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From Institution to Integration: The Perspectives and Experiences of Disability Sector Staff in the Transition to New Directions.

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Derek Bryan

M.A. in Child, Family and Community Studies   **2014**

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Derek Bryan

Declaration of ownership: I declare that the attached work is entirely my own and that all sources have been acknowledged.

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i

Abstract

Day services play a large part in the community life of people with intellectual disabilities. The challenge for the Health Service Executive in its 2012 review of adult day services was to propose a modern service. The review culminated in a new approach called New Directions. This study aimed to explore experiences and perspectives of staff from the disability sector on the proposed new ways of working with people with intellectual disabilities including how they believe New Directions can best work. This objective was achieved by interviewing twelve staff (including some volunteers) and managers from a disability organisation. At the time of the study all twelve participants were directly involved in the implementation of New Directions. Findings highlighted the best aspects of current day services that should be merged with New Directions such as a sense of belonging, connectedness and companionship. The findings also highlighted concerns that people with intellectual disabilities may be lonely. Further concerns were expressed about their friendships in general, both before and since New Directions. However, the research also demonstrates that people with intellectual disabilities are also very sociable. The study established participants' perspectives on person-centeredness and families emerged as somewhat challenged by New Directions. Framing person-centeredness in partnership with families is recommended going forward. The findings stated that people with intellectual disabilities bring awareness, diversity and joy to communities. However, New Directions emerged as a policy that communities may not be entirely ready for. Educating communities around inclusion was explored in this study. Finally, how New Directions can best work was examined in detail with both management and staff. Managers reflected on organisational culture, change management and the leadership now needed whilst staff considered changes to their roles, the challenges and the training now required. Identifying and coordinating supports within the community emerged under role changes, challenges and the skills now needed. Managers also referred to the need for this training under New Directions. The importance of communication with people with intellectual disabilities, their families, staff members and the wider community in relation to New Directions emerged throughout this study. The concept of support for all involved in New Directions was also a recurring theme in this research. Conclusions were drawn and recommendations presented in view of research and the findings from this study. Supporting people into the positions that create friendships, social, educational and employment opportunities were cited as the best ways to maximize New Directions. This study found strong support for New Directions with some concern there may be an 'over emphasis' on community. Finally, this research recommended that similar studies are carried out with service users, families and community organisations.

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Table of Contents

Chapter 1   Introduction

Chapter 2   Literature Review

Chapter 3   Methodology

Chapter 4   Findings

Chapter 5   Discussion

Chapter 6   Conclusion and Recommendations

Glossary of terms and list of abbreviations and tables

Glossary of Terms

For the purpose of this study the following terms are defined as;

Deinstitutionalisation: The process of transferring service users with disabilities from long-term institutions, which isolate the individual, to more integrated community-based services.

Normalisation: Making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.

Personalisation: Essentially the drive to put the service user in control of their own services. (The plan is for, in time, all eligible service users to have the option of taking control of the money used to provide services for them through an individual budget, where they can buy in the services they want, rather than make do with those provided by statutory services.)

Congregate settings: Congregate setting is defined as an environment where a number of people meet or gather and share the same space for a period of time

Individualised: made for or directed or adjusted to a particular individual

Person-centeredness: a standard of care that ensures the service user is at the centre of care delivery

Segregated: set apart from the rest or from each other; isolate or divide.

Outcome-focused: a focus on what you want to achieve (the changes that happen)

Person-centered planning: is a set of approaches designed to assist someone to plan their life and supports. It is used most often as a life planning model to enable individuals with disabilities or otherwise requiring support to increase their personal self-determination and improve their own independence.

Social network:	a network of social interactions and personal relationships
Normalised:	To make normal, especially to cause to conform to a standard or norm
Transitioning:	Passage from one form, state, style, or place to another
Social Exclusion:	being unable to participate in society because of a lack of resources that are normally available to the general population. It can refer to both individuals, and communities in a broader framework, with linked problems such as low incomes, poor housing, high crime environments and family problems.

Abbreviations

ID	Intellectual Disabilities
HSE	Health Service Executive
DIT	Dublin Institute of Technology
HIQA	Health Information and Quality Authority

List of Tables

List of Appendices

A   Information sheet guidelines

B   Letter to gatekeeper

C   Letter to participants

D   Preamble for participants

E   Informed Consent Form

F   Interview Questions

G   Sample Interview Transcript

H   Sample Coding

I   Declaration of Research Ethics and/or Assessment of Risk Form

J   Twelve Personal Supports for Adults with Disabilities

K   Awarding Bodies for existing day services

L   Examples of good practice community integration projects

M   Purposive sampling criteria used to select twelve participants for this study

N   Considerations taken into account when devising the interview schedule

Introduction

1.1   Introduction

This study explores perspectives and experiences of staff and managers from adult day services in the disability sector regarding the implementation of New Directions: Personal Support Services for Adults with Disabilities (2012). Chapter one introduces the aims of the study. It also explains the context and rationale for the research and provides an outline of the study.

1.2   Aims and objectives of the study

The overall research aim is to enhance understanding by engaging with these vital staff on the proposed new ways of working with people with intellectual disabilities (ID) within their organisation and how they believe New Directions can best work. To achieve the overall aim of this study, the following objectives will be pursued:

- What was good about existing day services that should be incorporated into New Directions?
- What is the staffs understanding of working in a person-centred way?
- Examples of community participation and how this can be supported?
- How to improve quality of life for families under New Directions?
- Perspectives on intellectual disability, the concept of friendship and New Directions?
- What do people with ID contribute to communities and how to support communities?
- How New Directions can best work? Under this objective managers are asked about organizational culture, change management and leadership. Staff and volunteers are asked about changes to their roles, challenges for staff and the type of skills and training required. All participants are asked; how can the potential of New Directions best be maximised and if they think New Directions is ultimately a good idea and why?

These objectives will be addressed ethically and qualitatively by exploring these objectives with twelve staff and managers from the disability sector through semi-structured interviews.

1.3   Background context, rationale for the study and research question

Day services play a large part in the community life of people with intellectual disabilities (Malin, 1995). The day service network for people with ID in Ireland provides significant support to over 25,000 individuals. People with physical, sensory and learning disabilities use these services. Individuals with mental health difficulties also avail of these services. The age range varies from young people to older people at retirement, in both rural and urban communities. The challenge for the Health Service Executive (HSE) in its 2012 review of the adult day services they fund was to propose a modern service that is capable of responding to a diverse set of interests, aspirations and personal circumstances. The review culminated in a new approach called New Directions (HSE, 2012). Following on from the publication of the New Directions report in 2012, the HSE established a National Implementation Group to support the recommendations in New Directions.

One key recommendation relates to developing a quality system to underpin delivering New Directions. Over the last year work has been ongoing with stakeholders in the disability sector to develop standards to ensure quality service delivery in respect of New Directions. Discussions with HIQA formed part of this work and the National Disability Authority have taken a key role in producing a set of Draft Interim Standards for New Directions. Information Sessions took place in September 2014 to launch the consultation process for the Draft Interim Standards. The events were used to update people regarding the implementation of the fuller recommendations in New Directions. Information sessions were arranged to facilitate service providers, service users and their families.

At present disability organisations around Ireland are at various stages of implementing the new HSE approach to adult day services, commonly known as New Directions. These organisations are in transition from their current models of service delivery to those proposed under New Directions. 'Person-centred' language and 'support' are strong themes in New Directions. However, to work with a person as a 'skilled helper' is achieved not from the position of an outside expert who privileges professional knowledge but from an acknowledgement of the subjectivity of each and every point of view (Baum & Lynnggard, 2006). The 'skilled helper' will also have the skills needed to interact and communicate with the person, service system, families and community – adopting less of an expert position towards a valuing of multiple perspectives and collaborations (Gardner & Nudler, 1999). It is in this context that this study aims to explore the perspectives and experiences of staff from

the disability sector on the proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work.

Therefore, the rationale for this study is that staff members are key to enriching the lives of people with ID, making them worthwhile research participants. Developing our understanding of staff and management in relation to the proposed new ways of working could help to maximise the potential of New Directions. It could also indicate areas for future research. This study does not directly explore the perspectives of service users, their families or community organisations.

1.4   Outline of the study

Chapter one introduces the aims of the study and explains the context and rationale for the research. It also provides an outline of the study.

Chapter two highlights relevant literature in relation to New Directions. This literature review is presented under themes including; Models of Service, Key principles underpinning community based day services, Social Networks, Support, Families and Planning, Community, Organisational Culture, Change Management, Leadership and Human Resources, Systems and Quality of Life. This literature review outlines the current institutional context, principles and systems guiding services, the need for change and nature of proposed changes.

Chapter three identifies and discusses the methodological framework underpinning the research. The chapter begins with an overview of the methodology, research rationale and design. Then, the research participants are discussed. Furthermore, data collection and analysis procedures are provided. The chapter concludes with an examination of ethical issues and limitations of the study.

Chapter four presents the main findings that emerged from twelve qualitative interviews carried out with staff, management and volunteers to meet the research aims. Questions were designed under seven themes to tap into research participants' perspectives and experiences regarding New Directions.

Chapter five discusses main findings from research completed with the twelve participants to explore their perspectives and experiences in relation to New Directions. In order to take the

findings to another level of analysis, a number of themes were developed (from the original themes used during data collection) that lend themselves to such analysis and critical discussion.

Chapter six concludes this research study. It also makes recommendations regarding New Directions based on the findings and discussion in this research.

Literature Review

2.1   Introduction

This study aims to explore perspectives and experiences of staff from the disability sector on the proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work. New Directions (2012) is the basis for this research study and this review highlights literature relevant to New Directions. The literature review is presented under thematic headings and outlines the current institutional context and principles and systems guiding services. The need for change and nature of proposed changes is also addressed.

2.2   Models of adult day services

A census of current day services began in August 2007 by the National Working Group. The data gathered contributed to New Directions. The census highlighted the diversity and lack of a nationally agreed definition for day services for people with disabilities (HSE, 2012). However, when Seed (1996) led a research team evaluating Scottish day services seven models of practice were found. These were; (1) *The Work Model (2) The Social Care Model (3)The Further Education Model (4)The Assessment and Throughput Model (5)The Recreational Model (6)The Shared Living Model and (7)The Resource Centre Model.*

Interestingly, Seed (1996) established the 'best' model changed depending on whether the perspective of the individual, parent, professional or management was considered. Service users believed centres were for making friends first and then learning. Seed (1996) believes to establish 'what are centres for?' it's necessary to combine the seven models. 'Care in the community' should be used by day services to help define their goals more carefully and credibly.

A wide variation of individualised plans and quality frameworks are utilised in HSE funded adult day services. The census highlighted the need for consistency in order to deliver high quality services. According to data, 61% of organisations use quality systems and are accredited or working towards accreditation. For awarding bodies see appendix K. This

demonstrates an important resource within the disability sector committed to achieving consistent quality services. However, some providers have no quality systems (HSE, 2012). Seed (1996) believes day services need to be more responsive to individual needs and accountable around this.

The census captured modernisation in the sector to date in terms of offering individuals choices about the way they live their lives (HSE, 2012). A need to balance good parts of what existing services have to offer with newer approaches emerged. However, an absence of choice, time spent doing nothing and performing low value and repetitious activity was also evident. According to Conneally (1993) we must look at our service structures to gauge how we may have isolated people with disabilities from the general public and limited their opportunities in communities, *"We have historically been more efficient in providing people for services, than services for people"* (O'Brien & Lovett, 1992, p. 9). Furthermore, Wolfensberger (1989) believes the human care industry was created to sustain large numbers of 'dependent' and 'devalued' people, in order to secure employment for health and social care staff and make profits for private companies.

Service users who contributed to New Directions want to engage in interesting and ambitious activities, "they want to do ordinary things in ordinary places and to be part of their community" (HSE, 2012, p. 14). Independence, support, influence over services, and joined up services were also requested by Service users. Service providers, families, carers and the general public were also consulted. Furthermore, the review considered national and international best practice. The policy and practice findings highlight the shift towards the 'social model' of disability and the commitment towards person-centeredness, arising from the social model.

Person-centeredness is not a new concept in itself. The ambitious change envisaged by New Directions is linked to the policy of mainstreaming that is a central part of the 2004 National Disability Strategy. The support of all stakeholders in advancing that strategy will be key to setting the context for New Directions to be successful (HSE, 2012). Both person-centeredness and New Directions have evolved from work already started.

2.3 Key principles underpinning community based day services; Person-centeredness, Normalisation and the Good Life

Person-centered planning was first named and described by a group of people in America including, *The Centre on Human Policy's Rehabilitation Research and Training Centre on Community Integration*. The key to person-centered approach is respecting the person. This approach is non-directive as opposed to directive. The person being supported is seen as central, with a focus on actively listening to the individual (Thomas & Woods, 2003). Key principles have been identified for supporting person-centered planning including choice, control, staff skills, values and attitudes, assessment and review, partnership and quality assurance (Purvis & Dick, 2005). However, person-centered work is not flawless: issues of power, funding and legislative control may all challenge its principles (Thomas & Woods, 2003). It's complex and challenging to implement and open to different interpretations. In Ireland families hold a lot of power and in terms of funding a system of direct payment has not yet been implemented before New Directions.

The concept of 'Normalization' promotes people with ID living lifestyles as close as possible to the rest of society (Thomas & Pierson, 1996). Normalization focuses on people with ID living and functioning within the same structural norms as the rest of society. This somewhat idealistic concept can also be desired by health and social care staff (Thomas & Woods, 2003). Normalization was dominant in the 1970s and 1980s and it elevated the importance of integration and inclusion. The concept believes society needs to change to support people with ID to live within the mainstream (Thomas & Woods, 2003).

O'Brien (1987) proposed the notion of 'five accomplishments' that should be aimed for and achieved by community based services; community presence, choice, competence, respect and community participation. These have become guiding principles for service development and support. 'Respect' is meant in terms of people with ID having valued roles within society. 'Community participation' refers to developing a wide variety of relationships with a range of people, from casual acquaintances and neighbours, to deep, warm and enriching friendships and lifelong partnerships. According to Pahl (2008) friends can help to form the basic structure of our lives. Caring services should find ways of supporting people with ID to develop an extensive network that provides 'positive and meaningful interaction' (O'Brien, 1987). However, Perske (1988) emphasizes health and social care workers cannot programme friendships but can set up frameworks where friendships can flourish.

Importantly, Perske (1988) points out regardless of money, technology, community programmes, highly trained staff and the kindest family support, no person can fully participate in a neighbourhood without friends. Friends help people move beyond an organisation's goals because friendships provide opportunities that cannot be programmed. Noteworthy, *"it's not possible to provide friendship or make friends for other people......friendships can only be chosen"* (Firth & Rapley, 1990, p. 21). People with ID have reciprocal friendships where they enrich the lives of their neighbours, friends and colleagues. The nature and type of these friendships add value to individuals, networks and communities.

Communities are the most important source of friendship, support and meaningful life to people with ID and their families (Bartnik& Chalmers, 2007). Building *'social capital'* in communities and neighbourhoods where people with ID live is a valuable goal worth pursuing (Bates & Davis, 2004). In terms of pursuing such goals, Johnson, Walmsley & Wolfe (2010) point out policy makers use undefined phrases such as '*an ordinary life*' or a '*life like any other*' or tight definitions like '*normalisation*' and the '*social model of disability*' whereas they should use the term '*good life*'.

Nussbaum (2000) believes unequal political and social conditions create inequality for women, the poor and people with disabilities. Nussbaum disagrees with socialist perspectives on equality of outcome, goods and services. Instead, she suggests states take responsibility to ensure material and institutional resources are provided to support *'well-being'*. Her concept is called *'distributive justice'* and Nussbaum's (2007) framework for gauging well-being recommends supplying resources to support well-being as defined by the capability of life, health, bodily integrity, imagination and thought, emotions, practical reason, affiliation, regard for other species, play and control over one's own environment. Nussbaum believes the *'good life'* is experienced by fulfilling such life needs to the maximum. According to Lindsay (2002) there is no agreement on the fundamentals of a *'good life'* or how to measure it. Positive lifestyle indicators may have to be personalized or tap subjective experience.

Seed (1996) also disputes *normalisation* on the grounds of what ordinary person uses such language and instead proposes *'quality of life'* as the vision for people with disabilities. Felce and Perry (1996) define *'quality of life'* as an overall general well-being that is inclusive of 'objective' and 'subjective' evaluations of physical, material, social and emotional well-

being. This definition is joined with the range of personal development and purposeful activity, all weighted by a personal set of values.

Normalization was considered a succes when people passed as 'normal' in communities. However, it failed to acknowledge difference. Disabled activists and theorists emphasised recognition of difference rather than its assimilation. They also stressed perspectives of people with disabilities rather than exercizing expertise and the idea that material and conceptual worlds were sources of discrimination and inequality (McDonnell, 2007).

2.4   Use of Social Networks

The Living in Ireland Survey (2001) found having even a mild disability meant you are less likely to be a member of a club or association, talk with your neighbours most days, meet friends or relatives most days or to have had an afternoon or evening out for entertainment in the last fortnight (Gannon & Nolan, 2005). New Directions (2012) states person-centeredness challenges organisations to shift from segregated services which limit social roles towards community inclusion. Individuals should be supported to build their capacities and competencies and assisted to make their own unique and valued contribution to communities. However, Seed (1996) believes integration is not an end in itself or the most important goal for service users. A vital goal is improving quality of life for individuals at home, where networks can be classified as embracing (outward focused with a rich array of contacts) or self-contained (inward looking).

Furthermore, in day settings where supervision is constant, making and sustaining mutually reciprocal and respectful friendships can be difficult. Where this is the case people with disabilities need more contact with trusted companions who are capable of forming a social 'umbrella' of support which encourages wider social networks and friendships. These networks can transcend boundaries of social status, gender and generations (Johnstone, 2001). According to O'Brien's (1987) *'community presence'* accomplishment, people with ID who have supportive networks and who are active in community life through work, leisure or just as part of it are more likely to have positive roles within the community. Being a friend, neighbour, employee and consumer are all examples of positively valued roles within society. According to Wolfensberger & Thomas (1987) creating valued social roles is the highest normalization goal and other benefits emanate from it like competency and image

enhancement in all aspects of identity. There is a need for ongoing support that enables, empowers and connects people. In this regard family, friends and volunteers in clubs also have key roles in a social network approach. (See Appendix L for examples of good practice community integration projects).

2.5 Support

Roulstone & Morgan (2009) established many people with disabilities using day services viewed those as their communities. They argued people can only know what they know based on their social horizons at that moment in time. According to Roulstone & Prideaux (2012) choices should be offered honestly and with ongoing support, given how new concepts may be experienced. People with disabilities who experience making simple everyday choices will be better prepared for more complex and abstract choices and decisions (Purvis & Dick, 2005; Shah, 2005). However, to offer realistic choice requires a lot of capacity building in the community. Choice cannot be considered in isolation. It needs to be balanced with the ongoing support required to realise choice.

Franklin & Sanderson's (2014) concept of 'Just Enough Support' refers to the optimum level of support to increase the chances of people connecting with local people in their communities. Regardless of its source, "support is a role that bridges the gap between what people want to be doing and what they are rejected from doing by the way things are" (Townson, Macauley, Harkness, Chapman, Docherty, & al, 2004, p. 74). New Directions proposes day services offer twelve individualised, outcome-focused 'supports', allowing individuals to choose to live their life in keeping with their own wishes, aspirations and needs (HSE, 2012). However, choice is also limited by level of disability and resources. Families and staff are sources of much support in the lives of people with ID. Unfortunately, there has been a lack of funding for day services in recent years. This has left some young service users with no day service after training and placed additional pressure onto family support systems.

However, funding for day service places was secured for people with ID who exited training in 2014. If these day services incorporate the twelve personal supports in New Directions (appendix J) they could potentially improve their quality of life because the twelve supports are similar to the aspirations of Colebridge's (1993) basic quality of life needs such as the need to be creative, exercise judgement, love, have friendships, contribute something of

oneself to the world, have social function and purpose and make choices, *"Valued activities will increase the variety and significance of the choices that a person makes"* (O'Brien, 1987, pp. 177-178). These are all longings everyone has which are constrained throughout life. There is a universality to these desires that is not exclusive to people with ID.

2.6   Families and Planning

New Directions (2012) states individual plans in line with principles of person-centered planning should be adopted. According to Seed (1996) a 'social network' approach can be used with a person to holistically establish both their needs and a person-centered plan. 'Holistic' covers all aspects of a person's humanity including the physical, mental, social and spiritual dimensions of living. The foundation of such a plan is a 'holistic community care assessment' which considers the needs of the individual and the needs of the carer, in other words the needs of the 'family'. A key feature of person–centred planning is that family and friends are viewed as partners in planning.

Both individuals and families have reported enjoying the person-centered planning process (Medora & Ledger, 2005). It was also found family satisfaction had a significant impact on facilitating a smooth, efficient and responsible deinstitutionalization (Ferguson & Pennock, 2000). Furthermore, involvement of families in person-centered planning and achieving outcomes in the community is essential when considered in the context of the following research. The National Disability Survey (2006) found 87% of people with disabilities engaged in 'social activities' with family. Even with this family support and as previously mentioned The Living in Ireland Survey (2001) found people with disabilities are less likely to be members of clubs or associations, talk with their neighbours, friends or relatives or to have gone out for entertainment in the last fortnight (Gannon & Nolan, 2005). It would appear that without support from families, engagement in community life would be considerably less. Families are essential connectors. A person-centered approach should be cautious not to promote concepts of independence and autonomy in ways that disconnect people from family, networks and communities.

By considering the concept of '*family quality of life',* it underlines the importance for disability services to consider the needs of both the individual and the family. The family quality of life can be improved in a very personal way by practitioners who focus on the

'family'. Some countries have practically and economically enhanced community awareness and support for families around disability through 'good neighbours projects' and social action groups (Brown & Brown, 2003). Furthermore, Hand, Trewby, & Reid (1994) concluded families cannot go it alone and full participation of people with disabilities in community life and culture depends on well-resourced public policies and programmes of inclusion.

2.7   Community

Community exists in the minds of its members and it should not be confused with geographical boundaries only. Community is expressed and embellished symbolically and people make it a referent of their identity (Cohen, 1985). It should be noted 'community' often has a geographical aspect also and the concept can be applied to different people and places. Critically, Cummins & Lau (2003) disputes the assumption the more people 'physically integrate' into the community of non-disabled people the better their lives will be. They advocate it is 'social' and not physical integration that positively impacts on well-being. Furthermore, as some people with disabilities find social integration within the general community very difficult to achieve, an overly enthusiastic integration program could become more stressful than beneficial. Services providers should aim to achieve a sense of 'community connectedness over physical integration. Compelling, is Cummins & Lau's (2003) conclusion that 'community connectedness' is more likely to be achieved within the community of people with an intellectual disability. Therefore, perhaps 'social integration' can be achieved through a further form of integration therefore: the weaving together of independence and interdependence as valued approaches (Carnaby, 1998). New Directions (2012) can support this form of integration as it proposes service users become 'independent' whilst also receiving 'support' from services, staff and family. The development of new integrated support 'hubs' by disability organisations under New Directions provides an opportunity for service providers to 'weave together' an approach that includes independence and interdependence.

A level of 'physical integration' should still be aimed for in light of findings from research which found people with ID use some community facilities less and reported significantly lower social belonging and empowerment than non disabled peers (Bramston, Bruggerman,

& Prettys, 2002). Additionally, Patterson & Pegg (2009) found people with disabilities can participate in leisure activities at levels that enable them to develop confidence, skills and self-esteem. Participation in leisure positively impacts on quality of life for people with disabilities. Examples include using facilities like swimming pools and bowling alleys which involves enjoyable leisure and being part of integrated leisure facilities.

According to McConkey (1994) educating communities about disability demands a great deal of time and energy which may result in disagreements and disappointment. The majority of people in local communities are responsive and welcoming but there is failure to realise they still need advice. Furthermore, the most effective community education involves creating relationships among people rather than giving information. Educating communities is a process rather than an event. Changing and sustaining public attitudes and behaviours does not come about from a single event. It results from multiple initiatives and diverse sources so the public accumulates experiences and knowledge.

2.8 Organisational Culture, Change Management, Leadership and Human Resources

In addition to changes for service users, the reconfiguring and modernisation of day services under New Directions will mean change for many service providers depending on the gap between their current offering and an individualised, person-centered approach. Organisational culture may also need to change (HSE, 2012). Organisational culture is concerned with an organisation's shared values, beliefs and assumptions held by its members and communicated through symbolic means. The culture develops from the prevailing national culture, nature of the industry and role of the organisation's founders. Organisational culture is developed from these three interdependent sources. In attempting to explain why some organisations are more successful than others authors have pinpointed cultural aspects that contribute to organisational performance as the reason why (Tiernan, Morley, & Foley, 2006).

According to research by Deloitte (2014) performance management and once yearly appraisal processes are broken. Companies should instead focus on combining diversity with the inclusive culture needed to truly build value. Harty (2014) points out changing a company's culture is the most difficult 'leadership' challenge a CEO will or is ever likely to face as

he/she tries to embody the organisation's core values through their daily activities and communications. Importantly, New Directions demands 'leadership' that can change an organisations culture.

New Directions also demands change management nationally. Locally, disability organisations are now expected to engage in 'planned organisational change' in order to implement New Directions. According to Goodman and Kurke (1982) planned organisational change is a set of activities and processes designed to change individuals, groups, structures and processes. New Directions (2012) states a priority responsibility for managers is to show leadership in creating an organisational culture favouring a person-centered approach. With regard to this, an orientation towards person-centeredness for senior management and proofing all policies for person-centeredness are suggested strategies.

For person-centered planning to be effectively delivered by staff, the organisation's culture and hierarchy must change. Effective person-centered teams support people to achieve lifestyles they want as part of their communities by listening, learning and valuing personal commitment and relationships with the people they support (De Pree, 1997). Person-centered organisations value staff and service users and devolve resources and authority to service users and staff to facilitate empowerment. They also tend towards non-hierarchical structures and management systems where managers support staff and have contact with service users (Sanderson, 2003).

Empowerment and advocacy are not optional extras for traditional services as they represent a significant shift in relationship between service users and service providers. An organisational culture modelling good practice communicates a message to service users, staff and families about the 'value' being attached to involvement and inclusion. The skills needed to help people make informed choices and decide what they want are different to those involved in telling people what their needs are (Malin, 1995). The training and education of professionals together with organisational policies and procedures can assist people develop an improved quality of life (Brown & Brown, 2003). Under New Directions new skills are required around person-centeredness and identifying and coordinating supports within wider communities and networks. The nature of the job will change for employees.

2.9　Systems and Quality of Life

According to Brown & Brown (2003) for a quality of life approach to be effective for practitioners, both policy makers and management need to understand the principles of a quality of life approach and then integrate these into the service's guidelines, procedures and systems. Therefore, policy guided by a quality of life approach can help management and staff to establish programmes that effectively support quality of life.

Four overall strategies for integrating policy, management and practice are put forward. Firstly, policy and management should fit facts, for example a lack of funding should not be accepted as a reason for not pursuing inexpensive, creative supports for a person. Secondly, take a long term view of improving quality of life over the life course rather than simply fixing short term problems. Thirdly, offer flexibility to frontline staff. A quality of life approach sometimes requires reasonable risk-taking and staff should feel permission from management to try out things and adapt interventions and supports within general policies. Lastly, ways should be developed to address needs of outside agencies where their policies are not in keeping with the practitioners own organisations around inclusion. (Brown & Brown, 2003). There is evidence of these strategies in New Directions.

2.10　Conclusion

New Directions (2012) is the basis for this research study. This review highlighted literature relevant to New Directions. The literature review was presented under a number of themes and outlined the current institutional context, principles and systems guiding services, the need for change and nature of proposed changes. This study aims to explore perspectives and experiences of disability sector staff on the proposed new ways of working with people with ID within their organisation including how they believe New Directions can best work. This literature review helps contextualise the qualitative research methodology used in this study.

Methodology

3.1 Introduction to the Research Design

This chapter identifies and discusses the methodological framework underpinning the research. The chapter begins with an overview of the methodology, research rationale and design. Then, the research participants (sample) are discussed. Following this, data collection procedures and data analysis are provided. The chapter concludes with an examination of ethical issues and limitations of the study.

3.2 Overview of the Research Rationale, Strategy, Design and Approach

Disability sector staff are directly involved in the current transition from the 'traditional' day care model of service delivery to the new 'community based' model, as proposed under New Directions. The purpose of this study is to explore perspectives and experiences of these staff on proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work.

Ultimately, the overall aim of the study is to enhance our understanding through engaging with these vital staff in relation to New Directions. Developing understanding through staff on the proposed new ways of working could help to maximise the potential of New Directions for all involved and future research. "A day service is understood and evaluated in terms of asking, does it enrich daily living?" (Seed, 1996, p. 12). However, staff are key in this enrichment process. Therefore, this study wants to seek their experiences and perspectives on New Directions. The rationale for this study is that staff members are key to enriching the lives of people with ID, making them worthwhile research participants.

Human experiences are examined through detailed descriptions of the people being studied. Creswell (2011) argues understanding 'lived experience' marks 'phenomenology' as both a philosophy and a method of research. Phenomenology believes knowledge and understanding are embedded in our everyday world and it cannot be quantified or reduced to numbers or statistics. Therefore, this study adopts a 'phenomenological' research strategy and design together with a 'qualitative' research approach.

Quantitative research aims to show you *what* is taking place whilst qualitative research aims to establish *why* things happen - through developing a detailed understanding of peoples' views, attitudes and behaviour. Semi-structured and depth interviews are used to allow participants to talk, often at great length, about their feelings and underlying values, beliefs and attitudes (Moore, 2000). Burnett (2009) also notes qualitative methods are useful for working out meanings, feelings, attitudes, perceptions and understandings. And in relation to interviews, they should be recognised as being co-produced by both interviewee and interviewer.

Practitioners who carry out research in their own workplace have privileged insight into their organisation's culture. These researchers have 'insider knowledge'. This can prove beneficial in terms of getting consent for research and access to participants. However, it can also prove problematic. A researcher from outside may find things which the 'insider' researcher finds too obvious or routine to catalogue. A practitioner carrying out research in their own workplace can also be constrained by his/her web of meanings. Action research respects the practitioner's knowledge. Nonetheless, where the aim of research is to enhance understanding, outsider advice will most likely be required also, as no insider's knowledge provides all the answers (Denscombe, 2010). The researcher of this study is also a staff member in the participating organisation. This will be addressed further in this chapter.

3.3   Research Participants (Sample)

The research participants are staff from an organisation in the intellectual disability sector. The twelve participants were directly involved in the organisation's transition to New Directions. Phenomenology believes truth and understanding of life can emerge from peoples' life experiences, as it provides a description of how things are experienced including how people interpret events and make sense of experiences. The staff members identified have varied backgrounds, qualifications, experiences and length of service.

As mentioned above the staff members are at different grades. Therefore, they are involved in the transition at different levels, stages and in different ways. Some staff members are senior managers with responsibility for conceptualising the change, strategy and leadership whilst other staff members are co-ordinators. Co-ordinators are middle managers with responsibility for communicating and supporting changes into operational plans. Other grades include staff

with responsibility for training Service Users, Job Coaches with responsibility for "Supported Employment" and Care Assistants. Job Coaches and Care Staff have technical skills and knowledge about their roles. They are also knowledgeable about their organisational positions and the tactical approaches they should adopt to advance the plan. During the recession there was a 500% increase in volunteering in parts of Ireland. The number of volunteers grew in the organisation participating in this research during that period. The arrival of volunteers coincided with a public sector recruitment embargo. As a result this led to a constant supply of meaningful plans that volunteers could support individuals to achieve in the community. The study also included an exploration of contributions made by volunteers in the organisation.

Table 1 below breaks down exactly what staff were interviewed for this research. Purposive/judgmental sampling was utilised based on the knowledge of the population and purpose of the study. This is where research participants are selected because of some characteristic (Crossman, 2014). All participants worked or volunteered in the department's day centres and already had a role in the new community based model. For the full selection criteria devised using purposive sampling see appendix M.

Table 1

Details of all those chosen for qualitative data collection for the purpose of this research

	GRADE	**AMOUNT**	**Reason for inclusion**
A	Senior Manager	x 1	Overall responsibility
B	Co-ordinator	x 1	Supports grades below
C	Job Coaches	x 3	Support individuals in communities from hubs
D	Care Staff	x 5 (two of whom are Community Employment Scheme)	Support individuals
E	Volunteers	X 2	Support individuals
Total		**12**	

The above list contains a cross section of the team in the organisation's day services. The range of research participants' roles, professions and experiences justifies their selection for involvement in a study which aimed to establish 'diverse' data around perspectives and experiences of the targeted staff sample on proposed new ways of working with people with ID. Additionally, New Directions (2012) states all staff and management have a

responsibility in advancing and achieving the delivery of New Directions. However, as the sample of twelve participants was still small in size, it does not guarantee to reflect the views of all those working in the sector. This was a limitation of the research.

Furthermore, reflexivity was considered throughout this study. According to Denscombe (2010) reflexivity concerns the relationship between the researcher and the social world. Researchers cannot achieve a perspective outside of the social world they are studying. A researcher cannot achieve full objectivity because concepts he/she uses to understand the world are part of the social world. Researchers use their experience, values, norms and concepts to make sense of the world and these are different for each person.

3.4   Data Collection Methods and Procedures Involved

According to Sarantakos (1998) qualitative methods aim to capture reality through the participants' lived experiences. Qualitative methods have been chosen for this study to capture the type of data required to address the aim of the research question - the perspectives and experiences of staff on the proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work. It is anticipated that this research will generate understanding and insight in relation to staff members in one organisation implementing New Directions. Qualitative methods can also capture the 'multiple voices' of different actors engaged in a process (Barbour, 2007) for example the perspectives of a multidisciplinary staff team, as per this study.

One audio recorded interview was carried out with each of the sample participants (see appendix G for a sample full transcript). The interviews were carried out in a comfortable office or in a setting that was more convenient/ preferable to interviewees. No interview exceeded one hour in duration and 'semi – structured' interviews were used. These type of interviews allow for both clearly defined goals whilst also providing flexibility in wording and sequencing of questions. Thus, assisting with establishing intended conversational context, without being fully formal in style or completely unstructured. According to Robson (1993) interviews are flexible and adaptable methods for obtaining information concerning facts, behaviour, beliefs and attitudes. Interviews as a research method are attuned to gaining insight into the intricacy of subject matter (Denscombe, 2010). Obtaining such information from the staff sample is essential in achieving the aim of this research study and in order for

those in leadership positions to better understand staff members' perspectives on achieving the best outcomes in the new structure.

According to Biggam (2008) how you prepare to collect your data has an impact on how easy it will be to analyse it. Qualitative interviews can be broken into easily identifiable 'themed subsets' of questions which allows for comparison and contrasting of each interviewees' responses (see appendix H for sample coding). However, themes should not be considered separately as they are inter-related. In order to create a fuller picture of what the data is saying, it's necessary to cross reference responses to questions under different themes also. It's essential to include these themes from the outset of initial interviews using appropriate headings. The themes in this research reflect the aim and objectives of the study and also echo main themes in the literature review. For the purpose of this study these topics are organised under seven main thematic headings; models of service, person-centeredness, supporting community participation, family, friendship, the contribution of persons with ID to their communities and how New Directions can best work. Questions were designed under each theme to tap into research participants' perspectives, experiences and how they believe New Directions can best work (see appendix F for full question list). Appendix N contains all the considerations taken into account when devising the interview schedule.

3.5   Framework for Data Analysis

Analyzing qualitative interviews is a sophisticated and taxing process requiring concentrated effort, a clear mind and an intuitive approach to data. There are some principles underlying analysis of qualitative data. Analysis should not come last and should not just start when interviews have taken place. Things need to be thought about from the outset such as attempting to develop explanations and interpretations of what is being explored. Ideas should be refined, questioned and understood as data is collected. Look for evidence confirming and refuting early interpretations (Moore, 2000). According to Moore (2000) putting principles into practice begins with identifying themes and issues and constantly referring back to both the aim and objectives of the research study and interviews. It's necessary to put some order to data in order to work through it seeking explanations. The aim is to move from description to analysis.

Analyzing data involves making sense of the data. Analyzing qualitative data like interviews is an ongoing and cyclical process that is reading data, asking questions of data, re-reading and repeating this pattern. It's essential to prepare data, become familiar with data and carry out coding of data. However, Hyncer (1985) points out the notion of producing a 'cookbook' of instructions, is against aims of flexibility and openness to data, which is at the core of qualitative research. It's important to utilise 'reflexivity' with qualitative research that is to reflect on the researcher's own role, position, biases and how this may impact on the quality and interpretation of data collected. This can be a disadvantage and limitation of qualitative research unless this challenge is overcome professionally and ethically. As previously mentioned, where the research aim is to enhance understanding, a good researcher must be open to outside, different and indeed opposing perspectives to his/ her own. There is more than one lens through which lived experiences can be viewed.

3.6   Ethical Issues and Confidentiality

According to May (2001) ethics is concerned with trying to devise codes and principles of moral behaviour. Social researchers are expected to carry out their study in an ethical manner that protects participants, ensures participation is voluntary and based on informed consent, avoids deception and acts within the law (Denscombe, 2010). The methodological choices for this research are aligned to the research question. It was also necessary to take adequate steps to meet ethical responsibility to protect professions, participants' rights and the researcher involved.

The research was carried out in keeping with ethical guidelines for taught postgraduate research dissertations at DIT. The organisation identified for participation was provided with written information as recommended as part of permission seeking (see appendices A and B). The individuals identified for participation were also given an explanatory information sheet. Participants identified for inclusion in this research received a detailed and informatory letter (appendix C) requesting their consent to partake in the research interviews. The letter contained information as recommended in appendix A. A copy of the consent form (appendix E) was also included. The consent form was issued, completed and stored confidentially.

As mentioned previously, this researcher is also a practitioner in the participating organisation. As a result, a 'preamble' (appendix D) was also devised for interviewees in

order to try to elicit as honest responses as possible while maintaining collegiality. The preamble was issued with the consent letter. It was also re-stated at the start of each interview to ensure participants would be comfortable and secure in participating.

According to Cassell & Symon (1994) with any social science research potential participants must be assured of confidentiality, know why the research is being carried out and what it hopes to achieve. The anonymity of all participants and organisations involved has been respected and upheld with clear information provided to the sample throughout. All participants were clearly informed participation was voluntary. Ethical issues have been discussed with the supervisor of this researcher and an ethical declaration form has also been completed (appendix I).

3.7   Limitations

Whether data is qualitative, quantitative or mixed, it's prone to misleading readings. There is scope for human error in handling data and a margin of error is expected with most sound research studies (Burnett, 2009). Even before the data analysis stage is reached there can be problems around data collection. According to Denscombe (2010) data from interviews are based on what people say rather than what they do. The two may not tally and this phenomenon is known as the 'interviewer effect'. Interviews can inhibit participants' responses and the reliability of interviews is another disadvantage.

Interviews with staff, volunteers and management were carried out in this study under the qualitative research methodology utilized. However, Bryman (2012) states that the majority of qualitative research findings are only applicable to the sample being studied and it doesn't facilitate making generalisations. As the sample is small in size and only representative of one organisation, it doesn't guarantee to reflect the views of all those working in the sector and these were limitations of this study.

Hyncer (1985) believes it is important to use reflexivity with qualitative research. This was particularly important in this study because the researcher is also a staff member in the participating organisation. This can be a disadvantage and limitation of qualitative research unless this challenge is overcome professionally and ethically. According to Bryman (2012)

complete objectivity is not feasible and once a researcher does not sway data collection and findings, the researcher can be shown to have acted in good faith.

3.8   Conclusion

This chapter identified and explained the methodological framework underpinning the research and justified using a qualitative data collection method to meet the aims and objectives of the research. The next chapter presents a summary of the main findings.

Findings

4.1   Introduction

This study aims to explore perspectives and experiences of staff from the disability sector on proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work. This chapter presents a summary of the main findings that emerged from twelve qualitative interviews carried out with staff, volunteers and management to meet the aims of this research. For data collection and analysis purposes questions were designed under seven themes to tap into the research participants' perspectives and experiences in relation to New Directions. These findings are now presented and analysed under the seven thematic headings used during data collection.

4.2   Models of Service

Participants expressed that structure, sense of purpose, belonging, connectedness and companionship are the good aspects of existing day services that should be incorporated into New Directions.

> *"Yeah, the only thing I could say that was good was...the connection, they had their friends. I find that since they have moved out they are a bit more lonely, they have lost that sense of belonging to a place because the hubs are just drop in, they are not meeting with a group, they used to meet with a group and I suppose it gave them structure...."* (Participant 4)

Concern was expressed about communication and support for staff under New Directions.

> *"....when you are in a centre you have more supports around you...Even your styles of even communicating.....your manager is there if you need to ask a quick question but I think when you are in the community a lot is put onto staff as well and I think communication can get mixed up in it."* (Participant 5)

4.3   Person–centeredness

Person-centeredness was described as a highly individualised way of working where the person is constantly the central focus of what is happening.

> *"The lads and the girls have aims and achievements about what they want to do in life and it's just supporting them around this...it's all about them going forward and their life, to work in a person-centred way."* (Participant 6)

4.4   Supporting Community Participation

4.4.1   Participants gave examples of where participation in community life was increased. Examples of community participation included a range of different types of engagement. The dominant narrative to emerge was the concept of empowerment. However, one participant questioned participation itself. Reciprocities were also evident.

> *".....if you are bringing someone to the coffee shop that's not actually involving them in the community, that's just bringing them for a coffee. So like what is somebody in the community? What does it actually mean?"* (Participant 7)

> *"Another guy I support in the gym is now on a first name basis with lots of other members.....He is reacting out there in the community. I said to him tell the guys you sell the local paper on a Thursday.....and now he sells them down there. It's a snowball thing."* (Participant 6)

Service users no longer attending the disability service emerged somewhat as a marker of success.

> *"I would have to say a man who joined the Men's Shed was enormous...He doesn't need staff or the organisation anymore because he has other areas to go."* (Participant 10)

4.4.2   Staffing, support, flexible hours and communication were cited as necessary to enable community participation.

> *"Oh there has to be some kind of communication between...NGO's, voluntary organisations and those kind of organisations. There is this mad rush to the community but the community is not necessarily ready for us or even aware that we exist.....say for example.....you want people to go to an art class but there can be this grey from providers when they say 'no this is not for people with disabilities, this is for people you know in mainstrean'. So there is that distinction there, no it's not a distinction, there is that ambiguity there between mainstream and community and is there a difference?"* (Participant 10)

Support was cited in terms of ongoing support, and 'just enough support'.

> *"...you don't want to over support and you don't want to under support, that's the challenge we have...but the main thing is the constant link in..."*(Participant 12)

4.5   Family

4.5.1   Although families were not explicitly mentioned when participants described person-centered care, participants strongly believed they are essential for New Directions to work but also challenged by it.

> *"...it's just as important to build a relationship with the family because they are going to need to be onboard with every decision. I have seen where they are not it is very difficult..."* (Participant 5)

> *....families are key to everything that we do....It is a very scary road for families...."* (Participant 9)

> *"...I think the parents might say 'if I hear it's my choice another time'. So, I think they are being challenged. Yeah, so I am not sure about their quality of life. I think they are doing more work."* (Participant 8)

4.5.2   Ideas on how organizations could support families more were sought and every one of the twelve participants talked about 'communication' in their responses. Building trust was also highlighted.

4.6   Friendship

4.6.1   These findings were the most surprising in this study. Ten of the twelve participants strongly believed that people with ID do not have friendships with their peers. The presence of staff in service users' lives was repeatedly mentioned as a contributing factor to this trend.

> *"I am not sure if they have very good quality friendships. I think it's poor.....I think they are probably too used to having staff listen to them individually. And they actually can't have a conversation...themselves...when we are not there maybe they are doing quite well.....if they were on their own maybe they could develop quite good friendships."* (Participant 8)

> *".....if two people are talking, let's say there is a staff floating around to see if everything is alright, it's not really just between two people. It's not proper*

conversation with the staff there. I don't honestly think that they have friendships."
(Participant 7)

It was mentioned that integration and independence can be somewhat at the expense of friendship. Participants believed the concept of friendship will drive future policy direction.

4.6.2 Participants indicated the type of support actually needed to support friendship under New Directions. Practical answers ranged from putting in foundations for friendship like work, educational opportunities and social components to providing opportunities for attendance at community facilities and events. Interaction with sporting organisations was also mentioned.

> *"On one hand staff need to back off yet there is a need for staff to help along the way with a community based model."* (Participant 7)

Providing ongoing support for activities that facilitate people meeting up with each other was also emphasised. Furthermore, flexible support that is not constrained by time was highlighted.

> *"It's actually living your life at the same time others are doing it."* (Participant 9)

4.7   The contribution of persons with ID to their communities

4.7.1   Awareness, diversity and joy were recurring sub themes from participants under this theme. Themes of empowerment, inclusion and education are also evident. The gym, an active age group and shops were some of the specific contexts mentioned.

> *"A lot of them would know more neighbours than what you would.....they get to know their neighbours quicker than we would.....they would be more open socially...."*
> (Participant 2)

4.7.2   Participants said disability organisations can support communities to include people with disabilities by informing the community about disability, spending time with people with disabilities, 'giving to' and 'partnering with' communities and being 'mindful' of others in the community.

"...Some course providers say they can't have six people with disabilities in the class because it could fall apart around progression to be made. 'One person will take time but we can do that much'. You have to be mindful of that. It will take time to do it properly and you need to support so it doesn't go wrong. Otherwise they won't get involved again..." (Participant 8)

"...I don't think any talks...I remember a course provider in the community asking me to sit them down and give a talk and I said let's let them learn themselves, let's support it, let's observe...If I sat down and listed off do's and don'ts around people with disabilities you are going to turn them off or send them down the wrong road or maybe make people apprehensive. Let people be natural and that's the way it should be." (Participant 12)

4.8   How New Directions can best work

4.8.1 The two managers who participated in this study both believe an organisation that buys into a set of person-centred principles is the type of organisational culture needed to realise New Directions,

"...there has to be buy in to the set of principles set by New Directions from above....I think we need a flatter system...it needs to be seen that we all roll up our sleeves to get this done...it does need resource...senior management...should use the guiding principles of New Directions in their decision making and our strategic plan because the two of them go hand and glove..." (Participant 9)

4.8.2   Regarding change management and leadership needed, a manager replied,

"...I think there is also a huge investment in staff training because staff have been working in a bubble of segregated settings, going out into your own community is a totally different business...there is a structural change I think in management also." (Participant 9)

The other ten (non-management) participants were asked about changes in roles, challenges and the skills now required.

4.8.3   Eight of ten participants felt strongly their roles had changed significantly. Examples given included, the shift towards the community, making better use of time with service users and also the difficulty in adjusting for some staff.

"....You are caring for people and now you are trying to help them care for themselves. There is a huge difference and it is really hard to adjust....."(Participant 5)

4.8.4 Participants cited the following challenges for staff; under staffing, time, cutbacks, support and motivation.

"...The challenge for staff is motivation...to keep going...I think it can be very lonely. There are less staff. It's not like a centre...out in a community finding one to one placements, that won't be attractive to some people so it's going to be difficult...I personally found it difficult. I get a lot of energy from groups..." (Participant 8)

One quarter of participants talked about constantly trying to find things to do in the community and associated challenges.

"It's a big challenge I think finding things for them to do and places for them to [go]...So they don't get boredom." (Participant 1)

"A challenge for staff – trying to gauge the pace the community is ready for." (Participant 2)

4.8.5 Under skills and training required ability to source meaningful opportunities in the community and communication skills were highlighted. Communication appears as a major recurring sub theme, under most of the seven themes in these findings.

"I think we definitely need people trained in how to make contact with an employer, how to approach a parent, how to approach a company like Dublin Bus, An Garda Siochana, how to get involved with your community...what community work is all about, what communities are about, what putting people out independently is all about...some form of training on communication. That kind of support is needed to help them think outside of the structure of day services and the structure of what was before."(Participant 4)

Mentoring and permission were also highlighted.

"I think some staff probably need permission. It's not so much training as permission...But I think yeah maybe assertiveness training...you are kind of driving into the unknown with a lot of this stuff. And a lot of staff all they need is reassurance, they don't need their hand held..." (Participant 10)

"It's like everything you need the formal courses...but most of all you need the mentoring, the guidance from senior staff and managers. It could do with an allocation of a specific head to a new person. I was at a couple of sessions with

volunteers and staff and the questions and answers, answers and responses from staff was an excellent way to gain insight into what was going on." (Participant 3)

The above finding raises the question of supervision.

4.8.6 Participants believe the potential of New Directions can best be maximised by supporting people into positions that create friendships, social, educational and other opportunities. Working with other partners in the process, managers who can give 100% of their time to New Directions, awareness and other policies were also cited.

> *"....I think making staff more aware of it...a lot of people don't know what New Directions is...I think people with severe - profound think New Directions is not for them..I think the staff could feel 'look this is not for us'..."*(Participant 8)

> *"...there is another document called Value for Money which is all about people having individualised budgets which I think is the next phase of New Directions...a lot of families will take up their own support mechanism and buy in a lot of private...New Directions changes....from us providing services to facilitating supports for individuals to have a life and that's a big power change...What I would hope and pray for is that people are self-determined to live their own life..."* (Participant 9)

4.8.7 Despite changes arising from New Directions a strong majority felt moving from segregated settings to the community was a very good idea.

> *"...ultimately it's the life change for a person. This is trial and error for us in the sense that it's going on the journey with the individual...so as long as we have a set of principles to follow...and we are actively listening to the individual, then we are on the right road."* (Participant 9)

However, concern was expressed around communication and a possible over emphasis on going out into the community. It was also questioned is New Directions a cost saving scheme?

> *"Yes I do...I really do think communication is the biggest downfall. We have to alleviate the fears of families who think centres are the only option...This would be better for staff also. Open and honest about what New Directions is about..."* (Participant 4)

> *"You see I would like to say it's brilliant but I think...You are out all the time but you are not in a comfortable environment all the time. There is even pressure that I can't go back because I have to be out. So yeah I do, it definitely has to be balanced you know, not all community and going to forget about the centre."* (Participant 7)

"Ultimately yeah....it's a great idea, you know...it's about independence, it's about employment, it's about community links, social capital, of course it's all great...but maybe a bit vague also in assuming that people want those things...I don't really like the idea of complete and total community based....think of the guys who are older...let them have what they have always been comfortable with you know. I think in theory great, in practice it leaves a bit of work. In theory when you mention words like independence and equality they all sound great but it's a lot bigger than that." (Participant 5)

4.9   Conclusion

This concludes the summary of central findings from this research. Please see appendices "Sample Interview" and "Sample Coding" for comprehensive coding of data. The following chapter discusses these findings in relation to New Directions, literature and the research question.

Discussion

5.1   Introduction

This chapter discusses the main findings from the research completed with twelve participants to meet the aims and objectives of this study. The study aims to explore the perspectives and experiences of staff from the disability sector on the proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work. In order to take findings to another level of analysis, a number of themes have been developed (from the original themes used during data collection) that lend themselves to such analysis and critical discussion.

Themes of *'Friendship'* and *'Models of Service'* have been combined to become *'Friendship and Services'* because a strong relationship emerged during data collection between those two themes. The *'family'* theme becomes *'Focus on Families'* and now includes discussion of findings gathered under *'Person – centeredness'*. The following themes, *'The contribution of persons with intellectual disabilities to their communities'* and *'Supporting Community Participation'* have been reorganised into, *'What Community Means'* and *'Demands on Communities'* in response to dominant findings that emerged. '*How New Directions can best work'* is discussed under the following important subthemes; *'Organisational Culture, Change Management and Leadership', 'Changing Roles of Staff'* and *'Maximising New Directions'*. This chapter discusses findings in relation to literature, New Directions and the research question.

5.2   Friendship and Services

Pahl (2008) believes friends can help form the basic structure of our lives. Important ideas were conveyed by participants on friendships that service users had in centres and what might be aspired to under New Directions. In terms of balancing good parts of existing services with newer approaches, participants cited a sense of belonging, connectedness and companionship as the best aspects of existing day services. New Directions advocates people with disabilities should now aim to achieve a sense of belonging, connectedness and companionship in mainstream communities. New Directions (2012) states people with disabilities should take their place in society. It advocates supporting people develop

relationships and social roles like being a friend and in places where opportunities exist for everyday exchanges of living. Some people with ID will also need support to re-establish and/or maintain friendships.

However, this research raised concerns that New Directions could actually be leading to loneliness for some. *"Yeah, the only thing I could say that was good before [New Directions] was...the connection, they had their friends. I find that since they have moved out they are a bit more lonely, they have lost that sense of belonging to a place because the hubs are just drop in..."* (Participant 4) Integration and independence were mentioned as possibly negatively impacting on friendship due to the highly individualised and busy lives people with ID are now living, with little/no time for friends. The narrative of New Directions contrasts sharply with concepts such as loneliness and not seeing friends.

However, observations can be more complex than they first appear. Ten of twelve participants strongly believed people with ID don't have friendships with peers in the first instance. Participants stated staff in their lives has somehow hindered friendships developing, *"I am not sure if they have very good quality friendships. I think it's poor...I think they are probably too used to having staff listen to them individually. And they actually can't have a conversation...themselves..."* (Participant 8) and *"...if two people are talking, let's say there is a staff floating around to see if everything is alright, it's not really just between two people. It's not proper conversation with the staff there. I don't honestly think that they have friendships."* (Participant 7) Furthermore, these beliefs concur with literature. According to Johnstone (2001) constant supervision in day services makes it difficult to form and maintain mutually reciprocal and respectful friendships. The literature then merges with the ethos of New Directions again as Johnstone (2001) states, in such situations people with disabilities need more contact with trusted companions who are capable of forming a social umbrella of support which encourages wider social networks and friendships.

This argument is further developed by O'Brien (1987) who believes caring services should find ways of supporting people with ID to grow a wide network that provides positive and meaningful interaction. The literature actually contains multiple perspectives. On one hand it is argued staff over supervise people with ID. Yet staff are also needed to support friendships. A participant tapped into this contradiction and the level of 'just enough support' needed for friendship under New Directions, *"On one hand staff need to back off, yet there is a need for staff to help along the way with a community based model."* (Participant 7) Perske (1988)

states staff cannot programme friendships but they can set up frameworks where friendships can flourish. The findings in this research referred to putting in frameworks/foundations for friendship like employment, educational and social components.

Providing 'just enough' ongoing support for activities that facilitate people meeting up with each other was emphasised in this study, *".....you don't want to over support and you don't want to under support, that's the challenge we have....."*(Participant 12) This finding corresponds with current literature. Franklin & Sanderson (2014) discuss the concept of 'Just Enough Support' – an optimum level of support that increases chances of people connecting with local people in communities. 'Just enough support' may increase the nature and types of friendships that people with ID have in communities as findings suggest people with ID have strengths socially also, *"A lot of them would know more neighbours than what you would.....they get to know their neighbours quicker than we would.....they would be more open socially...."* (Participant 2) The concept of community is discussed next.

5.3   What 'Community' Means?

Participants referred to awareness, diversity and joy people with ID bring to communities in different settings like shops, active age and gyms. Patterson & Pegg (2009) found participation in leisure in particular positively impacts on quality of life for people with disabilities also. The notion of people with ID using mainstream community facilities and enriching their lives and others in the process demonstrates the 'sense of belonging' and 'interdependencies' that is characteristic of community.

However, participants flagged New Directions could be fuelling a rush to and possibly 'over emphasis' on community. Participants quickly challenged misinterpretations and misunderstandings of community, *"Things don't always happen when you are in the park looking at the lake – it just doesn't happen."* (Participant 3) and *".....if you are bringing someone to the coffee shop that's not actually involving them in the community, that's just bringing them for a coffee. So like what is somebody in the community? What does it actually mean?"* (Participant 7) Critically, Cummins & Lau (2003) also challenges the assumption 'physical integration' within communities leads to better lives. They believe 'social' and not physical integration positively impacts on well-being. However, some people with disabilities find social integration within general communities difficult. This links to earlier discussions

on friendship around loneliness. If a person's previous day service offered a sense of belonging and purposefulness should it be bypassed for an ideal of integration in some imagined community, where people could actually be lonely? The discussion emphasizes the complexity of transitioning to New Directions. There are pitfalls which could potentially damage the process and its many positive aspects.

5.4   Demands on Communities

Participants demonstrated awareness of how much 'disability' communities are currently ready for, "*... A challenge for staff – trying to gauge the pace the community is ready for.*" (Participant 2) The importance of balancing the community's readiness with the pace of implementing New Directions was highlighted, so as not to risk doing too much too soon, "*There is this mad rush to the community but the community is not necessarily ready for us or even aware that we exist...say for example...you want people to go to an art class but there can be this grey from providers when they say, 'no this is not for people with disabilities, this is for people you know in mainstream'..*" (Participant 10) It's suggested some mainstream services and facilities within communities may need more support around New Directions and inclusion.

Some educational course providers say they can only support a limited number of people with ID at present, "*...'One person will take time but we can do that much'. You have to be mindful of that. It will take time to do it properly and you need to support so it doesn't go wrong. Otherwise they won't get involved again.*" (Participant 8) How can we consider these community facilities if people feel unwelcome? How can 'integration' be supported?

Brown & Brown (2003) advise developing ways to address outside agencies whose policies are not harmonious with the practitioner's organisations around inclusion. However, educating communities about disability demands time and energy which may result in disagreements and disappointment. The majority of people in local communities are welcoming and responsive but there is a failure to realise they still need advice. Furthermore, most effective community education involves creating relationships among people rather than giving information (McConkey, 1994). Participants concurred with this literature, "*....I don't think any talks....I remember a course provider in the community asking me to sit them down and give a talk... If I sat down and listed off do's and don'ts around people with disabilities*

you are going to turn them off...Let people be natural and that's the way it should be." (Participant 12) Additionally, participants believed in 'giving to' and 'partnering with' communities as ways of supporting communities to be inclusive.

People with disabilities (with carefully targeted support at times) seize everyday opportunities to educate people. They include themselves in communities and often in reciprocal ways, as per the New Directions philosophy, *"Another guy I support in the gym is now on a first name basis with lots of other members.....He is reacting out there in the community. I said to him tell the guys you sell the local paper on a Thursday.....and now he sells them down there. It's a snowball thing."* (Participant 6) McConkey (1994) believes educating communities is a process rather than an event. Changing and sustaining public attitudes and behaviours results from multiple initiatives and diverse sources so the public accumulates experiences and knowledge. Participants also prioritised creating enjoyable, face-to-face meetings rather than providing formal talks. This promotes positive images of people with disabilities whilst also addressing misconceptions and concerns in communities.

5.5   Focus on Families

Participants believe person-centeredness is where the person is constantly the central focus of what is happening, *"...it's all about them, what they want out of life, their goals and dreams...."* (Participant 7) Participants described a highly individualised approach. However, Barnes (1994) stresses independence is not about someone who can do everything for themselves, something no-one can do regardless of ability.

Staff also need to work with families to achieve person-centered planning, *"...it's just as important to build a relationship with the family because they are going to need to be onboard with every decision. I have seen where they are not it is very difficult..."* (Participant 5) Person-centeredness and independence is not about disconnecting people from family, friends, communities and support. However, disengagement from disability services emerged as an apparent marker of success in the findings, *"...He doesn't need staff or the organisation anymore because he has other areas to go."* (Participant 10) Disengagement from disability services needs to be carefully managed so as not to remove supports which were empowering and sustaining the person's independence.

Families who contributed to New Directions (2012) said they want to be on the team that supports a person to make decisions. Additionally, a key feature of person–centeredness is family and friends are viewed as partners in planning (Medora & Ledger 2005). Consistent with literature participants stated, *"....families are key to everything that we do...."* (Participant 9) Families facilitate friendships and support community participation. They are essential for maximizing New Directions.

According to Medora & Ledger (2005) both individuals and families have reported enjoying person-centred planning. However, these findings suggest families are challenged by person-centeredness and New Directions, *"...I think the parents might say 'if I hear it's my choice another time'. So, I think they are being challenged. Yeah, so I am not sure about their quality of life. I think they are doing more work."* (Participant 8) Noteworthy, is that family satisfaction significantly impacts on facilitating a smooth, efficient and responsible deinstitutionalization (Ferguson & Pennock, 2000).

The need for families to be closely involved seems well understood. However, bringing families on board to implement New Directions needs more focus. Participants expressed empathy with parents, understanding around their fears and clarity on the need to build trusting relationships with families. The need for communication with families was mentioned by every participant emphasizing its importance. However, participants expressed concerns regarding communication*"...I really do think communication is the biggest downfall. We have to alleviate the fears of families who think centres are the only option..."* (Participant 4) It is essential organisations enhance communication with families to make New Directions succeed. Practitioners who focus on 'family' can also improve quality of life for families. The greatest resource for helping a person with a disability is family and the community around the family can also be mobilised for support (Johnstone, 2001).

5.6   Organisational Culture, Change Management and Leadership

Organisational culture is an organisation's shared values, beliefs and assumptions held by members and communicated symbolically (Tiernan, Morley, & Foley, 2006). Harty (2014) believes changing a company's culture is the most difficult leadership challenge for managers. New Directions means change for organizations dependent on the difference

between their current service and a person-centred approach. Organisational culture may need to change (HSE, 2012). Managers involved in this study believe an organisational culture that buys into a set of person-centred principles needs to exist to realise New Directions, *".....there has to be buy in to the set of principles set by New Directions from above....I think we need a flatter system....it needs to be seen that we all roll up our sleeves to get this done..."* (Participant 9) Person-centred organisations tend towards non-hierarchical structures and management systems, where managers support staff and have contact with service users (Sanderson, 2003).

Person-centred organisations also value staff and service users. They devolve resources and authority to service users and staff to facilitate empowerment (Sanderson, 2003). Evidence of valuing staff was apparent when managers were asked about change management and leadership needed to achieve New Directions, a manager in this study said *"...I think there is also a huge investment in staff training because staff have been working in a bubble of segregated settings, going out into your own community is a totally different business..."*(Participant 9) This is in line with New Directions which states, *"A key element of staff training and development will be familiarisation with the concept of person-centeredness and what it means for day-to-day practice"* (HSE, 2012, p. 78). All staff, not only those involved in facilitating person-centred planning, should receive this training as part of induction and development.

Beyond induction staff need ongoing support especially when roles change to remain motivated, *"...The challenge for staff is motivation...I think it can be very lonely. There are less staff. It's not like a centre...out in a community finding one to one placements, that won't be attractive to some people so it's going to be difficult..."* (Participant 8) When organizational culture changes, staff may feel disempowered and teamwork may become fractured. Staff supervision and training should be increased when change impacts on an organisation's ethos and staff motivation. Whilst, the disability sector in Ireland has become increasingly influenced by the Social Model of disability, a *'Social Care model of disability'* has not yet been adopted nationally. Many organizations hire 'Care Assistants' for day services as opposed to 'Social Care Workers' and staff supervision is not common practice either, *"It's like everything you need the formal courses....but most of all you need the mentoring, the guidance from senior staff and managers. It could do with an allocation of a specific head to a new person..."* (Participant 3) Yet the work expected from staff has become increasingly skilled and according to Gardner & Nudler (1999) 'Skilled helpers' need skills

to interact and communicate with individuals, families, service systems and community – and ability to value multiple perspectives and collaborations (Gardner & Nudler, 1999) Care staff are capable, caring and committed. However, because of the skills now expected to work with people with ID, the components of a Social Care degree as a minimum qualification are now a closer fit with the work required. Draft interim standards for New Directions propose to address staffing requirements.

5.7   Changing Role of Staff

Organisational culture modelling good practice communicates a message to service users, staff and families about the 'value' of involvement and inclusion (Malin, 1995). Participants had concerns around support and communication under New Directions, *"....when you are in a centre you have more supports around you...your manager is there if you need to ask a quick question but I think when you are in the community a lot is put onto staff as well and I think communication can get mixed up in it."* (Participant 5)

Eighty per cent of participants felt strongly their role has changed in recent years. Changes cited included, more time now being spent in communities, Life coaching in place of Job coaching, making better use of time spent with individuals and also the difficulty in adjusting for some staff, *"....You are caring for people and now you are trying to help them care for themselves. There is a huge difference and it is really hard to adjust....."* (Participant 5) The skills needed to help people make informed choices and decide what they want are different to those involved in telling people what their needs are (Malin, 1995). It would appear that new skills are also required in regard to identifying and coordinating supports within wider communities and networks, *"It's a big challenge I think finding things for them to do and places for them to go...So they don't get boredom."* (Participant 1)

The communication skills needed was also highlighted, *"I think we definitely need people trained in how to make contact with an employer, how to approach a parent, how to approach a company...how to get involved with your community...what community work is all about, what communities are about...some form of training on communication...to help them think outside of the structure...of what was before."* (Participant 4) According to Johnstone (2001) the subtle dynamics of communities need to be considered and staff should tap into existing community patterns and interests rather than set up projects that may negatively

impact on existing community strengths. This links to the earlier parts of the discussion in terms of community readiness. Noteworthy is the timing of New Directions, communities are still suffering from the recession and disability organisations' should aim to form mutually beneficial and reciprocal relationships in communities. Otherwise, community groups and organisations who are already struggling may feel overburdened by the arrival of people with ID. Thus, the image of New Directions, service providers and more importantly people with ID could become tarnished.

Participants referred to the need for flexible working hours to really achieve New Directions. Recruitment of new staff should include flexibility to provide support outside of nine-to-five arrangements (HSE, 2012). According to Brown & Brown (2003) to establish a quality of life approach for people with ID, organisations should provide flexibility to frontline personnel. Furthermore, a quality of life approach requires reasonable risk-taking at times and staff must feel permission from management to try out things and adapt interventions and supports within general policies. Findings were consistent with this belief, *"I think some staff probably need permission...you are kind of driving into the unknown with a lot of this stuff. And a lot of staff all they need is reassurance, they don't need their hand held..."* (Participant 10)

5.8   Maximising New Directions

Despite all the changes arising from the New Directions *"...journey with the individual..."* (Participant 9) eleven of the twelve participants thought ultimately it was a very good idea. Although there were some specific concerns amongst those eleven participants, only one participant was entirely sceptical, *"...I would be afraid that it would turn into having to go back to centres anyway..."* (Participant 7) Programmes set up under New Directions will be evaluated against the twelve service supports in New Directions to see if they are going in right direction. These supports will have corresponding outcomes (standards) for setting goals, making plans and measuring progress.

However, it was questioned is New Directions primarily a cost saving scheme? *"...I don't know anybody who was asked or who inputted into New Directions. Is it a money making scheme? A lot of people think it is."* (Participant 8) It was also expressed that whilst New Directions may save money, it should still be pursued, *"Yes I do I think it's a great idea. Now the cynic in me would say it will save money for organisations and yeah it will....but it is*

100% the right decision....New Directions will give parents a future for their children if it is handled properly...” (Participant 10) Surprisingly, no participant mentioned the additional expense of a community based model on families who now have to buy in educational courses, pay for using mainstream social, leisure and recreational spaces and the associated travel costs. The concept of the 'money following the person' is at the heart of international policy initiatives like New Directions (HSE, 2012). However, New Directions has commenced in Ireland before the introduction of a system of direct payments/individualised budgets.

Participants were concerned about an over emphasis on going out into the community. Some believed a community based model is not suitable for every service user, all the time, *“...I don't really like the idea of complete and total community based...”* (Participant 5) A participant also cited experiencing pressure to be out in the community, *“...There is even pressure that I can't go back [to the centre] because I have to be out. So yeah I do, it definitely has to be balanced you know, not all community and going to forget about the centre.”* (Participant 7) New Directions (2012) states services should still have a physical presence/setting but preferably in integrated environments, *“Any new physical developments should take the form of a 'hub' from which people with disabilities can be supported to access local services.”* (HSE, 2012, p. 84) However, the word 'hub' is only mentioned twice in New Directions. It would help with implementing New Directions if 'hubs' were teased out further and defining more clearly. Presently, 'hubs' are open to interpretation, which can be a good thing.

In this instance there appears to be some ambiguity and tension amongst staff, management, service users and their families around the amount of 'time spent in the community' versus 'time spent in 'hubs' (if any). Support and clarity around this would benefit all those involved in New Directions. This is something that should be negotiated locally and with all partners involved in the person-centered planning process, especially when organisations are transitioning to New Directions. The New Directions standards which are currently at draft interim stage should definitely address this issue nationally as the development of 'hubs' could be used to help achieve, the weaving together of independence and interdependence as valued approaches through which 'social integration' may be achieved (Carnaby, 1998)

Participants believe the potential of New Directions can best be maximised by supporting people into positions that create friendships, social, educational and other opportunities. One participant felt New Directions can be best maximised when used in conjunction with another policy, *"...there is another document called 'Value for Money' which is all about people having individualised budgets which I think is the next phase of New Directions...I think a lot of families will take up their own support mechanism and buy in a lot of private [support]...* (Participant 9)

As previously discussed communication with staff, service users, their families and community partners was emphasised as important to maximise New Directions, *"....I think making staff more aware of it...a lot of people don't know what New Directions is....I think people with severe - profound think New Directions is not for them....I think the staff could feel 'look this is not for us'..."*(Participant 8) Additionally, the concept of 'support' for staff, service users, families and communities emerged as a common thread throughout this research.

5.9   Conclusion

This concludes the discussion of main findings from this study. The conclusions and recommendations in relation to New Directions are put forward next.

Conclusions and Recommendations

6.1   Introduction

The challenge for the HSE in its 2012 review of adult day services was to propose a modern service that is capable of responding to a diverse set of interests, aspirations and personal circumstances. The review culminated in a new approach called New Directions: Personal Support Services for Adults with Disabilities (2012). The overall aim of this study was to explore the perspectives and experiences of staff from the disability sector on the proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work. These objectives were addressed by interviewing twelve staff and managers from an organisation in the disability sector that was in the process of implementing major changes under New Directions.

6.2   Conclusion

This study found strong support for New Directions but some participants felt there was an 'over emphasis' on community. Some were concerned a community based model is not suitable for every service user, always. The staff interviewed stated that a sense of belonging, connectedness and companionship are the best aspects of existing day services that should be incorporated into newer day services under New Directions. However, this study also illustrated New Directions could be challenging companionship and connectedness for people. Concerns were raised that 'people with disabilities taking their place in society' could actually be leading to loneliness for some. If independence and physical integration are pursued without supporting people to maintain and develop relationships like being a friend, loneliness can result. Importantly, the depth of friendships that people with ID have with their peers in the first place was majorly questioned by participants in this research. Participants believed constant supervision of people with ID from staff has negatively impacted on their ability to form friendships. Simultaneously, people with ID tend to be 'more open socially'. Therefore with 'just enough support' it may be likely to increase the nature and types of their friendships in communities. Support can include setting up frameworks where friendships can flourish like employment, educational and social components.

Participants believed in the positive contribution that people with ID make to a community. The awareness, diversity and joy that people with ID bring to communities was emphasized. They also believed community participation for people with ID had to be done gradually. Participants challenged what they saw as misinterpretations of community participation. They also demonstrated awareness of how much 'disability' communities are currently ready for. Participants' highlighted the importance of balancing the community's readiness with the pace of implementing New Directions. Some mainstream services and facilities within communities need more support to include people with ID. This support demands time and energy. Both organisations and individuals should strive for authentic, face-to-face, reciprocal relationships with community partners like employers, educators and providers of social, leisure and recreational spaces. As this study highlighted people with ID can be strong at building a rapport with others in communities, they can also initiate interactions themselves to promote positive images of people with disabilities.

Interviewees were conscious that New Directions challenges families. Where person-centeredness challenges families, it should be clearly reframed so that the individual is seen as at the 'centre of a family' and at the 'centre of a community' rather than an independent entity who doesn't need support. Support from families is necessary for New Directions and families who contributed to New Directions said they want to provide support. Communication with families was mentioned by every participant in this study thus emphasizing its importance.

The managers' perspectives in this study suggested 'flatter' organisational cultures with person-centred principles are required to realise New Directions. Person-centred organisations tend towards non-hierarchical structures and management systems. Based on participants' experiences ongoing support and high levels of communication are needed to keep staff motivated during periods of change. Eighty per cent of participants felt strongly their role has changed. Participants said greater flexibility around working days/hours is now needed to achieve New Directions. New skills identifying and coordinating supports within wider communities and networks are also needed especially where community organisations are unaware of New Directions. Additionally, support for staff in terms of 'permission' from management to implement New Directions was highlighted especially where outcomes may be unclear from the outset.

The purpose and shape of 'hubs' mentioned in New Directions needs to be teased out locally and nationally to reduce ambiguity and tension amongst staff, management, service users and their families. Support and clarity around this would benefit all those involved in New Directions and this could be achieved through local negotiation. Furthermore, the setting up of 'hubs' presents an opportunity (if developed correctly) which could help to achieve, the weaving together of independence and interdependence as valued approaches through which 'social integration' may be achieved (Carnaby, 1998).

Finally, the last research objective was to explore how the objectives of New Directions can best be maximised. Participants proposed this can be achieved by supporting people into positions that create friendships and by providing social, educational and social opportunities. It was also cited the Value for Money Report (2012) will help maximise New Directions. During the change management process managers should use their leadership to ensure minimum qualifications are agreed for staff in adult day services, on a similar scale to residential services where staff must have a Social Care degree. The importance of communication and support for service users, staff, families and community partners were repeatedly emphasised throughout this study.

6.3   Recommendations

An obvious limitation of this study was the small number of research participants. However, to give the broadest yet most relevant perspectives possible, participants were selected from a range of grades within the organisation's day services, they were all working in the sector before New Directions and they were directly involved in implementing New Directions at the time of the study. Based on this study, this researcher believes the recommendations overleaf should be considered so New Directions can best work.

Table 2   Recommendations

1.	Staff should invest their time putting 'optimum' support into the frameworks where friendships can flourish like the employment, educational and social contexts of one's life.
2.	Both physical and social integration are necessary to maximise New Directions. Social integration may be achieved by the weaving together of independence and interdependence as valued approaches (Carnaby, 1998). 'Hubs' which will develop under New Directions should strive for this 'weaving together' of approaches in their pursuit of social integration for people with ID. The concept of 'Community Connectedness' should become the approach. Goals and plans should be supported under the outcome of Community Connectedness.
3.	Staff, management, service users and families need clarity around the amount of 'time spent in the community' and 'time spent in 'hubs'. This should be explored further both locally and at national level through negotiation with all those involved.
4.	Communities need to be educated and supported in relation to New Directions. The needs and aspirations of local people with ID should determine the agenda for educating communities.
5.	Families need to be 'on-board' with an organisation's efforts. Families need to be viewed and treated as essential partners in a person-centred approach. Building trust and enhanced communication with families is an integral part of this. It is necessary to tap into their own in-depth knowledge of the person.
6.	Staff should be equipped with the skills, training, resources, supervision and ongoing support to maximise New Directions. Flexibility in working arrangements is recommended. Specific training on identifying and coordinating supports within wider communities and networks is now needed. A degree in Social Care Practice or related fields should become the minimum qualification for staff in day services.
7.	It is recommended that similar studies are carried out with families, service users and community organisations. The concept of friendship in the lives of people with ID should also be the focus of future research.

Finally, whilst day services are not perfect they have some good aspects too. Communities have much to offer individuals and families in terms of social networks and social capital. Organisations should take the best aspects of their existing services together with New Directions to better peoples' lives.

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Appendices

Appendix A

An *information sheet* should be provided to all participants, with a plain language statement that clearly describes the aims of the project, and the nature of involvement of participants. Participants should be clearly informed of their rights and any risks associated with participation. At all times, the researcher must observe the welfare of the participants and respect the dignity and personal privacy of the individual.

An information sheet would normally include the following:

- The aims of the project
- A description of what will be required of the participants (including details of the amount of time required of participants)
- A statement which addresses confidentiality and security of information. Details of who will have access to personal information and the purpose(s) for which participant information will be used, included whether participants would be potentially identifiable in any published material. If not collected anonymously, the researcher should 'inform potential subjects of the way in which the results may be handled'

http://www.dit.ie/researchandenterprise/integrityethicsindit/forms/

Appendix B

Letter to gatekeeper

Dear (enter gatekeeper name here),

My name is Derek Bryan and I am a postgraduate student at Dublin Institute of Technology (DIT) where I am studying the Masters Degree in Child, Family and Community Studies. I am currently completing my Dissertation under the supervision of Doctor Carmel Gallagher. The title of this study is *"From Institution to Integration: The Perspectives and Experiences of Disability Sector Staff in the Transition to New Directions".* The purpose of this study is to establish the perspectives and experiences of disability sector staff who are directly involved in the current transition, from the 'traditional' day care model of service delivery to the new 'community based' model, as proposed under New Directions (2012). This study aims to gain greater insight of the staffs perspectives and experiences.

New Directions is based on the core values of person-centeredness, community inclusion, active citizenship and high-quality service provision. New Directions involves a radical shift from provider-led programmes to individualised, user-led supports. In the new approach, each adult will have access to flexible and outcome-driven supports to enable them to live a life of their choosing that meets their own wishes, aspirations and needs. The core purpose of the supports will be to enable people to participate as equal citizens in their community and to contribute to that community. New Directions will mean a radical reconfiguration of adult day services. Service provision will need to adjust in order to deliver a real shift from the traditional delivery of provider-led programmes in segregated settings to individualised, person-centred supports directed to community inclusion and active citizenship (HSE, 2012).

I would be most grateful if you could consider taking part in this research. Participation will involve each participant agreeing to an interview of approximately one hour with me to discuss their views on New Directions. Total anonymity and confidentiality is guaranteed as all interviews will be transcribed and analysed only by myself. All names and other identifying items will be removed during transcription and you may view a copy of your interview at any stage. Once the dissertation is completed these interviews will be disposed of securely. If you have any further questions or you wish to confirm availability please do not hesitate to contact myself on the number above. Alternatively, you can contact my supervisor Dr. Carmel Gallagher at DIT Mountjoy Square. Your cooperation and time is most appreciated. Thank you.

Kind Regards

_____

Derek Bryan

Appendix C

Letter to participants

Dear (Enter participants name here),

My name is Derek Bryan and I am a postgraduate student at Dublin Institute of Technology (DIT) where I am studying the Masters Degree in Child, Family and Community Studies. I am currently completing my Dissertation under the supervision of Dr. Carmel Gallagher. The title of this study is *"From Institution to Integration: The Perspectives and Experiences of Disability Sector Staff in the Transition to New Directions".* The purpose of this study is to establish the perspectives and experiences of staff from the disability sector who are directly involved in the current transition, from the 'traditional' day care model of service delivery to the new 'community based' model, as proposed under New Directions (2012). It is in this context that this study aims to explore the perspectives and experiences of staff from the disability sector on the proposed new ways of working with people with intellectual disabilities (ID) within their organisation and how they believe New Directions can best work.

New Directions is based on the core values of person-centeredness, community inclusion, active citizenship and high-quality service provision. New Directions involves a radical shift from provider-led programmes to individualised, user-led supports. In the new approach, each adult will have access to flexible and outcome-driven supports to enable them to live a life of their choosing that meets their own wishes, aspirations and needs. The core purpose of the supports will be to enable people to participate as equal citizens in their community and to contribute to that community. New Directions will mean a radical reconfiguration of adult day services. Service provision will need to adjust in order to deliver a real shift from the traditional delivery of provider-led programmes in segregated settings to individualised, person-centred supports directed to community inclusion and active citizenship (HSE, 2012).

I would be most grateful if you would consider taking part in this research. Participation involves each participant agreeing to an interview of approximately one hour with myself to discuss their views on the above. Total anonymity and confidentiality is guaranteed as all interviews will be transcribed and analysed only by myself. All names and other identifying items will be removed during transcription and participants may view a copy of their interview at any stage. Once the dissertation is completed these interviews will be disposed of securely. If you have any further questions please don't hesitate to contact me. Alternatively, you can contact my supervisor at carmel.gallagher@dit.ie. Your cooperation and time is most appreciated. Thank you.

Kind Regards

_____

Derek Bryan

Appendix D

Preamble

Thank you for considering participation in this research.

Please note the following

- this research is not being carried by or for {name of participating organisation here}

- this research is being completed solely as part of the researchers own studies

- there is no right or wrong answers, participation is not a test

- this research is interested in peoples own perspectives, based on their experience of working with people with intellectual disabilities

- questions will be general and open ended

- there will be no direct reference to {name of participating organisation here}.

- Neither will any specific experience of or opinion on {name of participating organisation here} be sought

- you may always opt out at any point

Appendix E

Informed Consent Form

<table>
<tr>
<td colspan="2">Researcher's Name:
(use block capitals)   DEREK BRYAN</td>
<td>Title:

Mr.</td>
</tr>
<tr>
<td colspan="3">Faculty/School/Department:
School of Social Sciences and Law</td>
</tr>
<tr>
<td colspan="3">Title of Study: From Institution to Integration: The Perspectives and Experiences of Disability Sector Staff in the Transition to New Directions</td>
</tr>
<tr>
<td colspan="3">To be completed by the:

interviewee</td>
</tr>
<tr>
<td colspan="3">

3.1 Have you been fully informed/read the information sheet about this study?   YES/NO

3.2 Have you had an opportunity to ask questions and discuss this study?   YES/NO

3.3. Have you received satisfactory answers to all your questions?   YES/NO

3.4 Have you received enough information about this study and any associated health and safety implications if applicable?   YES/NO

3.5 Do you understand that you are free to withdraw from this study?

- at any time
- without giving a reason for withdrawing
- without affecting your future relationship with the Institute   YES/NO

3.6 Do you agree to take part in this study the results of which are likely to be published?   YES/NO

3.7 Have you been informed that this consent form shall be kept in the confidence of the researcher?   YES/NO

3.8 Do you agree to the possible inclusion of unidentified direct quotes in the final study?   YES/NO

</td>
</tr>
<tr>
<td colspan="3">

Signed_____   Date _____

Name in Block Letters

_____

Signature of Researcher _____

Date_____

</td>
</tr>
</table>

Please note:

- For persons under 18 years of age the consent of the parents or guardians must be obtained or an explanation given to the Research Ethics Committee and the assent of the child/young person should be obtained to the degree possible dependent on the age of the child/young person. **Please complete the Consent Form (section 4) for Research Involving 'Less Powerful' Subjects or Those Under 18 Yrs.**
- In some studies, witnessed consent may be appropriate.
- The researcher concerned must sign the consent form after having explained the project to the subject and after having answered his/her questions about the project.

Adapted from;

 HYPERLINK   "http://www.dit.ie/researchandenterprise/integrityethicsindit/forms/" http://www.dit.ie/researchandenterprise/integrityethicsindit/forms/

Appendix F

Interview Questions/Schedule

1. **Models of Service**

    Day services for people with ID are changing, what was good that we should blend/merge with newer models?

2. **Person centeredness**

    What do you understand by working in a person-centered way?

3. **Supporting Community Participation**

    Can you give an example of where an individual's capacity to participate in community life was built or increased?
    What types of ongoing supports are needed to enable community participation?

4. **Family**

    Can you talk about working with and supporting families to improve their quality of life?
    How can staff & disability organisations further support families with models like New Directions? (Ideas on how organizations could support families more were sought.)

5. **Friendship**

    Can you talk about the different types of friendships that people with ID have?
    How can staff & disability organisations support friendship under New Directions?

6. **The contribution of persons with ID to their communities**

    What do people with ID bring to a community?
    What can disability organisations do to support communities to include people with disabilities?

7. **How can New Directions best work?**

    Managers only. What type of organisational culture needs to exist to realise New Directions?
    Managers only. What type of change management and leadership is needed?
    Staff only. Has your role changed in light of recent years? Can you describe those changes?
    Staff only. What are the challenges for staff?
    Staff only. What type of staff skills and training are required?
    How can the potential of New Directions best be maximised?
    Do you think New Directions is ultimately a good idea and why?

Appendix G

Sample Interview Transcript

This study aims to explore perspectives and experiences of staff from the disability sector on the proposed new ways of working with people with id within their organisation and how they believe New Directions can best work.

R: Researcher   P: Participant

1.   Models of Service

R: Day services for people with ID are changing, what was good that we should blend/merge with newer models?

P: *"Yeah, the only thing I could say that was good was, was the connection, they had their friends. I find that since they have moved out they are a bit more lonely, they have lost that sense of belonging to a place because the hubs are just drop in, they are not meeting with a group, they used to meet with a group and I suppose it gave them structure.......I was quite surprised how quickly they moved on from the old day centre.....but as time went on you could see how lonely some of them were getting. They were filling in their days with community placement, voluntary placement, their jobs but there seemed to be a lack of time for friends in the whole week, where they have had them. And they wouldn't have had the skills to meet to organise. We are trying to organise that ourselves now. They are lonely. There is a missing link."*

2.   Person centeredness

R: What do you understand by working in a person-centered way?

P: *"Well the person should be at the centre of the plan, emmm, it's not always the case, older parents I find still don't want their son or daughter to have so much of a say about their own lives, that's very difficult, we are finding that very difficult.....We are trying to build a focus for a person............they need to get to these places. So when we are looking at a person we also have to look at the family and see how much is the family prepared to help."*

3.   Supporting Community Participation

R: Can you give an example of where an individual's capacity to participate in community life was built or increased?

P: *"Oh god yeah when you have an older parent who drove their son everywhere, waked them, cooked their meals to now getting himself up, cooking for himself, travelling on buses, going to work, going out for an evening for a few pints with friends. To see a person come this far, getting to know people, having the craic, coming home, helps out at home – huge changes."*

R: What types of ongoing supports are needed to enable community participation?

P: *"Ongoing support is needed to keep up the standard of work and the level of interest. I do think we need to support them especially now that we are in the community so much. We can't just leave them there to get on with stuff for themselves. Friendship and communication with friends they find difficult, even just a simple plan."*

4.   Family

R: Can you talk about working with and supporting families to improve their quality of life?

P: *"....so we do need to support the families in trust....to let the families know we are not going to abandon their son or daughter...know they (staff) are going to train her (service user) to that ability....and know that I (parent) can go off for the day and know...they are going to be able to get themselves home, so it's kind of a relief."*
"I think families were terrified about this new structure of going out into the community, oh my god they have lost all the security of day services so you need to support the families that the children are going to be okay, they are going to be okay. That kind of support is needed to help them think outside of the structure of day services and the structure of what was before."

R: How can staff & disability organisations further support families with models like New Directions?
(Ideas on how organizations could support families more were sought.)

P: *"Information, information, information. You have to take the fear out of it. I don't think we have. In the initial stages, 'this is New Directions, this is the way it is going...' but we didn't explain it well enough to small groups of families."*

5.   Friendship

R: Can you talk about the different types of friendships that people with ID have?

P: *"....sometimes they form a friendship with a staff that has to be handled carefully with clear boundaries established, not a friend – there to support them. They would have friends from school but there is never a close bond friendship. They would talk about friends...going to see their friends but not many of them do. When you suggest they meet for coffee the response is often no!"*

R: How can staff & disability organisations support friendship under New Directions?

P: *"We find actually coming to the hub just for that initial time....and then show them the bus route to get to that place. You have to that a few times to realise that they can be friends that they can go places together and that can do it by themselves and that they don't need staff."*

6.   The contribution of persons with ID to their communities

R: What do people with ID bring to a community?

P: *"....they are very good employees....they also have very good, are very good at bringing a sense of pride particularly where they work in a local supermarket. They have a sense that they belong here. I think they do help communities bond as a community....they are missed when they are not around...."*

R: What can disability organisations do to support communities to include people with disabilities?

P: "*Inform, inform, inform. So we need to do something to inform the community and organisations other than our own of people with intellectual disabilities and their needs. The guards and Dublin Bus are doing well but could still benefit from more information as could people in general that they are no different to you and I."*

7. How can New Directions best work?

R: What type of organisational culture needs to exist to realise *New Directions*?
N/A   Managers only

R: What type of change management and leadership is needed?
N/A   Managers only

R: Has your role changed in light of recent years? Can you describe those changes?

P: *"god yeah it has because you have basically gone from being a Job Coach to now being a Life Coach, a multi-disciplinary team looking after service users, parents, everything, the community, making sure that person is okay in their community, making sure that the community is okay with that person with ID. So your role – we are not just Job Coaches anymore. I think we are community liaison officers, family liaison officers. We are everything to everybody......"*

R: What are the challenges for staff?

P: *"Time, there is more and more people working, with POMs, with community based, with community links, with voluntary placements, with employment, with everything out there and it's just to find the time to support the people that are in work, to support the families, to find the time."*

R: What type of staff skills and training are required?

P: *"I think we definitely need people trained in how to make contact with an employer, how to approach a parent, how to approach a company like Dublin Bus, An Garda Siochana, how to get involved with your community......what community work is all about, what communities are about, what putting people out independently is all about......some form of training on communication. That kind of support is needed to help them think outside of the structure of day services and the structure of what was before."*

R: How can the potential of New Directions best be maximised?

P: *"I really do think we are doing well but I do think communication is the biggest downfall that we have. And also from the HSE as well, that they should come on board a bit more in explaining to us, I mean should they be more involved with front line staff who are on the ground working...I think there should be more coming down to ground level, let's see what's going on. How can we help?"*

R: Do you think New Directions is ultimately a good idea and why?

P: *"Yes I do.....I just feel that centre based programmes breed an awful lot of problems for all the Service Users. I have found that since we have been out community based, there is less problems, less bickering because the lads don't see each other – the flip side of the loneliness – there is less big groups, you don't have the same amount of problems, you have different problems but I do think going forward definitely is the way to go, definitely is the way to go. I really do think communication is the biggest downfall. We have to alleviate the fears of families who think centres are the only option and open and honest is the only way to alleviate their fears and if we do this from the outset we don't have to wait for success stories to relax the parents. This would be better for staff also. Open and honest about what New Directions is about....the cuts and the money that's not available.....reassurance.....that we will be there and do as much and that we will do the best we can to the best of our ability. I am not going to lie it's going to be perfect and this is going to happen and that will never happen because things do happen and change but by being open and honest from the word go you have nothing to lose."*

Appendix H

Sample Coding

<u>**4.2**   **Models of Service**</u>

The participants were asked how day services have been delivered up until 2013 and specifically around what was good that we should blend/merge with newer models.

"They knew exactly why they were being dropped in or getting on the bus, you know, there was a purpose."(Participant 10)

"Service users used to know from the time they walked in the door until the time they walked out, exactly what they were doing, exactly what was expected of them." (Participant 11)

"There was a level of structure with a workshop model that people felt they were going into something.......it's about, like anything we do, going in somewhere, the same faces, there was a level of comfort of going in." (Participant 9)

"I think from the lads perspective they met each other and they see each other, they had contact with friends, they are there in front of them, they are accessible and they have a laugh together and lunch together and it is very easy to go off and head off somewhere because they are together, that is something I think, that's the main thing." (Participant 8)

"Yeah, the only thing I could say that was good was, was the connection, they had their friends. I find that since they have moved out they are a bit more lonely, they have lost that sense of belonging to a place because the hubs are just drop in, they are not meeting with a group, they used to meet with a group and I suppose it gave them structure.......I was quite surprised how quickly they moved on from the old day centre.....but as time went on you could see how lonely some of them were getting. They were filling in their days with community placement, voluntary placement, their jobs but there seemed to be a lack of time for friends in the whole week, where they have had them. And they wouldn't have had the skills to meet to organise. We are trying to organise that ourselves now. They are lonely. There is a missing link." (Participant 4)

"And I think by sheltering like in the old way, it has just hid them away but I think to come out into the community and they are in people's faces it just makes them more aware and it makes it easier for them to go through their own life." (Participant 6)

"I think there is, I always find pros to being in a centre. I won't say segregation because that is a taboo word but I don't think everything should be community based....I mean there is differences. There is always going to be differences. Equality is great but it's not realistic sometimes in some cases for some people." (Participant 5)

"Well the service users enjoyed each other's company and they used to all have a good oul chat, you know, that's what I thought was good and its gone very quiet up there now and I think some of them might miss that, the meeting up and having a chat with others." (Participant 1)

"The bigger the facility you have, the more chance you have of having different facilities like snooker and stuff like that.......Also, the fact that there is a larger number of people, there is more interaction and more varied interaction which I think is a benefit to both staff and volunteers and for the users themselves, you know they are not stuck with the same people." (Participant 3)

"I think an awful lot of staff are just doing too much admin..." (Participant 2)

"I think integration and the community is great...in theory...in practice not so much. I mean when you are in a centre you have more supports around you; you have more people around you. Even your styles of even communicating, I mean when you are in a centre you have loads of people around you, your manager is there if you need to ask a quick question you can do that but I think when you are in

the community a lot is put onto staff as well and I think communication can get mixed up in it."
(Participant 5)

4.3   Person – centeredness

The participants were asked about their understanding of working in a person centred way.

> *"That it's all about them, what they want out of life, their goals and dreams and it's not the staff dictating what they want to do, no they are telling staff I want to do this."* (Participant 7)

> *"The lads and the girls have aims and achievements about what they want to do in life and it's just supporting them around this. Its understanding also I think what they are saying and what you are getting from it. I think they have been saying it for so long and people have not been understanding and they clam up and just sit but when they do open up and do it, you can see the light in their eyes then, how happy and how much it does change them when they are after achieving like work or going back to education or anything. In that part of it I think the supporting is nothing to do with yourself – it's all about them going forward and their life to work in a person-centred way."* (Participant 6)

> *".....the first thing we have to do is actively listen to the individual and sometimes we get that very wrong in the sense that we impose our own views.........we have to actively listen to what a person is asking for. The responsibility of that is huge on the support person because the minute you engage with an individual in an active way, you have a responsibility to act on the information you get from the individual.........The second part of that is how can I support them to make this happen and I suppose there is a couple of key components to that – continuing support is key so that it happens every week, being active in your own community, its being active, having an active life. It's actually looking at an individual through their eyes, supporting them to have an active life, giving them the skills to do that, whether it be through communication or through an active participation but ensuring that it happens on a continuing basis in their own community."* (Participant 9)

> *"............take the person I am working with that it took a long time to get to know her needs and two years down the road, we are only still getting to know them but everything is focused on her....."* (Participant 2)

> *"Person-centred, I............individually would come to mind, one on one, person-centred, about the person, asking them what they want, their perspective, their take, it's all about them."* (Participant 8)

> *"Person-centred way basically is about the individual, you are striving for the best for the individual. I think there is so many policies and procedures in place now to ensure that you do that, I think you would probably do it anyway. The service users even use person-centred phrases. At the end of the day it is their service, they should be at the centre of it and they should be able to do what they want whether it's to get a bus here or there...And I think that is behind all of the policies and documents but I do think you can lose sight of that because you are so busy doing all of the paperwork around it, you know."* (Participant 5)

> *"Well the person should be at the centre of the plan, emmm, it's not always the case, older parents I find still don't want their son or daughter to have so much of a say about their own lives, that's very difficult, we are finding that very difficult.....We are trying to build a focus for a person............they need to get to these places. So when we are looking at a person we also have to look at the family and see how much is the family prepared to help."* (Participant 4)

4.4   Supporting Community Participation

4.4.1   Participants were asked can you give an example of where an individual's capacity to participate in community life was built or increased.

".....if you are bringing someone to the coffee shop that's not actually involving them in the community, that's just bringing them for a coffee. So like what is somebody in the community? What does it actually mean?" (Participant 7)

"She wanted to get a job. She goes into a house cleaning in her community. She is getting to know more people and she gets a few bob and you are there to support her." (Participant 2)

"One of the girls and one of the lads volunteers in the hospital, so they have gotten more involved and more outgoing in their community and their confidence has grown." (Participant 11)

"One of the lads got a voluntary position in a shop, NCBI, 2 days per week............his father and I helped him get the bus there at the start. He is doing well, the people know him. He was invited to their Christmas party. He was even collected and dropped home, he had great craic. I think it is good, very good." (Participant 8)

"Another guy I support in the gym is now on a first name basis with lots of other members. He used to not make eye contact whereas now he is standing tall. He tells stories. He is reacting out there in the community. I said to him tell the guys you sell the local paper on a Thursday. So they all started saying they would take a paper off him so he started bringing down a few papers and now he sells them down there. It's a snowball thing." (Participant 6)

"He reaches out to the community in that he is always very anxious to chat and talk to people no matter who they are, where they are at, so I try to encourage that....................you know if we are playing bowling we say something to the people in the next lane or something like that. A few times I have had tea or coffee with him, he would interact with the person next to him. I think he follows that. He leads it too actually. He is good at doing that.........." (Participant 3)

"I would have to say a man who joined the Men's Shed was enormous; it rippled across my life, his life, another family. You know the connections that that brought, that occurred because of that. His confidence is gone up but his neediness if that is a right word is less. He doesn't need staff or the organisation anymore because he has other areas to go." (Participant 10)

"Ah there is loads of examples, hundreds of examples. I suppose the best one I have seen is the Men's Shed. We have two people in them and one has gone onto a second Men's Shed and now the other guy actually refuses to come into any part of the service because they are his mates, he has made friends." (Participant 12)

"Oh god yeah when you have an older parent who drove their son everywhere, waked them, cooked their meals to now getting himself up, cooking for himself, travelling on buses, going to work, going out for an evening for a few pints with friends. To see a person come this far, getting to know people, having the craic, coming home, helps out at home – huge changes." (Participant 4)

"Then he moved into a community house and he was taught so many skills and this was through the hubs, this was through community links, social capital, everything it was through all of this................He had all these skills anyway but didn't realise he could use them. I think person centred planning comes into this and made him so capable. I think this is the best example I can think of for how positively it can impact on a person's life." (Participant 5)

4.4.2 Under the theme of support participants were also asked; what types of ongoing supports are needed to enable community participation?

"Oh there has to be some kind of communication between, because amongst NGO's, voluntary organisations and those kind of organisations. There is this mad rush to the community but the community is not necessarily ready for us or even aware that we exist.....say for example.....you want people to go to an art class but there can be this grey from providers when they say no this is not for people with disabilities, this is for people you know in mainstream. So there is that distinction there, no it's not a distinction, there is that ambiguity there between mainstream and community and is there a difference?" (Participant 10)

"Well firstly you need staff and then once you start a routine, you need to keep it going. It can't be hit and miss you know, so that's the biggest problem, you know, routine. (Participant 11)

"Ongoing support is needed to keep up the standard of work and the level of interest. I do think we need to support them especially now that we are in the community so much. We can't just leave them there to get on with stuff for themselves. Friendship and communication with friends they find difficult, even just a simple plan." (Participant 4)

"....you don't want to over support and you don't want to under support, that's the challenge we have............but the main thing is the constant link in, you know with loneliness and mental health issues they are not going to be understood....." (Participant 12)

"I think you have to support the lads the same way you would as if they got a job, go to the placement and meet the people and connect with them and see how things are going that kind of stuff but there is something more.......We will have to find places first because I think you don't want to be in a situation where they are doing the same thing in NCBI for 20 years and it is just another timetable. You want to say to people they can leave that and move on and get something....different......" (Participant 8)

"You obviously need opportunities to get out, you need to build up their own courage and confidence so that they can kick off an interaction without having to wait for a minder to do it, you know. It's a long term project that you have to build up – interaction......work is one opportunity. Bobby (name changed) is limited in that he doesn't work but you can still go to libraries and other places like that where staff are great for interacting and people are moving around, you need to get into places like that so things happen. Things don't always happen when you are in the park looking at the lake – it just doesn't happen." (Participant 3)

4.5   Family

4.5.1   Participants were asked, to talk about working with and supporting families to improve their quality of life?

....families are key to everything that we do and if we don't bring the family along on the journey of where the individual is going........we need families to come along with us on that. It is a very scary road for families. We often have to intervene and say please come along with us on this journey, even things like independent travel, letting their son or daughter." (Participant 9)

"I think when you are building a relationship with a person, it's just as important to build a relationship with the family because they are going to need to be onboard with every decision. I have seen where they are not it is very difficult to even strike up a relationship with the individual because you are being met with sometimes negativity." (Participant 5)

"Hmmm, I am not sure how much the family's quality of life has improved, if at all. Well, I think we are challenging the families more so. They are being challenged. I think the parents might say, 'if I hear it's my choice another time'. So, I think they are being challenged. Yeah, so I am not sure about their quality of life. I think they are doing more work." (Participant 8)

"I would say the families have a hard time alright and I would say communication – talking to the family, let them know the progress the individual is making, it does give a bit of a boost....and seeing what kind of problems they have and if we can help on it this end. Providing stability for a person I hope helps their Mams and Dads a little bit." (Participant 6)

".......keep in touch with the family, it's very important to bring the family into what they are doing and to make sure the family agree....." (Participant 1)

"By being honest with families whether it's good news or bad news – it gains their trust because you are speaking to them on an equal level. You are not going in and talking down to them or talking to them as if they don't understand." (Participant 2)

"....so we do need to support the families in trust....to let the families know we are not going to abandon their son or daughter.......know they (staff) are going to train her (service user) to that ability........and know that I (parent) can go off for the day and know............they are going to be able to get themselves home, so it's kind of a relief." (Participant 4)

"I think families were terrified about this new structure of going out into the community, oh my god they have lost all the security of day services so you need to support the families that the children are going to be okay, they are going to be okay. That kind of support is needed to help them think outside of the structure of day services and the structure of what was before." (Participant 4)

".....community links and social capital and social inclusion – it's all very new to them (parents) I think a recent enough development. They are being met with all these new ideas – achievable to us but to them not so much. I think they kind of find it hard to adjust to it.......especially where they are so attached to the idea of their son or daughters disability.....even though they have their own lives now and are not as reliant on their parents and siblings, it is huge for parents. They can construct their lives back to a certain degree but it takes time to get there. It seems to shock them at first – the idea that their son or daughter can do things that they never thought they would be able to do." (Participant 5)

4.5.2 The participants were also asked how staff and disability organisations can further support families with models like New Directions. (Ideas on how organizations could support families more were sought.)

"Information, information, information. You have to take the fear out of it. I don't think we have. In the initial stages, this is New Directions, this is the way it is going to but we didn't explain it well enough to small groups of families." (Participant 4)

"Hmmm, hmmm, hmmm, I think it is easy to say inform them, give them more communication, communicate it more clearly what we are going for but I think there has been a reluctance to do that because I think they are afraid people won't like it." (Participant 8)

"I think we are actually supporting families........I speak to families way more than I did. I speak to parents weekly and I never did that before. It might have been once every three months and that's just huge......I don't think it is being recognised very much by management or anybody that that is needed or the amount of energy that goes into that but I think it is definitely a good thing." (Participant 8)

"So I think the way to do it is make sure everybody is informed, know where we are going, educate staff and make sure you train staff and move it on from there." (Participant 8)

"It's by example. I don't think it's worth sitting down someone with a slide show and showing them what New Directions is. It's by saying well look this is Joe Bloggs he has gone through the procedure himself...and let him tell you and let his family tell you what he has done and you can learn from that................I would like to see the lads giving their own talks but these are the ones we need to be telling because we (staff) can spoof, we can elaborate too much. We always put our tone on it to suit the audience." (Participant 12)

"It's just communication. We tend to think of ourselves as experts, you know, I'm studying or I studied this.............organisations and management do this also and we forget that those are parents. They know everything about Down's syndrome because they know what they need to know as in their son, what he is going through and his difficulties. so we need to give the parent's permission to come onboard with us, do you agree with this, do you not agree with this, is there better way of doing this. Some of the parents when you pull back the layers with them really and tease it out with them, they have really good ideas, really good ideas but they are parents, it's natural for them to want to protect their children." (Participant 10)

"I think the key to it is that we need to have a very clear communication line with families. We need to not over commit. We need to explain the journey we are going on. We need to bring them on that journey with their son or daughter but we need them to be beside them, not in front of them, not behind

them, we need them to be there with them....one family were very nervous about going the new direction......I asked would they come on the journey for three months and after that point if they still weren't interested......then we will stop.........After the three months they said they would never go back to the old way of and it was about their son developing the skills, their son going to ...Even you talk about what gains, their son called to an elderly woman who lost her husband next door and he called into her every morning, went over to the shop, got her milk and a paper and brought it back to her. So he had a valued role in the community, he felt better than going into a segregated setting like a workshop...." (Participant 10)

4.6   Friendship

4.6.1   The participants were asked to talk about the different types of friendships that people with ID have?

"I suppose this is an area I worry about. We have created a situation where we are finding more and more of this that people with disabilities coming into disability centres are not even connecting with their peers with disabilities, they will sit there. They will tend to be drawn towards staff in a lot of cases. I think there is a good piece of work to be done around what is a friend, what is an equal relationship. I look at it in a lot of ways – a person with a disability's life seems very similar to their non-disabled persons life up to eleven or twelve and then it takes a drastic change around puberty time where there is an experimental stage for non disabled people where a person with a disability...........goes a different direction and I think that is the change mechanism of how friendship builds. " (Participant 9)

"I am not sure if they have very good quality friendships. I think it's poor. I don't think a lot of people have the skills to have that level of friendship and really commit to another person and really listen to them and really hear them and hear what they are saying. I think they are probably too used to having staff listen to them individually. And they actually can't have a conversation...themselves...........they are all talking about individual things to us, it's like being in this conversation with four different people and nobody is listening to each other and they are all telling you what happened at the weekend...or yesterday....when we are not there maybe they are doing quite well.....if they were on their own maybe they could develop quite good friendships." (Participant 8)

"Ahem, you see like if two people are talking, let's say there is a staff floating around to see if everything is alright, it's not really just between two people. It's not proper conversation with the staff there. I don't honestly think that they have friendships. I really don't that's honest." (Participant 7)

"....sometimes they form a friendship with a staff that has to be handled carefully with clear boundaries established, not a friend – there to support them. They would have friends from school but there is never a close bond friendship. They would talk about friends....... going to see their friends but not many of them do. When you suggest they meet for coffee the response is often no! " (Participant 4)

"They are inside in the centres, are asking to meet up with friends but then walk past each other on the street, so I don't know about friendship. Many of the friendships are facilitated by family members who bring them out for dinner, you don't see them going out with friends on their own." (Participant 2)

"It has struck me that there is seemingly a lack of interaction or craic......we all do...........to pass the day and it also helps to bond the form." (Participant 3)

"I think there are so many blurred lines for friendship for people with id. It sounds awful but it's true. You could have a girl who in her head is friends with someone else but in the other girls head they are not friends and it's a struggle for them to understand when it turns into rejection. With boyfriends and girlfriends – there always seems to be drama attached around people wanting other people's partners......................their timetables are huge and they don't have the same level of time for friends or even for their social lives............Integration is great because it brings more freedom and responsibility. They have support. They have the responsibility of working also which is hard so I think that friendship gets muddled along the way. I think independent living is hard.................is great because it gives them independence but friendship is lost and timetables make meeting friends hard." (Participant 10)

"They have friendships amongst themselves. Going out into the community, they are a bit more reserved when they are trying. They nearly need to know the person a little before they can open up a little piece. It probably goes back to the first question (on models of service) where they were put into boxes all the time and they never kind of got out there to see. I can see where everybody is spread out into the community now and that is they are generating friends when they are out there now with people." (Participant 6)

"This is something that has really come to the fore for me in the last twelve months because of the new model we are working within. I call it environmental friendship because they are friends with the people they have been around for the last twenty years or so in day centres..... These friendships are wobbling now because we have removed the environment. also, we are starting to see that maybe the friendship was never real in the first place....as we are moving into this new model we are starting to see that some people are lonely. New friendships are blossoming also...yeah it's a huge area that definitely will be the next big thing. It won't be getting a job. It will be this side of things – self development." (Participant 10)

"Some of the more disabled people actually talk more but they don't necessarily attract as much conversations. But that's our next big move. It is societies not only ours but society's next big move." (Participant 12)

4.6.2   Under the theme of friendship the participants were also asked how staff and disability organisations can support friendship under New Directions.

"On one hand staff need to back off yet there is a need for staff to help along the way with a community based model." (Participant 7)

"We need to change our supports from 9-5 to get people out living. We should have a flexible support mechanism that support people to get out playing 5 a side soccer, do that evening course....meet a friend for a pint, go to the cinema at the times others are. It's actually living your life at the same time others are doing it." (Participant 9)

"We find actually coming to the hub just for that initial time....and then show them the bus route to get to that place. you have to that a few times to realise that they can be friends that they can go places together and that can do it by themselves and that they don't need staff." (Participant 4)

"....they do rely on staff an awful lot and where they would be looking around to see am I doing this right? Am I doing that right? I think they have to be phased into doing things like that." (Participant 2)

"...with the greatest of respect we handed friendship to them, that was the model, you two go for coffee, go bowling and then at four o' clock the friendship ends, there was no contact outside of that. It's trying to look at the self-actualisation for these guys – that's something they have never been taught how to do, told how to do and that they can do it. I suppose it comes back to choices and like some friendships blossom and some don't and that's allowed, that's okay. We need to move on from bringing people by the hand through friendships." (Participant 10)

"Well I think it's all about bringing their families, getting them involved as well because there is only so much that you can do.....People are working different times and have different schedules....a lot of it might need to be done outside of working hours, 9 - 5, Monday to Friday." (Participant 5)

"I think this person, your daughter wants to see her friend outside of the organisation on a Saturday afternoon or whatever. And then trying to get that going is definitely challenging. I think it takes a lot of input. It takes a lot of planning, organising and you have to link in with parents because if you are not, it's not going to happen. You can have as much individual goals as you want but if someone's parents are not behind it, it's not going to happen." (Participant 8)

4.7   The contribution of persons with ID to their communities

4.7.1   Under this theme participants were first asked what people with ID bring to a community?

"I think they bring joy and they bring joy out. In the gym everyone says a loud, hearty hello." (Participant 6)

"...people love them....There is something good going on in their interactions with the public, they bring out the best in people. People make themselves known to them and frequently introduce themselves and they get to know..." (Participant 1)

"I don't want to say laughter in the wrong way....we have brought them up to the active age and they are the life and soul of the place so they bring new interest from the older people and they are very protective of them. I notice the older men and women....I have noticed people are listening to their stories and boyfriend problems and all that and they are interacting very well." (Participant 11)

"....empathy...compassion.....awareness....They obviously provide thoughtfulness...They obviously provide opportunities for people to show aspects of their personality, their compassion. It is good for them. It creates a feel good in people for doing that."(Participant 3)

"I think they bring fun...they educate people because it may be the first time they have worked with a person with a disability. Sometimes a person just becomes that – a person and not a person with a disability....They add fun, different dynamic, awareness, awareness that wow this lad can actually do a job and work and connect with people and input and you see their quirks but I think they give a good contribution..." (Participant 8)

"Awareness is a huge one ....when you go into local shops nowadays the store staff no longer address the staff. They communicate directly with the person with intellectual disabilities because the public are more educated now. The lads will let them know anyway, I want you, I am talking to you." (Participant 5)

"A lot of them would know more neighbours than what you would.....they get to know their neighbours quicker than we would.....they would be more open socially...." (Participant 2)

"......willingness and wanting to be there......They are bringing the same things you and me bring. They are bringing themselves, the joyfulness, they are relatively happy, they are always relatively willing to learn........." (Participant 12)

"....there is a willingness to be a part of things, to be drawn into things, without meaning sounding condescending there is the idea that people with id are very positive, let's do this , let's go for it....So I think in communities at the moment especially after a downturn...people with id if they were in those communities, they would herald a more motivated, a more we can do it kind of an attitude....They bring enthusiasm, an energy, a vibe that you know and that's really positive. They bring this to all things whether it's their employment...soccer team, a community initiative project whatever it may be........they bring energy, enthusiasm and positivity to make a team work." (Participant 9)

"....they are very good employees....they also have very good, are very good at bringing a sense of pride particularly where they work in a local supermarket. They have a sense that they belong here. I think they do help communities bond as a community....they are missed when they are not around...." (Participant 4)

"....people spend their money. This is just as valuable as the next.....they bring diversity, they bring difference........a society without imperfection creates a very insecure society....It's good for society to see people who might have crutches or wheelchairs or mental health issues because then it makes nobody feel that they are strange, you can see that the world is not perfect. It helps you to be comfortable within your community. They are just people and the more diverse the world is the better...." (Participant 10)

4.7.2   Secondly, the participants were asked what can disability organisations do to support communities to include people with disabilities.

"...are people concerned they are not involved? It's different for us we are working in this area but I don't know for someone who isn't or who has never been involved or who has little interaction – I don't know if they are particularly in disability." (Participant 5)

"There can be a fear factor amongst the public and getting to know the lads reduces this." (Participant 1)

"The school curriculum I think and from the early stages so they haven't got the stigma about disability....It is a disability but it shouldn't be seen as a disability. It should be seen as another person..... From a young age children should walk by a person in a wheelchair, say hello and just walk on. Just to say hello you know can make an awful lot." (Participant 6)

"Inform, inform, inform. So we need to do something to inform the community and organisations other than our own of people with intellectual disabilities and their needs. The guards and Dublin Bus are doing well but could still benefit from more information as could people in general that they are no different to you and I." (Participant 4)

"....I think what we are doing is the right way to go and hiding of people with disabilities and now the exposure and it's up to us to support that exposure in all forms...........and I don't think any talks....I remember a course provider in the community asking me to sit them down and give a talk and I said let's let them learn themselves, let's support it, let's observe because we have to. If I sat down and listed off do's and don'ts around people with disabilities you are going to turn them off or send them down the wrong road or maybe make people apprehensive. Let people be natural and that's the way it should be." (Participant 12)

"..Any potential that an organisation has they give of the community. If we have transport...it should be given to...an example...older people's centres and groups within the community...So instead of saying it's for our organisation, say it's for the community...We should be saying, what is the need in the community? And have we potential resource to support that need? And then also we also need to be more active in lobbying for different gaps in the community. We should connect more with the community and say what does this community need?...So we should be more of the community and active participants of the community...It's important to bring the community leaders together and have them working to build the community's capacity together." (Participant 9)

"......invite them in, let people come in, if the local community residents association want to have an AGM, give them your hall you know, give it to them for free. Try and partner with the community. It's not about like taking from the community. It's about opening yourselves, opening up to the community. Giving back as well, not going in with the hand out, you know looking for things all the time. Find out what organisations and things are in the community. Can our Quality Manager give advice to someone down the road or our Financial Controller? It's about partnering with the community through opening up not taking from or taking over the community." (Participant 10)

"I think by actually going to places and shops looking for placements for people, people are seeing them working and voluntary organisations. Make sure they are respectful placements and not hidden away in a corner, the back of a store house or something. They are out in the public interacting with people....Some course providers say they can't have six people with disabilities in the class because it could fall apart around progression to be made. One person will take time but we can do that much. You have to be mindful of that. It will take time to do it properly and you need to support so it doesn't go wrong. Otherwise they won't get involved again. It will all go to pieces. I definitely think we should do a bit of work with shops, restaurants, and facilities like that around making accessible menus which people can understand and also can we support these services around helping people with intellectual disabilities to buy within their budgets." (Participant 8)

<u>**4.8**</u>   <u>**How New Directions can best work**</u>

4.8.1   Two participants in managerial positions were asked what type of organisational culture needs to exist to realise *New Directions*.

> *".....focused on the individual.....It's person centred.....So, it's getting into that culture you know it's business, the business is getting that guy or that girl there and that's the culture we need to get across for everybody – not just staff, for managers, CEO, you know it's about using your time and money and so on, on the individual."* (Participant 12)

> *" ...there has to be buy in to the set of principles set by New Directions from above....I think we need a flatter system....it needs to be seen that we all roll up our sleeves to get this done...it does need resource....senior management.....should use the guiding principles of New Directions in their decision making and our strategic plan because the two of them go hand and glove......So the decisions we make, the actions we do, determine what our support mechanism looks like so if we make a bad....decision over here it affects....they are saying New Directions but....I'll give you an example giving taxis when someone can actually independently travel......* (Participant 9)

4.8.2   Two participants in managerial positions were also asked what type of change management and leadership is needed?

> *"I think it's a push along change management rather than a bring along....We should have brought in. We should have done change management programmes. You know like bring in outside experts.....before we would have sat down a big group of people and said we are closing (down a sheltered occupational service) but what we did was individual, about the individual, with the parent, sibling or whatever and sat them down together and explained we have to close...because and we are going to go here because."* (Participant 12)

> *"....I think there is also a huge investment in staff training because staff have been working in a bubble of segregated settings – going out into your own community is a totally different business.....there is a mindset change that needs to happen in management, there is a structural change I think in management also. We need to take some managers out of that institutional setting and bring them out into the community and get them working in that now.....staff the same.......And also communicate to the individuals that we support. If we keep them in the centre of what we do and then move outwards then we won't go too far wrong."* (Participant 9)

The other ten non-management participants were asked about changes in staff roles, challenges for staff and the skills and training now required for staff.

4.8.3   Ten of the participants were asked, has your role changed in light of recent years and can you describe those changes.

> *"God yeah it has because you have basically gone from being a Job Coach to now being a Life Coach, a multi-disciplinary team looking after service users, parents, everything, the community, making sure that person is okay in their community, making sure that the community is okay with that person with id. So your role – we are not just Job Coaches anymore. I think we are community liaison officers, family liaison officers. We are everything to everybody......" (Participant 4)*

> *"Oh yeah I don't think it's even possible to describe them but in more recent times going from centre based Job Coach.....it's gone more into Life Coaching....you are working with individuals out in the community, you are making sure that they have access to things, you are trying to build that up all the time.......we are based in an office....Oh the lads drop in but it's not even a drop in centre, it's just something for them to kind of grab hold of as such, physically they still like that idea but I think*

changed as in I think it will expand more to be out more....we are still intensely working with people and that could be wearing and you can only do so much at one time and I don't think it's maxed out to the point where we are getting other stakeholders involved...it probably goes back to previous comments around education, this is so important, this is why it matters and we can't do this on our own...." (Participant 8)

"Yeah, yeah because we used to be stuck in a room doing earphones and then you were stuck in a centre...doing Jobs Clubs with people who didn't want a job....and then we were told go out into the community. I got a person a job as an Avon Rep....and we done everything in her community and she knew all her neighbours then................And now you wouldn't be half afraid of doing it because I think we had a fear of approaching the community about someone with special needs and people aren't afraid anymore either to take them in, there is now Men's Groups, Active Age, there is an awful lot more for people that's linking in with their community. Now with the changing model, it feels right to be doing it in the communities." (Participant 2)

"Yes. The role has changed. It was in the door, get things done, time, you're watching the time.....So now I can have a conversation with somebody and know about their lives and what they did at the weekend, what they are doing tonight. I can have more craic with them, come up with more ideas of you know doing things..............There is still a few gaps where there is no great routine but you're kind of more on a level with them now because you are able to interact better because you have the time, you should have the time." (Participant 11)

"....You are caring for people and now you are trying to help them care for themselves. There is a huge difference and it is really hard to adjust.....more could have been involved in it and that could underestimate that you can just move from this area to this area which are completely different without a huge amount of training or even communication. I learned what I am doing now from my colleagues but not from any formal training.......so that's something we could learn when we are moving away from day services. I think it has pros but it needs to be recognised that it can be hard and difficult and a lot needs to go into it and a lot more needs to go into training........" (Participant 5)

"Yeah, there is more out and about with the lads now, there is not as many people in the building now, today there was no one in the building." (Participant 1)

"So you are out more but it brings with it more disappointment definitely because their vision and what actually happens is different. I have seen it where a wheelchair user can't get on a bus because there is already a buggy on board and sometimes we don't have time to wait for the next bus and I hate that. It's scary out there also and I wonder how the lads would cope with having a bag stolen for example." (Participant 7)

"Mmm yes the role has changed. the biggest change is that there is no centre anymore.............when you take the centre out of someone's life, you realise the vacuum that might exist in someone's life but you also realise the lack of friendships because it was all environmental and conditional. And outside of the four walls what exists for this person and for some people it was a big surprise they had very little going on during the day but for others they had more going on during the day that we gave them credit for.....you can't hide now with this new model and that's a good thing." (Participant 10)

4.8.4 Ten participants were also asked what are the challenges for staff.

"Under staffed, that would be the biggest....I think volunteers could work." (Participant 6)

"Time, there is more and more people working with POMs, with community based, with community links, with voluntary placements, with employment, with everything out there and it's just to find the time to support the people that are in work, to support the families, to find the time." (Participant 4)

"....The staff are all really good in all areas and they have been through so much, the recession, the cuts....they can get fed up but they don't let it affect their work and I think there is something that needs to be looked at as well because I think from high up they need to contribute more....it's such a process yet it can be underestimated just how hard it can be, it can be very hard." (Participant 5)

"...The challenge for staff is motivation...to keep going. To be able to keep going and I think the value of what we are doing could be very easily overlooked and if that happens and staff feel de-motivated, it's going to hit and then things won't be achieved and outcomes won't be reached...I think it can be very lonely. There are less staff. It's not like a centre.......out in a community finding one to one placements, that won't be attractive to some people so it's going to be difficult.....I personally found it difficult. I get a lot of energy from groups....I think that the danger is that people will be just farmed out and staff will be thrown out into the community and it's great. I think it is a good model but I think it is how to resource staff to do it has been completely overlooked and not even looked at properly in any way, in any logical way anyway." (Participant 8)

"Well in some cases I have observed that some of the users can be particularly difficult...The other big challenge then is the whole motivation just to get them interested you know and then how far you push that. There is a good few things I would like to do then you're getting a negative response back. I don't feel I can push it, it wouldn't do any good anyway. Motivation is the best...." (Participant 3)

"It's a big challenge I think finding things for them to do and places for them to.....So they don't get boredom." (Participant 1)

"Challenges – filling the space and people have to understand that you are doing all these new things with people, there is going to be gaps where people are doing nothing.....but then that's the time they should be interacting with themselves talking and that should be praised rather than are they doing nothing, you know. With the older crowd we are busy.....by two o' clock...some of them will even sleep...." (Participant 11)

"The challenge is that there is many people out in the community now that you don't want to suffocate them with people with disabilities.......one Active Age group in the community that I am familiar with has seen a drop off in their numbers of 50% since people with disabilities started going over, some feel they took over......A challenge for staff – trying to gauge the pace the community is ready for." (Participant 2)

"....in the old model bus pulled up, everybody off, you did your thing then home, that was the line, you know. With this new model – it is where is the line? It's trying to find where the line is. That to me is a huge challenge emotionally, trying to find the boundary....you can get so consumed going down this road with this person" (Participant 10)

4.8.5 These ten participants were asked what type of staff skills and training are required.

"Patience, I honestly am a firm believer you have to be a caring sort of person.....staff need to constantly do refresher courses just to keep up with the time." (Participant 7)

"...you have to accept everyone's different ability......so the training would want to understand people's disabilities more, just because you have Down's syndrome, it doesn't mean every person with a disability is the same...." (Participant 11)

"Again they have to look up things and find activities that are out there......" (Participant 1)

"I think we definitely need people trained in how to make contact with an employer, how to approach a parent, how to approach a company like Dublin Bus, An Garda Siochana, how to get involved with your community......what community work is all about, what communities are about, what putting people out independently is all about......some form of training on communication. That kind of support is needed to help them think outside of the structure of day services and the structure of what was before." (Participant 4)

"Communication training is needed." (Participant 6)

"It's like everything you need the formal courses.....but most of all you need the mentoring, the guidance from senior staff and managers. It could do with an allocation of a specific head to a new

person. I was at a couple of sessions with volunteers and staff and the questions and answers, answers and responses from staff was an excellent way to gain insight into what was going on." (Participant 3)

"...you are working alongside people that are trained in what they are doing and I think that I am coming and I am not trained in what they are doing. Look I went to college, I did Social Science but there are certain areas in this I mean that's all theory, I think there are certain areas that you need to be trained and possibly people on the ground....are better placed....to tell you/ new staff what you need to know about working in this area." (Participant 5)

"I think some staff probably need permission. It's not so much training as permission....There is a huge difference between caring for a person with a disability and supporting a person.........And an awful lot of staff both young and older staff hold people back because they are caring for that person........But I think yeah maybe assertiveness training........you are kind of driving into the unknown with a lot of this stuff. And a lot of staff all they need is reassurance, they don't need their hand held. They don't even necessarily need training or whatever. They just need the nod, they need the nod and they need to know there is a net here and I will catch you." (Participant 10)

"...keep staff motivated keeping the picture in their heads, why are we doing this....where we are heading.....give them a lot of positive feedback..........even simple things have to be recognised and built up. Keep vision of where it's going, what we are doing has to be kept at the forefront....I think skills.....I think ultimately you need staff who are....I suppose there is room for all staff but dynamic I think out there a bit, mmm willing to go off, try new things, willing to go into places, go down the road. Flexibility is always a word often thrown around but I don't know how meaningful it is, more dynamic......and eh the skills, how do you train that into a person.....training from any HR Dept based on policies and procedures....physical lifting and that kind of thing...is not going to do it......that's a different type of training from actual motivational saying yes we can do this, yes we can get into that shop and get that lad a placement. I think you need a lot of energy orientated, team building, driven, fun orientated because I find the more I achieve if I am having a really good day....the more I create and it kind of multiplies...But the reverse is true of that also....I think you need to build momentum. I think staff building, team building, going out for drinks, meeting together, having meetings together, having different kinds of goals, kind of urging people on to go for it, keep at it and you know that it's worth it, what we are doing is good and mmm yeah all that kind of stuff." (Participant 8)

4.8.6   The participants were asked how the potential of New Directions best can be maximised.

"It needs to be in good hands, steady hands....who can hold it, just hold the model, keep it still. You are steadying a ship basically and manage the expectations of the people involved in that process but it needs full support....In my opinion New Directions is the single biggest transformation of day services ever, ever because it's taking away the centre. This is not something that an existing manager should have added onto his workload." (Participant 10)

"Well we are doing it....by putting people in those positions to create friendships and the social and the educational and all those models that we see the way of where people should be....Eventually we won't need buildings. It's about the guys and where they are......we could say maximise it more with more staff but we don't have more staff. I suppose the other way is with the partners..." (Participant 12)

"I really do think we are doing well but I do think communication is the biggest downfall that we have. And also from the HSE as well, that they should come on board a bit more in explaining to us, I mean should they be more involved with front line staff who are on the ground working...I think there should be more coming down to ground level, let's see what's going on. How can we help?" (Participant 4)

"Mmm I think making staff more aware of it. I mean that sounds like a very simple thing but I still think...a lot of people don't know what New Directions is.....you don't know if people have even read it....I think it's actually an interesting document.......you know what would help and I think yeah to show people what has been done in the hubs and to say that this works...these people are happy. And they have moved out of a centre and a lot of them don't want to , would not go back to a centre, most of them actually, I think all of them actually and I think once they experience something new no, no I don't want to go back......... I think people with severe - profound think New Directions is not for them.......I think the staff could feel 'look this is not for us'.....so it needs to be thought out a bit and

ways it can be done and definitely when it comes to people with severe – profound disabilities and I think there is ways it can be done or applied." (Participant 8)

"It can be best maximised number one if the organisation buy into it, number two if the proper training and skills are for all parties within it, number three if the organisation are brave enough to shed off individuals who won't buy into it....that's a difficult one because it happens more easily in private business than in the voluntary. I have seen a lot of documents come out of the HSE in twenty years. For me this is the best I have ever seen. It's very inclusive...individualised...person-centred. there is another document called 'Value for Money' which is all about people having individualised budgets which I think is the next phase of New Directions...I think a lot of families will take up their own support mechanism and buy in a lot of private.....New Directions changes....from us providing services to facilitating supports for individuals to have a life and that's a big power change.....What I would hope and pray for is that people are self-determined to live their own life..... (Participant 9)

4.8.7   Finally the participants in this research were asked whether they thought New Directions is ultimately a good idea and why?

"It is a good idea because we are getting away from the whole sheltered workshop, we are getting away from all that even though everywhere has to make a change...." (Participant 2)

"Yes I do think it's a good idea, well again it's getting them out into the community and getting people to know them and them to know people. It's much better than sitting around the day care centre all day you know because it's kind of going back into the institution but they are just all out and about now having a good time. Yeah, it's a great idea." (Participant 1)

"It's a great idea obviously because the opposite is not too pleasant, you know the institutional based thing and idea, so the main thing is to get out and help to try and develop and brighten up their days, this obviously helps the parents and homes....and the communities are responsive to it and everybody doesn't mind what you are doing...." (Participant 3)

"Yes I do.....I just feel that centre based programmes breed an awful lot of problems for all the Service Users. I have found that since we have been out community based, there is less problems, less bickering because the lads don't see each other – the flip side of the loneliness – there is less big groups, you don't have the same amount of problems, you have different problems but I do think going forward definitely is the way to go, definitely is the way to go. I really do think communication is the biggest downfall. We have to alleviate the fears of families who think centres are the only option and open and honest is the only way to alleviate their fears and if we do this from the outset we don't have to wait for success stories to relax the parents. This would be better for staff also. Open and honest about what New Directions is about....the cuts and the money that's not available.....reassurance.....that we will be there and do as much and that we will do the best we can to the best of our ability. I am not going to lie it's going to be perfect and this is going to happen and that will never happen because things do happen and change but by being open and honest from the word go you have nothing to lose." (Participant 4)

"Of course it is a good idea we needed a New Direction.....In France we have been talking about this thirty years ago and put it in place but not with a big national document...." (Participant 12)

"Excellent, excellent I think it is really an excellent, excellent idea. it gives all the individuals a purpose in life like everyone needs a reason to get out of bed in the morning......All the achievements you know, if you are after finding someone a bit of work now and they are getting up and going to work straight. I can see the idea of them winding down all the day care centres and that part where they are coming straight out of homes and going direct to work or school or what they are doing, it makes sense....they are coming in there from 8:30 in the morning and they are there until ten, half ten before they even do anything then whereas if you were in work at half eight or nine you are getting up and having breakfast and going straight to employment or whatever." (Participant 6)

"I think it is a good idea.....years ago supported employment was the buzz thing and everyone was getting a job.....now it has kind of cooled and that is part of it but not the whole picture....I think the

model can't be improved on but I think the things in that model can be. Yes we can get people different placements, we can change how we do it, how they interact with the public, how the public interacts with them all that can be better, better, better...." (Participant 8)

"I think three quarters of it is a good idea. I do think maybe the lads that are in between working and can keep up with average people doing a job and the lads that can do it in their own time, that there is nothing there for them." (Participant 11)

"Yes, I think it is a fabulous document...but the HSE who hold the purse strings, the voluntary organisations, families, all the parties who support individuals have to buy into it. Resource and money has to be given to it. Restructuring has to happen....disability organisations are moving towards a place that I haven't in twenty years, it was stagnant but it moved slowly and slowly in very, very small steps. I see an acceleration of change happening now and it excites me more than when I started in that I see the change happening at a more rapid, rapid pace......yes it's, it's, it's very progressive in its make up but the key to it....is that all the partners must buy into it.....from the funders to the person, it should be from the person to the funders but ultimately it's the life change for a person. This is trial and error for us in the sense that it's going on the journey with the individual. Mmm, sometimes we go the right and sometimes we go down the cul de sac, so as long as we have a set of principles to follow that are on a sound basis then and we are actively listening to the individual, then we are on the right road." (Participant 9)

"Yes I do I think it's a great idea. Now the cynic in me would say it will save money for organisations and yeah it will....but it is 100% the right decision....New Directions will give parents a future for their children if it is handled properly. it's about a person's ability and it's about maximising his ability, you know, not necessarily him compared to someone else....but New Directions will help him to keep that essence of him...it is really exciting New Directions and I don't think enough people know about it or appreciate how big this is,....I suppose people are probably a bit jaundiced and burnt out and they see the HSE and just roll their eyes and assume the worst but no it's really good" (Participant 10)

"I was definitely suspicious, who was involved and what groups were asked the questions and who came up with this who were the people that said people in the centres weren't happy and weren't fulfilled because I don't know anybody who was asked or who inputted into New Directions. Is it a money making scheme? A lot of people think it is." (Participant 8)

"You see I would like to say it's brilliant but I think.....it shouldn't just be all about, I would be afraid that it would turn into having to go back to centres anyway. It's a hard one because it can't just all be about getting out there and you know, I know, I get it, they have to be out, they have to be included and I am for that but I don't think it should all be just about community, community, community because how come that was going on for years and there was no change years ago. I know we are trying to keep up with the times. Some people can't be out always, they have to go back – familiar places. That's what I would be concerned about. You are out all the time but you are not in a comfortable environment all the time but you should be, you know just a little break here and there. So no I am not fully for it all the time but I do understand why it has to be done. There is even pressure that I can't go back because I have to be out. So yeah I do, it definitely has to be balanced you know, not all community and going to forget about the centre." (Participant 7)

"Ultimately yeah....it's a great idea, you know there is negatives....it's about independence, it's about employment, it's about community links, social capital, of course it's all great....but maybe a bit vague also in assuming that people want those things and maybe not everyone wants those things.....I don't really like the idea of complete and total community based....think of the guys who are older....let them have what they have always been comfortable with you know. I think in theory great, in practice it leaves a bit of work. In theory when you mention words like independence and equality they all sound great but it's a lot bigger than that." (Participant 5)

Appendix I

DECLARATION OF
RESEARCH ETHICS AND/OR ASSESSMENT OF RISK

All research and scholarship proposals, whether funded or not by internal or external funds, must submit a RESEARCH ETHICS/ASSESSMENT OF RISK FORM to the DIT Research Ethics Committee.

This is a self-declaration process. The researcher is asked to formally identify any possible ethical issues or risks that might arise in the course of the work, and to sign the documentation.

Please refer to the Guiding Principles and Procedures indicated on the DIT Research Ethics website prior to completing this form:

- http://www.dit.ie/DIT/graduate/ethics/index.html

PLEASE NOTE

- You are requested to attach a copy of your research application to this form.

- The RESEARCH ETHICS /ASSESSMENT OF RISK FORM must be signed by the applicant(s)

- Ethical Approval must be granted prior to start of any research/scholarly activity or prior to funding being released for the project, as appropriate.

- No postgraduate research student will normally be registered until the proposal is cleared by the DIT Research Ethics Committee.

Completed forms should be returned to: Research Ethics Committee, c/o Office of Graduate Studies, DIT, 143-149 Lower Rathmines Road, Dublin 6.

Title of the proposed project:		
From Institution to Integration: The perspectives and experiences of disability sector staff in the transition to New Directions		
Applicant Details (Use Block Capitals): DEREK BRYAN		
Surname: BRYAN	Forename: DEREK	Title: MR.
Present appointment: M.A. CHILD, FAMILY AND COMMUNITY STUDIES		
School/Department/Centre: School of Social Sciences and Law Faculty: Work Tel: 0868846815 Fax: N/A E-mail: d12122670@mydit.ie		

Other departments/organisations/individuals involved:

a) {participating organisation}
b)
c)

Source of Funding:
SELF FUNDING

Has the current research project already received approval from another research ethics committee?
NO
If so, please enclose relevant information and documentation

Generic Projects:

Researchers may receive approval for a cluster of similar research activity by approval of a *generic protocol* to cover repetitive methodologies or activities. A *generic protocol* should comprise a covering letter setting out the circumstances and rationale for generic approval, outlining the procedures to be followed in all such projects, in addition to completion of the appropriate appendices.

If this project is part of a cluster of research with similar methodology, please tick here and submit a generic protocol to cover all such projects. ❑

Insurance

Normally, DIT insurance covers standard research activity, including fieldtrips. Are you aware of any unusual or exceptional risks or insurance issues to which DIT's insurance company should be alerted? If so, please list the issues:

Please note that no contract should be entered into for clinical/medical (including drug testing) or surgical trials/tests on any human subject until written confirmation has been received from the DIT's insurers that the relevant insurance cover is in place.

Are you or any members of the research team a member of any organisation that provides professional indemnity insurance?

Name of the organisation:

Please provide written confirmation of the terms of insurance cover.

Professional Code of Conduct

Please reference, if appropriate, the Code of Ethical Conduct produced by your relevant

professional organization(s), which also informs your research.

Please note that: Where those requirements conflict with DIT requirements, the latter will normally be followed. In all such circumstances, please contact the Office of Research Ethics for clarification.

All researchers must confirm with the Data Protection Act 1988. Please consult the DIT Data Protection Officer for advice.

IDENTIFICATION OF ETHICAL ISSUES AND/OR RISK

<table>
<tr><td colspan="4">Do any of the following ethical issues or risks apply in your research? If so, tick all box(es) which apply and complete the relevant Appendix, which can be downloaded from http://www.dit.ie/DIT/graduate/ethics/index.html</td></tr>
<tr><td>Yes</td><td>No</td><td colspan="2">Does your research involve…</td></tr>
<tr><td></td><td>x</td><td colspan="2">Impact on human subject(s) and/or the researcher(s) [Appendix 1]</td></tr>
<tr><td>X</td><td></td><td colspan="2">Consent and advice form given to subjects prior to their participation in the research [Appendix 2]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Consent form for research involving 'less powerful' subjects or those under 18 years [Appendix 3]</td></tr>
<tr><td></td><td>x</td><td colspan="2">Conflict of interest [Appendix 4]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Drugs and Medical Devices [Appendix 5]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Ionising Radiation [Appendix 6]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Neonatal Material [Appendix 7]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Animal Welfare [Appendix 8]</td></tr>
<tr><td></td><td>X</td><td colspan="2">General Risk Assessment [Appendix 9]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Hazardous Chemical Risk Assessment [Appendix 10]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Biological Agents Risk Assessment [Appendix 11]</td></tr>
<tr><td></td><td>X</td><td colspan="2">Work involving Genetically Modified Organisms Risk Assessment [Appendix 12]</td></tr>
<tr><td></td><td>x</td><td colspan="2">Field Work Risk Assessment [Appendix 13]</td></tr>
<tr><td colspan="4">If other risk and/or ethical issues are identified please provide a written submission which outlines the issues and the manner in which they are being addressed.</td></tr>
</table>

Please tick the appropriate box below

X   No, there are no ethical issues and/or risks involved in your research project, **please tick here, and sign the declaration on page 5.**

☐   **Yes, there are ethical** issues and/or risks involved in your research, **please tick here and complete the appropriate forms identified above.**

In accordance with the Principles of the Declaration of Helsinki and DIT Principles and Procedures, I declare that the information provided in this form is true to the best of my knowledge and judgement.

I will advise the DIT Research Ethics Committee *of any adverse or unforeseen circumstances or changes in the research which might concern or affect any ethical issues or risks, including if the project fails to start or is abandoned.*

Signature of applicant 1: Derek Bryan

Signature of applicant 2: _____

Signature of applicant 3: _____

(An electronic signature is permissible)

Checklist

Please ensure the following, if appropriate, are attached:

Documents to be attached	Tick if attached	Tick if not appropriate
Research Proposal		x
Letters (to subjects, parents/guardians, GPs, etc)	x	
Questionnaire(s)		x
Advertisement/Poster		x
Ethical clearance from other ethical research committees		x
Copy of signed agreement of professional indemnity		x
Generic Protocol		x
Other (please specify)		x

Appendix J   Introducing the Twelve Personal Supports

Every adult benefits from support in his or her life. People with disabilities need more tailored supports. The purpose of a modern person-centred day service is to offer a flexible and individualised set of supports to enable each adult with a disability to live a life of their choosing in accordance with their own wishes and needs.

The range of supports to which the individual has access should equip him or her to achieve the following outcomes and goals:
• make choices and plans to support personal goals;
• have influence over the decisions that affect his or her life;
• achieve personal goals and aspirations; and
• be an active, independent member of his or her community and society.

The nature of the support will depend on the particular needs and abilities of each individual. It is the responsibility of the service provider to work with each individual to tailor the supports to the individual's needs.

Against the background of a commitment to person-centeredness and community inclusion, the **personal supports** that should in future be available to an adult with disability are:
1. Support for making choices and plans;
2. Support for making transitions and progression;
3. Support for inclusion in one's local community;
4. Support for accessing education and formal learning;
5. Support for maximising independence;
6. Support for personal and social development;
7. Support for health and wellbeing;
8. Support for accessing bridging programmes to vocational training;
9. Support for accessing vocational training and work opportunities;
10. Support for personal expression and creativity;
11. Support for having meaningful social roles; and
12. Support for influencing service policy and practice.
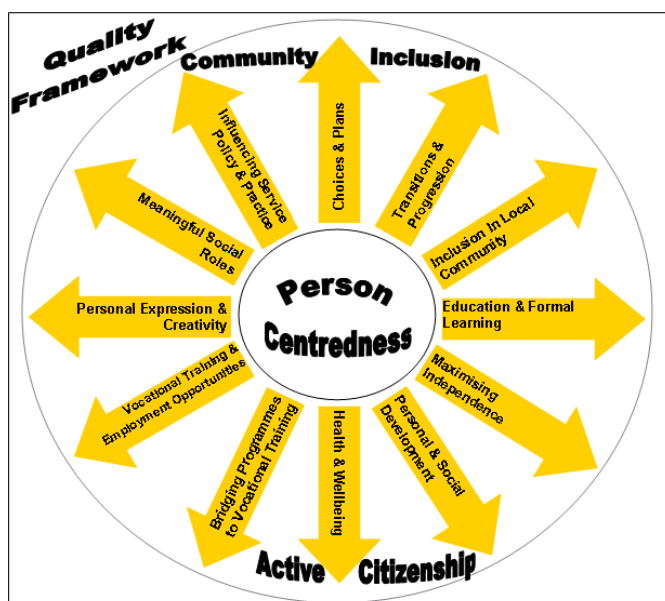
Source; New Directions (2012)

Appendix K

Awarding Bodies

A wide variation of individualised plans and quality frameworks are utilised in HSE funded adult day services. Awarding bodies include;

- European Foundation for Quality Management (EFQM),
- European Quality in Rehabilitation Mark (EQRM),
- National Accreditation Committee,
- International Organisation for Standardisation (ISO),
- Council for Quality and Leadership (Personal Outcome Measures) and
- Excellence through People.

Appendix L

Examples of good practice community integration projects

Ran's & Green (2005) researched four community integration projects in Canada and America deemed examples of good practice. They all focused on the gifts and dreams of individuals rather than their needs. They also focused on *'Citizen Space'* - everyday social settings other than health and social care environments. This is considered important because connections and associations develop in this space. Finally, the study established *'Connectors'* are central, these are local people who know many people and who are good at connecting people in the course of everyday life.

Similarly, the Grapevine Community Connections Project in Coventry in the UK supports people with ID to access community facilities, activities and social networks to reduce service dependency and enjoy a network of friends and associates in their neighbourhoods. Grapevine uses a person-centered planning tool called 'identity mapping' and 'community mapping' to gather information about the community. Interestingly, this project places more value on staff than some others, as people are connected to their local community with the help of a support worker. Support for connections to grow is also provided (Keogh, 2009).This project highlights the need for ongoing support that enables, empowers and connects people. Family, friends and volunteers in clubs have key roles in a social network approach. Race (2007) points out people not services, lead ordinary lives. Ordinary and varied lives exist and develop locally because they are about people making the best of 'who' and 'what' they are and interacting with others.

Appendix M

Purposive sampling criteria used to select twelve participants for this study;

- that there was representatives from as many grades as possible in the department implementing New Directions,
- that those selected were also working in the field pre 2012/before New Directions was launched and
- that those selected are currently directly involved in the implementation of some aspect of New Directions.

Appendix N

Considerations taken into account when devising the interview schedule;

- the aim of the study which is to explore perspectives and experiences of staff from the disability sector on proposed new ways of working with people with ID within their organisation and how they believe New Directions can best work and

- the main thematic headings in the literature review which influenced the following interview themes; models of service, person-centeredness, supporting community participation, family, friendship, the contribution of persons with ID to their communities and how New Directions can best work.

- those in management positions were asked specific questions in relation to organizational culture, change management and leadership whilst

- staff and volunteers were asked specifically about role changes, challenges and skills and training requirements.