formal evaluation of person-centred plans and processes. As a result person-centred plans can have little or no impact on the quality of the lives of people with disabilities and outcomes are seldom measured. There is a general lack of oversight and sign off from senior management in relation to person-centred planning, and little drive for transparency or accountability. Evaluation can be driven by HIQA but the interviewees felt it actually should come from within the organisation rather than from outside. One interviewee noted:

“It is common to find a process or plan in place but there is no monitoring of this plan”

5.6.1. Collecting evidence

The interviewees noted that it is often hard to track who is responsible for supporting the person to achieve a goal, for example a plan might say ‘staff will support x with this goal’. It was highlighted that plans contain very little tangible evidence of the individual working towards and achieving their goals or of quality of life changes for the person. One interviewee commented that staff have a poor understanding of what ‘engagement in meaningful activity’ means and as a result they find it very hard to set goals which are specific and measurable. They can find it difficult to demonstrate progress and achievements, and to engage in reflective practice.

The interviewees reported very little if any data collection within services in relation to person-centred planning. There were no examples given of specific software packages or business information systems being utilised to support information gathering at the organisational level. Most information collected is done so on the basis that it is a requirement for the HSE or HIQA.

5.6.2. Reviewing Plans

There was a sense that this happens in an ad hoc way in many services with little structure. Evaluation and review, where it happens, tends to focus on whether an activity happened or not, rather than on measuring outcomes.

Audits by management are described as 'tick box exercises', 'of very poor quality', which concentrate on numbers, for example the number of plans completed in a given time period or the number of goals set, rather than on actual delivery and outcomes.

5.6.3. The link between plans and service development

There are very few examples of providers connecting person-centred plans and service plans. Those using services should be able to influence the design and development of services; the goals and aspirations identified in individual plans should feed into service goals and action plans. The HIQA interviewees commented on the lack of involvement of residents in the development of action plans following inspections.

6. Key findings in relation to supports, barriers and good practice in person-centred planning

This section outlines the key supports and barriers to person-centred planning which consistently emerged in both the key informant interviews and the case study interviews. These are grouped into the barriers and supports at the organisational level and at the personal level. The areas for improvement put forward by participants across the two elements of the research are summarised.

A number of examples of good practice were consistently evident across the different case studies; these are discussed at the end of this section. These findings should inform the development of a national framework for person-centred planning in disability services.

6.1 Key supports and barriers

6.1.1. Key Supports at organisational level:

6.1.1.1. Organisational culture and ethos

Across the interviews, participants spoke about the importance and impact of organisational culture on the person-centred planning process. In particular, they identified the organisational values and principles which they believed to be essential to the development of quality person-centred plans with people using their services. There was a strong consensus on these values across both the case studies and the key informant interviews; individuality, dignity, respect, empowerment, choice, independence, community participation, active citizenship.

Participants suggested that where organisations have a positive culture and ethos, with a focus on achieving quality of life outcomes for each person, the PCP process is more effective. There needs to be high expectations of individuals and a respect for the talents and lived experiences of each person.

6.1.1.2. Positive leadership

Participants highlighted that strong, confident leadership within an organisation – this includes PICs, service and regional managers, the senior management team and the Board of Directors – is a key support to PCP. They commented specifically on the positive effects of proactive management styles on person-centred planning, where leaders are open, willing to listen, ambitious, encouraging and eager to problem solve. Participants emphasised that leaders and managers must be intolerant of poor practice and stated the importance of performance management processes. Leaders and systems, that support the effective management of resources, were identified as another key support to good person-centre planning.

6.1.1.3. The Regulations and Standards

Within residential services, a number of participants felt that HIQA inspections and the Regulations have encouraged a greater focus on person-centred planning, an awareness of the need for quality plans, more formal PCP systems and improved standards of practice.

6.1.1.4. A system of review

There was agreement amongst participants that having a system for reviewing plans on a regular basis is a key support to PCP. This gives the individual who owns the plan and their facilitators an opportunity to share information, to provide evidence of achievements and to reflect on practice and outcomes. Participants felt that a system of review helps to establish timeframes and adds to a sense of transparency and accountability. Participants in the case study research emphasised the importance of ongoing informal review, for example through discussions with keyworkers, analysis of monitoring data, observation or communication with families.

6.1.1.5. Access to information technology and assistive technology

Participants explained that a significant number of people require communication and information supports to engage fully in the PCP process. They identified the specific challenges associated with facilitating plans for individuals who are non-verbal or who have autism. Key supports include access to assistive technologies, access to everyday IT supports (internet and broadband, digital camera, video camera, laptop, colour printer, symbols database, PowerPoint, projector) and the provision of accessible information.

6.1.1.6. Staff skills

There was a strong consensus across the interviews that facilitators and staff teams, engaged in PCP work, need to be creative, resourceful and motivated. Almost every group spoke about the importance of opportunities for learning and development in relation to person-centred planning for staff and managers. There was no agreement however on what these learning and development opportunities should look like. Some participants felt that individual coaching and mentoring was the key support, others advocated for formal staff education and accredited courses.

6.1.2. Key Barriers at organisational level:

6.1.2.1. Lack of understanding of person centredness and person-centred planning

Participants described how there can be a lack of understanding within organisations of person-centredness and what person-centred planning means. Staff often believe they are delivering person-centred supports when this may not actually be the case, for example where activities still centre around groups of people or where activities of daily living are identified as PCP goals.

6.1.2.2. Fear and resistance to change

A lack of understanding of person-centredness and person-centred planning can contribute to a lack of motivation towards or resistance to change. Participants described a lack of flexibility and fear of change which can come from management, staff teams, individual staff members, clinicians or the community.

Industrial relations and Human Resource issues; in particular around roles, rosters and performance management, can exacerbate the problem and create further barriers.

6.1.2.3. The skills of leaders and managers

Participants felt that some managers and service providers may not have the capacity (understanding, motivation, expertise) to make the necessary changes to deliver high quality person-centred plans.

Other participants noted that some organisations and managers are too focussed on HIQA and the Regulations, to the detriment of other aspects of service delivery, including person-centred planning. Participants commented that some Regulations seem 'over-protective' and work against providers establishing a culture of positive risk taking as staff (in particular managers) become more risk aware and sometimes risk averse.

6.1.2.4. Systems and structures

Participants described how there can be over-reliance on PCP paperwork and templates. The focus can then be on the system and the administration rather than on the person, and there is a risk that more time is spent on paperwork than with the individual.

Financial systems, policies and budgetary constraints can restrict the amount of control and choice which people experience. For example if decisions about spending are made centrally rather than in the individual day or residential service, if policies in relation to procurement limit the choice of individuals (the organisation has a contract with one supermarket only), if individuals and services have no access to petty cash, debit or credit cards (difficult to book cinema or concert tickets).

6.1.2.5. Lack of funding and resources

Participants identified that a lack of funding and resources can impact on the quality of the plans produced. In some cases, the issue arose in relation to funding from the organisation for supports such as staffing or equipment. For others, the issue related to the financial circumstances of the individual who owns the plan. Some participants reported having very little money after all their bills were paid, and this imposed restrictions on the goals they set, for example holidays, attending events, visiting friends and family. Some of the interviewees felt that this difficulty arose for many other individuals in society; however, others believed that the cost of living with a disability imposed additional financial burdens on people which affected their overall standards of living, for example transport costs.

6.1.2.6. Access to multi-disciplinary team supports

There can be very limited access to multi-disciplinary team supports – this can impact on a number of aspects of the PCP process including:

- assessments of need
- staff learning and development, in particular in relation to supporting people with more complex needs
- making the PCP process accessible to people with high communication support needs.

6.1.3. Key Supports at a personal level:

6.1.3.1. Relationships

All of the participants talked about the quality of the relationships that exist between the person who owns the plan and the facilitators. Almost all the individuals who owned the plans expressed the view that they wished to be supported through the PCP process by someone who knows them well (usually their keyworker) and felt this was a key support. Only one individual had experience of working with a designated PCP planner (internal to the organisation) and no-one had experience of working with an external PCP facilitator. Participants expressed the view that for those with significant communication support needs, it is essential that the facilitator is someone that has known them for some time, understands their communication, and recognises their likes and dislikes.

The participants emphasised that the relationship with the facilitator needs to be based on mutual respect and trust. They suggested that there needs to be time and space for the individual who owns the plan to develop this relationship, along with their understanding of the PCP process.

The people who owned the plans emphasised the importance of opportunities for one to one time with their plan facilitator.

In most of the case studies, the facilitator is the keyworker. Those interviewed felt this was an advantage and there was no evidence that this influenced the robustness of the plan.

6.1.3.2. Communication

Participants unanimously stressed the importance of good communication; between the person who own the plans, staff in day and residential services, management, family members and external stakeholders.

6.1.3.3. Family Involvement

Participants noted that the support and involvement of family members (where this is the choice of the individual who owns the plan) is key to good person-centred planning. This support and involvement included attendance at meetings, phone contact, practical support to work on goals, advocating for the individual, sharing information and ideas.

6.1.3.4. Learning and development

A small number of participants had the opportunity to engage in learning in relation to person-centred planning. Examples included informal and formal information sharing, in-house training programmes on PCP, advocacy or decision making, QQI accredited courses on decision making and advocacy, involvement in advocacy groups and service user fora. All those who had participated in this type of learning found it to be a very useful support and identified how they had carried over their learning to their person-centred plan (understanding of decision making processes, knowledge of rights and responsibilities, learning around goal setting, familiarity with person-centredness and PCP tools and processes).

Few family members had the opportunity to engage in learning in relation to PCP but a significant number expressed a desire to participate in such programmes and the belief that it could be a key support for families, particularly those who may be new to a service.

6.1.3.5. Stimulating environment

Participants noted the importance of a pleasant, stimulating environment to person-centred planning. Stimulating environments offer new and different experiences, promote engagement and raise expectations.

6.1.4. Key Barriers at a personal level:

6.1.4.1. Poor environments

Participants explained that there can be significant difficulties motivating people using services, staff and families towards person-centred planning, if the overall physical and social environment in which the person lives is very poor. Poor environments were reported to impose restrictions such as lack of opportunities for community participation and the development of circles of support or limited chances for engagement in meaningful activities.

6.1.4.2. Fear and resistance to change

Participants explained that sometimes fear and resistance to change stems from the person who owns the plan or their family. Individuals may lack motivation towards the PCP process for a variety of reasons – lack of trust, lack of understanding of the system, previous experience, low expectation of self or the system, mental health difficulties.

Participants suggested that families may present barriers, particularly in relation to risk taking, new experiences or independence.

6.1.4.3. Transport

A lack of accessible public transport was identified as a key barrier to person-centred planning, particularly in rural areas. Participants described the difficulties travelling around and outside of their immediate communities. In particular they talked about the extremely limited transport options at night which make it difficult to engage in social and leisure activities. A lack of public transport also imposes significant financial costs, for example if the individual has to use taxis. It can also reduce independence, with some individuals explaining how they are reliant on parents, siblings or staff members to transport them to activities and events.

6.2 Areas for improvement

Participants consistently identified a number of areas where improvements could be made in order to improve the PCP process:

- Systems of governance– in particular interviewees commented on organisational planning, performance management, leadership, communication and engagement between people using services, staff and management teams

- The link between person-centred plans and service development should be more obvious
- There needs to be more thorough evaluation of the PCP process and plans; there is a need for more formal systems of process and outcome measurement
- There is very limited use of software or business systems to record or evaluate PCP information – services are heavily reliant on paper systems
- There needs to be more learning and development opportunities for people using services, their family members and members of the community
- Any learning and development opportunities provided through internal supports or external facilitators should be evaluated in relation to attitudinal change, influence on everyday practice and outcomes for those using the service
- There is limited access to external advocacy services and supports
- There is a need to create awareness and establish relationships with community services and supports. Few services are using external supports to help an individual to achieve their goals
- In general participants described the facilities that people use in their local communities which would indicate a community presence. However, there were very few examples given of meaningful relationships with people in the community, which would indicate community participation. Community members and supporters from outside the service should be included in circles of support
- The provision of accessible transport needs to be addressed to enable people with disabilities to contribute fully to their communities
- Service providers need to create opportunities for people using services to influence service development through service user committees and advocacy groups, and representation on organisational committees and groups.

6.3. Findings in relation to good practice

Across the ten case studies, a number of principles and elements of good practice were consistently observed. These include:

6.3.1. Principles

- Each person is respected as an adult
- Each person is regarded as an individual with their own personhood, sense of self, skills and talents
- There are high expectations of each person, of the PCP process and of the outcomes that can be achieved

- Everyone is considered to have the capacity to make choices and decisions about their plan
- Each person is viewed as having a role to play in their local community.

6.3.2. Organisational structures and practices

- The PCP process emphasises the person's needs, wants and dreams
- There is a PCP policy in place across the service, which is evidence based
- Individual plans can influence service development and the allocation of resources
- Leadership; senior management teams are aware of person-centred plans and how they are developed and used by staff, have an understanding of the supports and barriers, are open to discussion and debate and strive to achieve good practice standards across the service
- There are arrangements in place for performance management, supervision and/or appraisal for staff and managers; staff are accountable for their work, feel valued and supported, good practice is recognised and championed
- Organisations engage in positive risk taking and have risk assessment and management policies in operation
- There is a transparent process for reviewing progress and evaluating outcomes
- Internal audits are conducted on a regular basis and address person-centred plans, goal setting and outcomes
- There is a mechanism for issues and complaints to be channelled 'up the line' to the senior management team
- Leaders and managers enable a culture of continuous learning, development and evaluation as part of creating structures that support person-centred planning.

6.3.3. Involving the person who owns the plan and their supporters

- The person who owns the plan is the lead facilitator wherever possible
- The person who owns the plan is involved in all aspects of the process
- The plan facilitator knows the person well or takes time to get to know the person, understands how they communicate, is observant and attentive, is organised and motivated, knows how to gather and record evidence, can reflect on their practice, is willing to learn
- Plans are developed with the individual. Where the individual cannot communicate their choices and/or where decisions are made on their behalf, they are based on the consensus of the different people who engage with them on a regular basis, and not just on the perspective of one facilitator

- Staff, family members and those involved in circles of support have a clear understanding of what person-centredness means and are aware of their specific role in the PCP process.

6.3.4. Developing the plan

- Person-centred planning is a continuing process and not an annual event. Information is gathered with the person throughout the year and there are opportunities for constant review, reflection and evaluation to ensure the plan meets the needs and wishes of the individual
- The process is accessible to the person who owns the plan and takes into account their communication and literacy needs. Where necessary, a Total Communication approach is used which includes objects, photos, pictures, symbols, video and assistive technologies. The person who owns the plan holds the main copy of the plan in a format which is accessible to them. The service provider will have a copy of the plan
- The individual and their supporters can access the expertise and advice of members of the MDT team if they need to. They can also access specialist supports if necessary
- Person-centred plans focus on the personal goals and aspirations of the individual. While a person-centred plan will be informed by a person's medical, clinical and care needs, they should not be the focus of a person-centred plan. In some exceptional cases where the individual is facing significant physical or mental health difficulties, goals related to health and well-being may be appropriate for a period of time
- Activities of daily living do not constitute goals. Again in exceptional circumstances more basic goals may be appropriate for a period of time but there should be clear evidence of progression for the individual as time goes on. Goals must be person-centred; it should be recognised that a basic goal for one person could be a huge achievement for another
- Achievements and outcomes are recognised and celebrated.

6.3.5. Implementing the plan

- There is an action plan which consists of a set of SMART goals
- Long-term goals are broken down into a series of smaller steps
- Those responsible for supporting the person to achieve their goals are clearly identified.
- There is a defined timeframe for achieving the goals and a continuous focus on learning and evaluation of the process and outcome of goal setting
- Where difficulties arise in the implementation of the plan, the issues are addressed initially at the local level. If barriers persist, information is fed up the organisation and the advice and support of management sought

Research on current practice to inform the development of a national framework for person-centred planning in disability services

- A step by step approach is taken in relation to risk-taking. This approach encourages and enables the individual to gradually build the skills necessary to partake in different tasks, activities and experiences. Management support this positive risk-taking. Family members are given the necessary time and supports to contribute their ideas and to allay any concerns they might have.

7. References

1. NATIONAL DISABILITY AUTHORITY (2005) *Guidelines on person-centred planning*. Dublin: National Disability Authority
2. ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS (2016) *Position paper on Inclusive Communication and the Role of Speech and Language Therapy*. London: RCSLT

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Appendices

- Appendix 1 – Information provided in the call for expressions of interest – Case study research
- Appendix 2 – Survey Monkey profile questions – Expressions of interest
- Appendix 3 - Topic frameworks

Easy to Read and Plain English consent materials are available on request

Research on current practice to inform the development of a national framework for person-centred planning in disability services

Appendix I - Information provided in the call for expressions of interest - Case study research

A Research Project on Person-Centred Planning

The HSE and the National Disability Authority are carrying out a research project on person centred planning.

This research will help disability services to do person centred planning well.

We are looking for people to take part in this research project.

We would like people to share their learning and experiences.

We are asking people to tell us about good person centred plans.

Have you achieved goals that are important to you?

Did you get good support to reach your goals?

What worked well for you?

The research team will choose 10 individual plans for the project.

The 10 plans will include:

- men and women
- people of different ages
- people living in the city and the country
- people with different types of disability
- different service providers

The research team will look at the plan.

They will interview:

- the person who owns the plan
- their keyworker
- their family or advocate
- a service manager

The interviews will take place in July and August 2016.

If you would like to put your plan forward for the research project, please fill in the consent form.

Your service provider will then fill in a form online with basic information about you and your plan.

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Your name will not be included on the form.

We will let you know if your plan is chosen.

If your plan is chosen, we will contact you with more information.

If you have any questions, please contact ...

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Appendix 2 - Survey Monkey profile questions – Expressions of interest

Questions for Profile Submission

1. Name of your organisation
2. Contact name for follow up
3. Email address
4. Phone number
5. County
6. To which of these categories of service provider does your organisation belong?
 - HSE
 - Voluntary (Intellectual Disability and Autism)
 - Voluntary (Physical and Sensory)
 - For Profit
7. Does your organisation have a research ethics committee?
If yes, what is the date of the next meeting?

Outline profile of potential participant

Please answer the following questions to give us an outline profile of someone that you feel is a potential participant in the project (a person that has experienced positive outcomes arising from good practice in person-centred planning in your service and is interested in sharing their experiences). If there is more than one potential participant, please complete a separate form for each person.

1. What is the person's gender?
 - Male
 - Female
2. What is the person's age category?
 - 18 to 25
 - 26 to 50
 - 50 +
3. What is the person's primary disability?
 - Complex physical disability
 - Physical disability
 - Sensory disability
 - Mild to moderate intellectual disability
 - Severe profound intellectual disability

- Autism
 - Other (please specify)
4. What type of disability service does the person use?
- Residential service (10 or more residents)
 - Residential service (5 to 9 residents)
 - Residential service (1 to 4 residents)
 - Day support service
 - Respite service
 - Other (please specify)
5. Does the person live in an urban or rural location?
- Urban (including cities and medium to large towns)
 - Rural
6. What types of person-centred tools/processes were used in the person-centred planning process?
- None
 - Planning Alternative Futures with Hope (PATH)
 - Making Action Plans (MAPS)
 - Social Role Valorisation (SRV)
 - Other (please specify e.g. an in-house or custom designed tool)
7. In which of the following areas did person-centred planning lead to positive outcomes for the person?
- Living in the community
 - Having choice and control
 - Participating in social and civic life
 - Having meaningful personal relationships
 - Education and personal development
 - Having a job or other valued social roles
 - Enjoying a good quality of life
 - Achieving best possible health and well-being
 - Feeling safe and secure and free from abuse
 - Other (please specify)
8. The person and other relevant parties involved in the person-centred planning process will be available for interview in
- July

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- August
- Other

9. We confirm that the person has consented to having their outline profile submitted.

- Yes

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Appendix 3 - Topic frameworks

Person Centred Planning Topic Guide – Case Study Interviews

Development of the plan

- What was the process for developing the plan?
- Who was the lead facilitator for the plan?
- How much was the individual involved in the process? Is the plan owned by the individual?
- How much were the individual's family and/or friends involved in the process?
- How were they involved?
- Did the service provider/other stakeholders offer training in PCP to the individual who owns the plan, family members or advocates?
- Did the service provider/other stakeholders offer training in PCP to staff supporting the development and implementation of the plan?
- What type of training is on offer?
- What worked well during the development of the plan?
- What challenges arose during the development of the plan?
- If the person has particular communication needs, how were these addressed?
- What format is the plan?

Content

- What is the content of the plan?
- Does it address
 - big life issues (such as where and with whom you live, having a job)
 - everyday choices and how mainstream life is lived
 - treats and occasional outings
 - building independence
 - milestones towards achieving personal goals
- Does the plan have an action plan and a set of goals/outcomes? Are the implementation strategies clear with responsibilities well defined?
- Is the language used in plans person centred?
- Map the contents of the plan against the 12 supports in New Directions, the relevant sections of the Interim Standards for New Directions and the outcomes in the draft outcomes measurement framework

- Are there examples of good practice and poor practice when the plan is analysed against the NDA Guidelines on Person Centred Planning, and emergent findings of the literature review?

Implementation of the plan

- Is the plan informing the delivery of services and supports? Ask for examples
- Does the plan include services and supports to be provided directly by the service provider in particular, as well as other services and supports which are outside the service?
- Does the service provider works in partnership with the person and other stakeholders where appropriate, to enable services and supports available outside the service to be put in place.
- What are the barriers to achievement of the goals / outcomes in the plan and how are these addressed?
- Where is plan located?
- How often is the plan reviewed and updated? How does this happen?
- Who is involved in reviewing the plan?
- What worked well and helped someone to achieve the goals / outcomes in their plan?
- Are there any particular supports which facilitated the individual to achieve their goals?
- Are there any barriers which hindered the individual from achieving their goals?
- How are issues of risk and positive risk taking addressed?
- How is the development of valued social roles addressed?
- Are there examples of good practice and poor practice when the implementation of the plan is analysed against the findings of the literature review and the relevant requirements of the Interim Standards for New Directions?

Service Level Issues / Monitoring and Evaluation

- Is there a system or model underpinning person centred planning in the service, or it is an ‘ad hoc’ process?
- Is there an overall system of monitoring and evaluation in place across the service?
- How does the service provider record information and collect data in relation to PCP and outcomes? What data is collected in relation to PCP?
- How is the effectiveness of the plan and the outcomes measured?

- Is there a quality assurance system in place in the organisation (ie EQUASS, CQL/POMS) and has it influenced person-centred planning in the organisation?
- Are there policies on issues related to person-centred planning such as person-centredness and positive risk-taking
- How do the values and the culture of the organisation support person-centred planning?
- Have the regulations, standards and the inspection process influence PCP in this organisation?
- What was the role of the MDT in the development and implementation of the plan?

Person Centred Planning

Topic Guide – Key Informant Interviews

General Questions

- Experience/ Background in relation to person centred planning
- What systems and models of person centred planning have you observed in use in services in Ireland?
- What do you feel are the current areas of good practice in relation to person centred planning?
- What are the current gaps in practice in relation to person centred planning?
- Are plans outcomes focussed?

Development of the plan

- Who tends to be the lead facilitator in the development and implementation of person centred plans?
- How much are the individuals who own the plans involved in the planning process?
- How are families, friends and advocates involved?
- What formats are the plans in?
- Have you noted any particular ways in which people who communicate in different ways are supported to develop their plans? (accessible materials, visual supports, use of multi-media profiling, assistive technology)

Content

- In your experience, what is the usual content of the plans?
- Do plans address

- big life issues (such as where and with whom you live, having a job)
- everyday choices and how mainstream life is lived
- treats and occasional outings
- building independence
- milestones towards achieving personal goals
- Does the content differ significantly from one service provider/centre to another?
- Do plans have an action plan and a set of goals/outcomes? Are the implementation strategies clear with responsibilities well defined?

Implementation of the plan

- Are there examples of services working in partnership with mainstream/community agencies to deliver supports / community building approach?
- How often are plans reviewed and updated? How does this happen?
- Who is involved in reviewing the plan?
- Are the issues of risk and positive risk taking addressed in plans?
- How is the development of valued social roles addressed?
- Can you identify any particular supports which facilitate individuals to achieve their goals?
- Can you identify any barriers which hinder individuals from achieving their goals?
- Are there any specific challenges which arise for individuals or service providers in the development and implementation of person centred plans?
- How are these challenges addressed?

Systems of monitoring and evaluation

- Do service providers tend to have a system or model in place for PCP or is it an ad-hoc process?
- How do service providers record information and collect data in relation to PCP and outcomes?
- What data is collected in relation to PCP? How are the effectiveness of plans and the outcomes measured?
- Do service providers tend to have a monitoring and evaluation service in place
 - internal or external?

Factors influencing PCP and good practice

- How do the values and culture of an organisation support PCP?

Research on current practice to inform the development of a national framework for person-centred planning in disability services

- What policies influence PCP?
- Do service providers have a quality assurance system in place and how does this influence PCP in the organisation?
- Do service providers offer training in PCP to staff, individuals who own the plan, family members and advocates?
- What type of training is on offer? Have you seen examples of this in practice?
- Is the language used in plans person centred?

HIQA/Regulations and Standards

- How do regulations, standards and the inspection process influence PCP?
- How does person-centred planning fit with the definition of ‘personal plan’ as it is in the regulations and standards? (Use of terminology, lack of consistency, variation in content, different perceptions and lack of understanding)
- What is the role of the MDT in person centred planning / in the development of personal plans as outlined in the regulations and standards?
- What understanding does the sector have in relation to these two concepts?
- Are there specific issues for respite services in relation to personal plans and PCP?