

# **Assessing the Impact of Person-Centred Planning on the Community Integration of Adults with an Intellectual Disability**

Final Report

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## Executive Summary

Irish policy relating to people with intellectual disabilities has prioritised community living and integration, alongside a support service infrastructure that places the individual at the centre. These recent developments have aligned Ireland more with the intent of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), particularly with regard to deinstitutionalisation policy expressed in the Health Service Executive's 'Time to move on From Congregated Settings' (Health Service Executive 2011) and a shift towards more individualised and integrated service provision supported by person-centred planning (PCP) in the 'Value for Money and Policy Review of Disability Services in Ireland' (Department of Health, 2012) and 'New Directions: Review of HSE day services and implementation plan 2012 – 2016' (Health Service Executive, 2012). Alongside this, person-centred planning has been recognised as a potential mechanism for advancing community integration (Bigby and Knox 2009; Beadle-Brown, 2006; Robertson et al., 2006).

## Aim & Objectives

In this context, this study aimed to assess the impact that person-centred planning had on the community integration of adults with an intellectual disability (ID) by examining the experiences of implementing the **Planning Alternative Tomorrows with Hope** (PATH) (Pearpoint et al. 2003) approach to PCP at Stewarts Care Ltd., a service provider for people with intellectual disabilities in Dublin. PATH is based upon identifying what is important to the individual – their strengths, needs and vision/aspirations for the future, and how they want to live their life. A particular focus for the study was the experience and outcomes of PATH for people with severe-profound ID. Under this aim, the study had a number of specific objectives:

1. Determine the extent to which community integration is embedded as a goal within the person-centred plans of adults with an intellectual disability.
2. Evaluate how successfully community integration goals developed as part of the person-centred planning process have been achieved.
3. Identify the key factors, including enablers and barriers, in achieving community integration goals within the PCP process.
4. Make recommendations for policy and practice towards using PCP for the community integration of adults with an intellectual disability.

Community integration, inclusion or participation is held within policy and the research literature as a central to quality of life for people with intellectual disabilities. However, there has been a lack of theoretical basis for the study of participation (Verdonschot et al., 2009) and a limited conceptualisation and understanding about what 'community' means (Ben-Moshe, 2011, Cummins and Kim, 2015). From a sociological perspective, community may be best understood as bonding between people and having a sense of belonging; however, in the disability discourse community is understood more as a spatial concept based on people with

ID being physically present and integrated into the general mainstream community (McCausland *et al.*, 2016). In the current study, community integration is primarily understood as activity which the person with ID performs in the context of general or mainstream community, as an integrated rather than segregated activity. In the report, this type of social activity is differentiated from social activity that takes place within the specialised or segregated context of Stewarts Care services.

## Methods

This study partnered with a service provider, Stewarts Care Ltd., based in Palmerston in West Dublin, where it provides a range of residential and day services to 775 people with intellectual disabilities. In 2013, the TCD research team completed a pilot study to develop recommendations for the implementation of person-centred practices within Stewarts (McCarron, *et al.* 2013). Since then, Stewarts has implemented a person-centred approach to provision amongst its residential and day service users using the *Planning Alternative Tomorrow with Hope* (PATH) approach (Pearpoint *et al.* 2003).

The current study followed up on these activities and consisted of two main phases of data collection and analysis. The first phase accessed Stewart's data on 169 completed PATHs using secondary analyses, to provide a descriptive overview of their content. The second phase of the study recruited seven individuals with severe-profound ID for case studies to examine the process and outcomes of PATH in more depth, particularly with a view to community integration. Interviews with these individuals, their family members and their support staff were used to construct each case study.

Ethical approval for the study was granted by the Stewarts Research Ethics Committee and also by the Faculty of Health Sciences Research Ethics Committee in Trinity College, Dublin.

## Findings: PATH Data

The analysis of secondary PATH data from Stewarts (n=169) identified a number of key findings:

- Community integration was a strong focus of planning amongst individuals using PATH, with goals of this nature included in the majority of service users plans.
- Service users with mild-moderate ID and those living in community-based residences (regardless of level of disability) had higher numbers of community-integration goals.
- Service users with severe-profound ID and those living in on-campus residences (regardless of level of disability) were more likely to plan social goals within the facilities and amenities of the organisation rather than the wider community.

- The vast majority of service users identified potential barriers to achieving all of their PATH goals.
- Those with severe-profound ID and service users living in on-campus residences were more likely to identify barriers to achieving their PATH goals.
- Family members attended the PATH planning meetings of 25% (n=42) of the sample (though the number who had family is unknown); and subsequently just under half (47.6%, n=80) of completed PATHs were viewed by family (including families who did not attend the meeting).
- There was an average of eight goals of all types in each PATH, and the majority of these (six) were achieved.
- Service users with severe-profound ID and those living in on-campus residences achieved less goals than others.

### Findings: Case Studies

Five key enablers were identified that supported a successful PATH process for people with severe-profound ID and complex needs, from development through implementation. PATH was perceived as successful when community integration goals were met, as reported by case study participants.

- (i) Staff who are familiar with the person with ID
- (ii) Preparation for PATH
- (iii) Communication and sharing information amongst staff and with family
- (iv) Family involvement in the PATH process
- (v) Activity planning

Barriers to the PATH process and the achievement of PATH goals identified in the case studies included:

- (i) Staff who are not familiar with the person with ID
- (ii) Inadequate staffing resources to support community integration
- (iii) Inadequate funding for one-to-one support with community integration
- (iv) Lack of transport to engage in community integration
- (v) Change in health circumstances

### Conclusions

Among the key points reached by the study are:

- Community integration was a key focus for person-centred planning (PATH) in Stewarts, with a majority of service users having these types of goals in their PATH.
- The majority of PATH goals were achieved; and the case studies demonstrated that service users with severe-profound ID largely had good outcomes and were able to achieve some degree of community integration.



- However, challenges to setting and achieving PATH goals for community integration, particularly for people with severe-profound ID and associated complex support needs were both of a personal nature (such as behavioural, mental health or communication) and organisational (such as resources, staffing and communication).
- Challenges experienced limited the potential benefits of PATH for community integration for people with severe-profound ID.
- Family involvement in the PATH process contributed to benefits.

## Recommendations

Following on from this analysis and conclusions, the researchers propose a number of recommendations for future implementation of PATH within Stewarts, and for the broader policy and practice of person-centred planning:

### Staff and Family Supports

1. More staffing, including where needed, one-on-one supports and maintenance of familiar staffing, may be needed to better support individualised goal achievement for individuals with severe-profound ID and complex support needs. This may simply relate to funding to hire and maintain adequate levels of (familiar) staff; however, in a wider context a review of organisational practices that impact on the retention of familiar staff should also be considered.

At a broader level, policy and practice needs to recognise that personalised or individualised approaches to support people with severe-profound ID and complex support needs is often more costly than group-based activities. Additional staffing and other resources are needed to support community integration for this cohort of people using these person-centred approaches.

2. Greater family outreach to increase involvement with their loved one where possible may be an important resource to support the development and achievement of person-centred goals of community integration; this may be especially important in a time of ongoing funding restrictions.

Natural supports are recognised in policy as an important resource for people with an intellectual disability. In the current climate of funding restrictions, service providers must explore every possible avenue to opening up communication and involvement with families of the people they support.

### The PATH Process

3. Periodic refresher training and embedding PATH within the orientation and induction programme for all new staff will better underpin person-centred planning throughout the organisation

This is instructive to all service providers that person-centred planning should not be a one-off exercise. Rather it should be integrated into the core business of every organisation, underpinned by ongoing training and development in the ethos and practical application of person-centred planning for the staff who are expected to implement it; and should include self-assessment by the organisation.

4. Continuing attention is needed to how PATH goals and activities are communicated to all staff who work with an individual so they become embedded and integrated into the everyday support for each individual.

Again, all services should be aware that person-centred planning does not end after a plan has been written on paper. Agreeing a plan is just one stage in the process. What happens to the plan afterwards, and how that is incorporated into the everyday business of supporting individuals, will in many ways determine the potential success of the initial exercise.

5. Periodic formal review of individuals' PATH goals and their implementation should be built into the PATH process, to assess the achievement of goals and to review and maintain their continued relevance for the individual. Reviews should involve the individual, their friends and family, advocates, and support staff. In addition, keyworkers should monitor the achievement and relevance of PATH goals for the individuals they support on an ongoing basis.

Stewarts is to be commended for its continuing commitment to developing and implementing PATHs, seeking to involve families, encouraging and training staff to believe in and pursue with individuals with ID their desired lives, and for a thoughtfulness about the challenges and barriers that make implementation more difficult. More needs to be done and the resource challenges identified here particularly in support for persons with severe and profound ID need to be addressed. However the benefits of a sustained commitment to person-centred planning are well documented in the experiences here.

## List of Abbreviations and Acronyms

DS	Day Service
FN	Field notes
ID	Intellectual disability
NDA	National Disability Authority
PATH	Planning Alternative Tomorrow with Hope
PCP	Person Centered Planning
SAG	Study Advisory Group
SPSS	Statistical Package for the Social Sciences
TCD	Trinity College Dublin

## Context

While no consensus on the definition of person-centered planning (PCP) exists in the international literature, in Ireland the National Disability Authority (NDA) developed national PCP guidelines defining PCP as a “way of discovering how a person wants to live their life and what is required to make that possible” (NDA, 2005: 12). The overall aim of PCP is good planning leading to positive changes in people’s lives and services (NDA, 2005). In the NDA guidelines, person centredness is defined as “seeking to put the person first” and it is identified as a helpful way to steer the PCP process (NDA, 2005: 13). Robertson’s et al (2005) six indices of PCP efficacy of social networks, community involvement, scheduled day services, contact with friends, contact with family and choice are regarded as a standard measure. This study is set in the context of recent policy development which emphasise individualised approaches – such as ‘New Directions’ (Health Service Executive, 2012)– and the recognition to embed effective person centred services in Ireland (McCarron et al, 2013). The challenge is even when PCP is implemented that authentic participation of individuals is at the heart of the PCP process.

## Relevant Literature

### Method

A summary review of relevant international peer-reviewed literature was performed. The methodology employed to conduct the literature review consisted of snowballing approach which involves using the reference list of a paper or the citations to the paper to identify additional papers (Greenhalgh and Peacock, 2005). For this study this was primarily based on a prior agreement with the NDA to utilise a previously commissioned literature review of PCP (2016). Given the short timespan since this review a basic search in one major database (CINAHL) was run from January 1<sup>st</sup> 2017- May 29<sup>th</sup> 2018 using two key words, intellectual disability and person centred planning. The search included all related terms to these key terms. Criteria for inclusion was less expansive than the original review and only included peer-reviewed journals in English. A search for key words in the full text of the article was applied. This simplified search returned 7 results (29/05/18). There was one article of relevance published in this timeframe. The article focuses on leisure pursuits and choice making as a component of person centred planning for people with intellectual disabilities.<sup>1</sup>

There was a particular focus not only on approaches to person-centred planning but more specifically to their implementation and outcomes. Studies with a focus on

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<sup>1</sup> HASSAN, N. 'Putting music on': everyday leisure activities, choice-making and person-centred planning in a supported living scheme. *British Journal of Learning Disabilities*. Malden, Massachusetts, 45, 1, 73-80, Mar. 2017. ISSN: 1354-4187.

community integration were of particular interest, including transition studies assessing the quality of life outcomes associated with movement to community settings.

### Summary of Relevant Literature

Claes et al. (2010) identified 15 research papers published between 1985 and 2009 that reported empirical findings regarding the effectiveness of PCP. These researchers found that PCP was associated with an improved social network (Claes et al. 2010). Improved choice, communication and parental involvement was found as a result of PCP. Nevertheless, Claes et al. (2010) also found that people with communication problems, severe intellectual disability and challenging behaviour were often not included in the process. This led some researchers to conclude that PCP may have little genuine impact on people's lives. In addition, it was found that it was a challenge to access the flexible support that is needed to make PCP work in traditional large services (Claes et al. 2010). It is also reported that the process may be confounded by over emphasis on optimistic outcomes based on unrealistic goals for the individual (Holburn and Cea, 2007). To overcome issues related to PCP outcomes, acknowledging the quality, content, process and life-style related outcomes has been recommended (Robertson & Emerson, 2007).

### Implementation and outcomes of person-centred planning (PCP)

Research and policy recognise person-centred planning as a potential mechanism for advancing community integration (Beadle-Brown, 2006, Bigby and Knox, 2009). However, to date, peer reviewed research literature has predominantly examined PCP's use and best practices rather than investigating its effectiveness (Claes et al, 2010; Dowling et al., 2007; Parsons et al., 2009; Robertson & Emerson, 2007; Robertson et al., 2006; Taylor & Taylor, 2013).

In the Northern Irish context, McConkey and Collins (2010) explored personal goal setting to promote social inclusion of people with intellectual disability. This study involved 130 adult participants who lived in a variety of types of supported housing (both congregated settings and supported living projects) in Northern Ireland. The study used a goal setting approach in three stages including an interview and two review meetings. Key workers were invited to be present at the first interview. Goals were set around social activities, entertainment, sport, independence, work and training and social contacts. Staff assistance was identified as most the critical factor in goal accomplishment, followed by accessibility, availability of volunteers, support and contact from family and friends and their own independent living skills. Planning, behaviour problems, ill health and personal competence, finances and lack of social contacts hindered achievement.

In the USA context, Mirza and Hammel (2009) tested an intervention (Assistive Technology Long-Term Advocacy and Support- ATLAS) based on a collaborative approach involving service users, their social supports and service delivery. Thirty

individuals were randomly selected to receive the intervention from a sample of 75 community dwelling adults. Participants in the intervention group reported significantly higher levels of performance and satisfaction related to goals identified at baseline than participants in the control group. Basic self-care goals and participation/environmental/systems level goals were the two broad categories of goals addressed during the intervention.

A recent doctoral study in Ireland qualitatively examined the lives of ten people with ID who were removed from their families and placed in institutional settings and subsequently transferred to community dwellings (Fitzsimons, 2012). The study found that the structure of the PCP meeting to be over formal with a limited understanding of the aims and impact of PCP by all involved. Two distinct roles for staff were identified; key worker to facilitate the plan, and other staff to implement the plan (Fitzsimons, 2012).

In the NDA's recent review PCP participation was found to result in a range of positive outcomes for the individual who is the focus of PCP. These included involvement in more activities, improved personal opportunities, self-esteem and self-determination (Claes et al., 2010; Espiner and Hartnett, 2012; Robertson et al., 2006; Wehmeyer et al., 2006). Communication, involvement and teamwork were also found to improve through the process (Claes et al., 2010). However, these indirect positive outcomes were typically not targeted as PCP goals (García Iriarte et al. 2018). A common challenge to effectively implementing PCP identified in the literature is the development of a person-centred culture (Dowling et al., 2007; McCarron et al. 2013; Ratti et al., 2016).

#### [Impact on Community Integration and Transition to Community Experience](#)

Moderate changes in social and community inclusion resulting from PCP are identified in the NDA's recent review (Claes et al., 2010; Robertson et al., 2006). Robertson et al. (2006)'s longitudinal analysis of the impact and cost of PCP for people with intellectual disabilities in England found that PCP was helpful for social inclusion. However this study also found that relying solely on the PCP process was ineffective, as there was also a need to support individuals with intellectual disabilities build their social network by developing naturally occurring opportunities for socialising.

McCarron et al. (2013) acknowledged the opportunities PCP offers people with intellectual disabilities to set goals to attain independence. Lawlor et al., (2013) found that PCP goals that focus specifically on developing skills (for example, employment, finances and communication) lead to increased ability to live more independently. Nevertheless, a range of factors influence achieving independence; such as the availability of services, restricted choice of day services, a limited choice of housing, waiting lists for services, limited employment opportunities and the choices offered by staff can limit the opportunities of people to live more independently (Robertson et al., 2007).

## Study Aims and Objectives

The aim of this research is to assess the impact that person-centred planning has had on the community integration of adults with an intellectual disability.

Key research objectives within this aim include:

1. Determine the extent to which community integration is embedded as a goal within the person centred plans of adults with intellectual disability.
2. Evaluate how successfully community integration goals developed as part of the person-centred planning process have been achieved for people with severe-profound ID.
3. Identify the key factors, including facilitators and barriers, involved in achieving community integration goals within the person-centred planning process.
4. Make recommendations for policy and practice towards using person-centred planning for the community integration of adults with intellectual disability.

Stewarts Care is a voluntary organisation in Dublin established in 1869 and provides services to adults and children with intellectual disability in the surrounding areas of West Dublin and Kildare. Amongst its services are:

- Residential services for 262 people in on-campus residences and community group homes;
- 25 congregated housing units on main campus;
- 30+ group homes dispersed throughout surrounding local communities;
- Primary day services for 377 people;
- Pre-school and school services for 186 children;
- Respite services for 144 adults and 39 children;
- Family support service with 140 adult places and 70 child places.

'Planning Alternative Tomorrows with Hope' (hereafter referred to as PATH) (Pearpoint et al. 2003) is the model of PCP that has been implemented within Stewarts. PATH is based upon identifying what is important to the individual – their strengths, needs and vision/aspirations for the future, and how they want to live their life. It aims to involve those who know the individual well including family and staff. It employs a creative approach using symbols, words, images and colour to capture what is important to the individual, identify their personal goals and the steps to achieving them. In Stewarts, all relevant staff attended an initial PATH workshop, for training in the principles and procedures of PATH. Each individual service user's PATH involves four stages:

- a) A Pre-PATH – which is a process of information gathering and discussion between the individual and his/her keyworker;
- b) The PATH meeting - where the individual, people who know the individual including family and support staff, and PATH facilitators develop the

individual's PATH (i.e. their plan). This takes place in the dedicated PATH room within the main Stewarts building. The PATH process and resulting plan is set out in eight stages:

- i. Values – What things are important to you in life? What is precious to you? What things do you like?
  - ii. Vision/goals – Your future? What would you want to have achieved a year from now?
  - iii. Now – Tell me about your life now? What do you do here? Is this what you want?
  - iv. Enrol – Who can help you achieve these goals? Who can help you with this?
  - v. Blocks – What might get in the way? What might stop the PATH from happening?
  - vi. Keep strong – How are you going to keep strong and focused on the goals?
  - vii. Short-term Goals – If you are to complete the course by this time next year what will you need to have done in 3 months' time?
  - viii. First steps – Would you like help with this? What sort of help would you like? Who would you like to help with this? (McCarron, *et al.*, 2013)
- c) Implementation of PATH – where goals set out in the plan are delivered with the supports identified;
- d) PATH review – whereby a questionnaire was sent to each individual's keyworker to identify progress with PATH goals and any changes to the plan. This review was undertaken as a once-off exercise within the organisation. Ongoing or periodic review of PATHs is not currently a formal part of the PATH process for individuals.

There has been a commitment over a number of years within Stewarts to base its services on person-centred planning approaches.



## Methods

The study adopted a mixed methods design comprising of quantitative and qualitative approaches, underpinned by a contextual review of relevant literature. There were two broad elements of data collection and analysis:

- 1) Secondary descriptive analysis of PATH dataset from Stewarts Care
- 2) A multi-stage process to create case studies of seven individual service users with severe-profound ID

### Secondary Data Analysis

Analysis of a dataset of PATH data for 169 service users who had completed their PATH and PATH review was performed to provide a descriptive profile of the person-centred planning process as well as its output and outcomes of PCP. This involved a number of steps:

1. Creating a database of completed PATHs for analysis which included:
  - (i) Assessing the completeness of an existing Excel database of 169 completed and collated PATHs that had been compiled to date by Stewarts including the variables of gender; age; level of ID; type of residence (i.e. residential, community); staff type; staff involvement; family involvement; number of PCP goals; type of goals; blocks (i.e. potential barriers identified during PATH meeting); and goals achieved.
  - (ii) Compiling, collating, cleaning and reviewing the database of 169 PATHs.
  - (iii) Coding and re-coding variables and response options for analysis and entering into a new SPSS database.
2. Performing descriptive analyses including frequencies and cross-tabulations with tests of association for bivariate analyses including chi-square and independent sample t-test where relevant; and creating a profile of the PCP process, outputs and outcomes that included:
  - (i) Mean/median number of PCP goals created in each PATH.
  - (ii) Range of goals created, and proportions of each type of goal including identification of the percentage that represent community integration goals.
  - (iii) Overall percentages of goals achieved by types of goals and mean/median number of PCP goals achieved, also by type.
  - (iv) Type of barriers identified; correlation between blocks identified and goals achieved/not achieved.
  - (v) Differences in number and type of goals established and achieved by level of ID and residence type.
3. Drafting a summary profile report based on the above analyses.

### Case Studies

The second phase of data analysis involved the development of case studies. From

the preliminary data analysis, a sampling frame was created to target individuals who (a) have community integration goals within their PATH, and (b) have a severe-profound level of intellectual disability. Case studies of seven individuals who met these criteria were undertaken to provide qualitative analysis regarding the outcomes and impacts of PCP on their community integration.

Seventeen individuals were randomly selected by the researchers from those eligible within the sample of 169 service users who had completed a PATH; while seeking to maintain a balance of male and female respondents, representation of different residence types (community and campus-based), and whether family members had participated in their PATH. These individuals and their families were invited to participate in focus groups or semi-structured interviews (depending on the number of people available) to discuss their participation in the PCP process and the outcomes achieved (see interview schedule in Appendix C). A sampling frame of seventeen individuals was identified to ensure that a target sample of 6-8 participants was met; with a final sample of seven individuals included in this stage of the study.

Accessible study information materials were developed to recruit case study participants (see Appendix B). Based on existing IDS-TILDA protocol these materials were developed in easy to read formats for service users, family members and staff following standards of best practice. The study information packs contained a letter of invitation to take part in the study, a study information booklet with the researcher's contact details and individual consent forms. Given that the degree of intellectual disability of potential recruits was in the severe-profound range of ID, proxy consent for participation was sought from a family member for their participation in the study; while direct consent was sought from family members themselves.

When individuals/families consented to take part, support staff involved in each individual's PATH process were invited to take part in a second focus group to discuss the process and outcomes achieved with the person they supported. This included keyworkers and other staff. The Stewarts PATH Coordinator acted as the project liaison to facilitate contact with relevant staff. While the primary aim was to hold two separate focus groups for each case study (one with the individual and his/her family; and a second with support staff), there were practical and logistical difficulties to achieving the required number to achieve this. Therefore, in most cases two semi-structured interviews were used to create the case studies; one interview with a family member and the person with ID, and a second interview with one staff member (two staff in one case). In all cases, staff participants in the case studies were very familiar with the individual and had been involved in their PATH process.

In total, 13 semi-structured interviews with service users, family members and staff were carried out. Seven of these interviews were with staff members and six with family (five of which also included the service user). Six out of the seven case study participants had at least one family member participate in an interview. While all service user participants were invited to participate, two out of the seven could not participate due to health circumstances, meaning five persons with ID were interviewed. On average interviews lasted approximately 45 minutes, with the

shortest interview lasting approximately 30 minutes and the longest approximately 75 minutes. All interviews with the exception of one with a family member took place at Stewarts at a location that was most comfortable for the service users.

A semi-structured interview method was employed for the development of the case studies. The method was chosen as it offers the researcher, as Lofland and Lofland (1995: 273) point out, “the possibility of modifying one’s line of inquiry, following up interesting responses and investigating underlying motives.” Given the aim of the case studies was to illustrate the individuals’ particular PATH experiences, this method was a good match. It permitted the interviewer to concurrently guide the “conversation with a purpose” (Bingham and Moore, 1959: 4), to target the study’s precise research questions and be led by the interviewee to explore topics specific to the individual. To ensure participant anonymity, pseudonyms were assigned (McCann and Clark, 2003). Data was audio recorded and transcribed verbatim. The development of the case studies was based on a thematic analysis of the data to identify emerging issues and cross-cutting themes to uncover “patterned meaning” (Braun and Clarke, 2006). The analysis was informed by a thematic topic guide that was developed in preparation for the data collection and based on the previous literature review and the secondary data analysis. There was particular focus on identifying factors that facilitate or hinder the achievement of community integration goals. Data was analysed line-by-line and coded based on the emergent cross-cutting primary themes (e.g. enabling factors including familiar staff, family involvement etc.; barriers including staff resources, transport issues). The person’s own statements were given weight where there were differences with staff/family respondents but this was rare. Subsequently, the researchers interpreted these themes to investigate their impact at individual and organizational level.

Data from these sources (that is, from service users and family members, and from the individual’s support staff), in addition to the quantitative data from phase one for those individuals, contributed to the development of individual case studies. The aim of these case studies was to illustrate the extent to which community integration goals have been achieved through the PCP process and the implementation of its goals, including the identification of specific enablers and barriers.

### Ethics and Governance

Ethical approval for the study was granted from both TCD’s Faculty of Health Sciences Research Ethics Committee and Stewarts Care Services Ethics Committee in late March 2018. A Study Advisory Group (SAG) was established of Stewart’s service users, staff and family members. The SAG met twice during the study. A key role for the SAG was to provide feedback to the research team on the proposed approach and methods at the start of the study; and to provide feedback towards the end of the study on draft findings and proposed recommendations. The SAG included three representatives from Stewarts Service Users’ Council, one relative of Stewarts Care service users and three staff members. All members were selected based on their individual knowledge and experience of PATH, including the service

users who had completed their own PATHs. These individuals were selected and invited to participate on the advisory group in liaison with the study's gatekeeper from Stewarts Care.

## Findings: Secondary Data Analysis

Following cleaning of the data, one participant was removed before the analysis as this individual did not meet the residential type criterion. Therefore, a total of 169 participant PATH profiles were included in the SPSS data analysis presented in this section.

### Demographic Profile

The mean age of participants at the time of conducting their PATH was 50.1 years (Std. Dev. 12.424) with a range of 21 to 93 years old. Table 1 presents a profile of the 169 participants by gender, level of ID and type of residence.

Table 1: Demographic Profile of Participants

Demographic	%	n
<b>Gender</b>		
Male	50.9	86
Female	49.1	83
<b>Level of ID*</b>		
Mild-Moderate	31.7	53
Severe-Profound	68.3	114*
<b>Residence Type</b>		
Community	36.1	61
Campus	63.9	108

**\* Level of ID was not reported for two individuals**

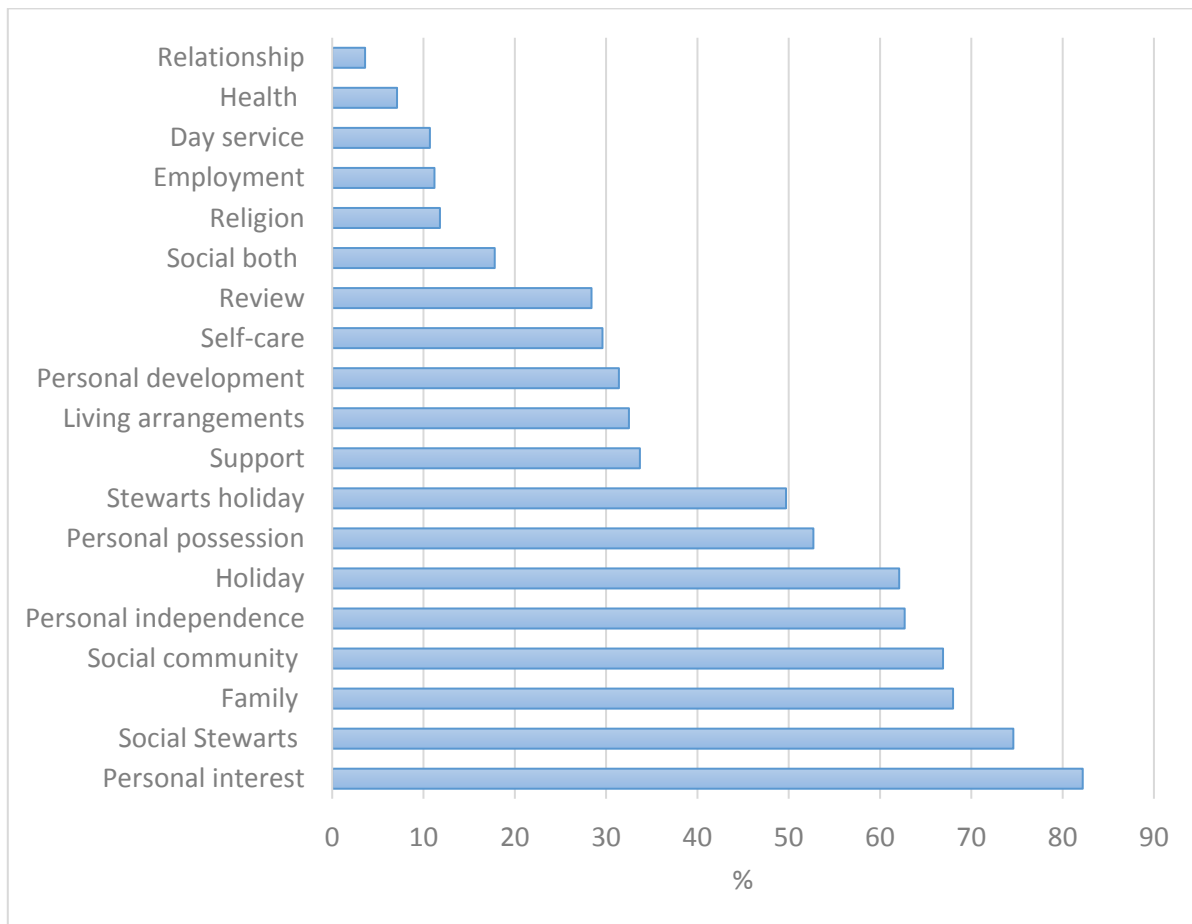
There was an even distribution across gender with slightly more men (50.9%) than women (49.1%) in the sample. With regards to level of ID, just over two-thirds (68.3%) of the sample consisted of individuals with a severe or profound level of ID, while just under one-third (31.7%) had a mild or moderate ID (two in the sample had an unverified level of ID). People living in community-based residences comprised 36.1% of the sample, while a majority of 63.9% were living in campus-based settings. There was significant overlap between level of ID and type of residence. Of the 114 people with severe-profound ID, 82.5% (n=94) lived in campus-based residences and just 17.5% (n=20) lived in community settings. Of the 53 people with mild-moderate ID, 75.5% (n=40) lived in community residences and just 24.5% (n=13) lived in

campus-based residences.

### PATH Goals

Figure 1 presents the participants' PATH goals. PATH goals refer to the goals individuals identified as important to them during their PATH meeting (see also Table A.1 in Appendix A). A code book was developed to thematically categorise data. In total, 19 categories of goals were identified. The most common type of goal were goals related to pursuit of personal interests by individuals (e.g. hobbies, arts and craft, music and gardening), while goals of social activity and interests as well as family and personal independence were also amongst the most commonly cited goals.

Figure 1: PATH Goals



A number of goals identified may be important to community integration. 'Social community' goals were identified by two-thirds of participants, and were specifically goals of social participation within the general community. However, social goals located within Stewarts facilities were more commonly included within PATHs than community-based social goals, included in three-quarters of plans. These were social participation goals that took place within the environment of the organisation or one of its satellite services (e.g. café or restaurant). In addition to these, a smaller

proportion of participants (17.8%) also included a social goal that may be performed in both contexts ('Social Both') – e.g. going to the café on campus and one in the community.

In addition to these specific social goals, a majority of participants (almost two-thirds) also had a goal to take 'holiday' within a mainstream community setting such as a hotel. Around half of the sample had another holiday goal for a break in the organisation's holiday home in Kinvarra, County Galway ('Stewarts holiday'), which was distinguished from specifically community-based holiday goals in the analysis. Two other common goals had potential for community integration, but this could not be determined from the level of information in the dataset. These were goals related to family (68%) and personal independence (62.7%), which included independent living activities, decorating bedrooms and tidying their outdoor space, public transport and travel. A number of other less commonly cited goals also had potential for community integration, including goals related to living arrangements, personal development, religion, employment and relationships.

The relationship between PATH goals and type of residence and level of ID is presented in Figures 2 and 3 below. With regard to residence type, Figure 2 shows some key differences between those living in community and campus-based settings within the sample, with many of these differences being statistically significant (see also Tables A.2 and A.3 in Appendix A). While those living on campus had higher rates of goals among the top three types of goal (personal interest, social Stewarts and family), community-based residents were much more likely to develop specific goals of community integration within their PATHs. This group had an 8.2% higher rate for 'social community' goals ( $p=ns^2$ ) and a 36.1% higher rate for 'holiday' goals ( $p<0.001$ ). Community residents also had higher rates for living arrangements (+13.2%,  $p=ns$ ), personal development (+45.9%,  $p<0.001$ ), employment (+23.4%,  $p<0.001$ ) and relationships (+7.3%,  $p<0.05$ ). Campus-based residents were more likely to have segregated goals in their plans, including 'social Stewarts' goals (+3.8%,  $p=ns$ ) and 'Stewarts holiday' goals (+52.1%,  $p<0.001$ ).

Analysis of the relationship between PATH goals and level of ID (Figure 3) also shows some key differences between service users with mild-moderate ID and those with severe-profound ID, particularly in relation to community integration goals. People with mild-moderate ID had substantially higher rates for the integrated goals of 'social community' (+6.8%,  $p=ns$ ) and 'holiday' (+25.7%,  $p<0.01$ ). They also had higher rates for other PATH goals that may have potential for community integration including living arrangements (+5.1%,  $p=ns$ ), personal development (+47.5%,  $p<0.001$ ), social both (+7.7%,  $p=ns$ ), employment (+27.6%,  $p<0.001$ ) and relationships (+8.5%,  $p<0.05$ ). Service users in the sample with severe-profound ID were, on the other hand, more likely to have more segregated goals of 'social Stewarts' (+12.1%,  $p=ns$ ) and 'Stewarts holiday' (+34.1%,  $p<0.001$ ).

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<sup>2</sup> ns = not statistically significant

Figure 2: PATH Goals by Type of Residence

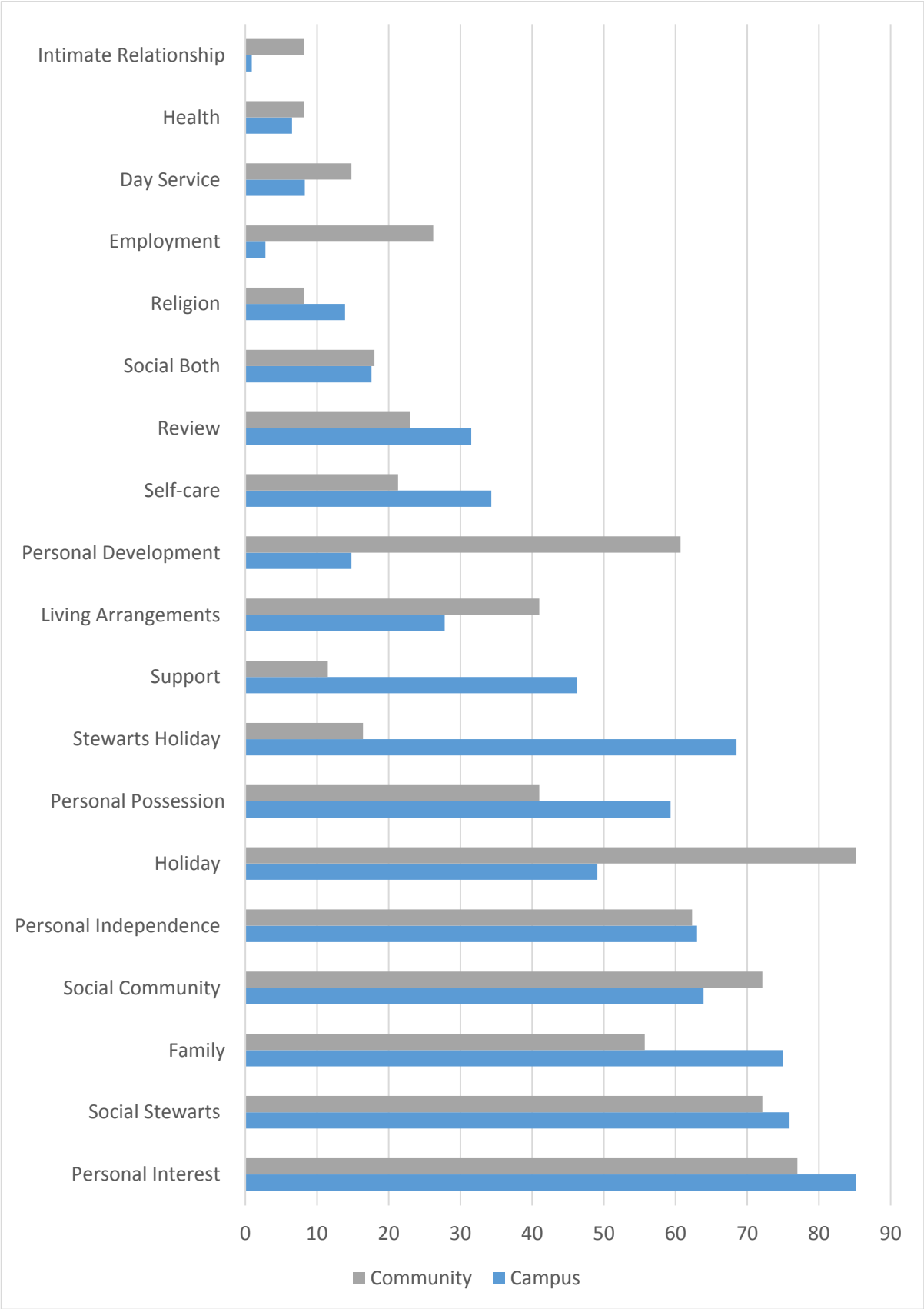
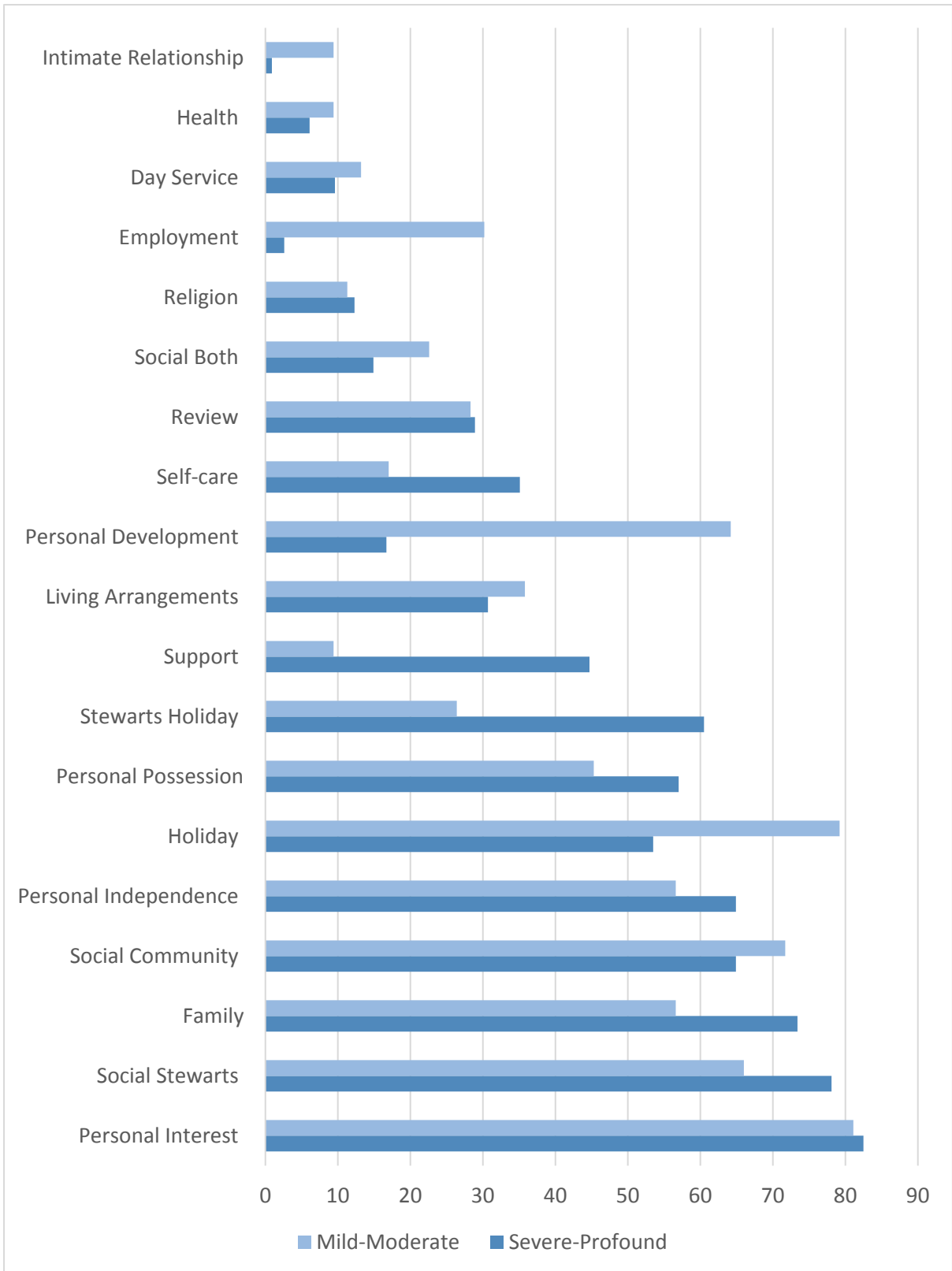




Figure 3: PATH Goals by Level of ID



## PATH Barriers

Potential barriers to achieving PATH goals were identified at the outset in 84.6% (n=143) of cases. Figure 4 below illustrates the most common barriers included in plans during their development (see also Table A.4 in Appendix A). The most frequently identified potential barrier raised during PATH meetings was 'myself', which was included in just under half of plans (46.7%, n=79). This refers largely to behaviours that challenge and other individual characteristics such as anxiety and other mental health difficulties that may act as a barrier to achieving the goal for an individual. Issues related to staff support were also common, with familiar staff (30.8%, n=52) and adequate staffing levels (29.2%, n=50) included as potential barriers in around three out of ten plans. Just over a quarter of plans (27.9%, n=46) identified the Stewarts organisation as a potential barrier to achieving PATH goals.

Figure 4: Barriers to PATH



Figures 5 and 6 illustrate differences within the sample with regard to PATH barriers (see also Tables A.5 and A.6 in Appendix A). A total of 80.3% (n=49) of community residents identified potential barriers to PATH at the outset; compared to 87.0% (n=94) of campus-based residents ( $p=ns$ ). Service users from campus-based residences were substantially more likely than community residents to identify 'myself' (+9.0%,  $p=ns$ ), familiar staff (+25.0%,  $p<0.001$ ) and staffing levels (+20.6%,  $p<0.01$ ) as barriers to their PATH goals.

With regard to level of ID, a total of 77.4% (n=41) of respondents with mild-moderate ID identified potential barriers to PATH at the outset; compared to 87.7% (n=100) of respondents with severe-profound ID ( $p=ns$ ). There was little difference between service users with mild-moderate ID and severe-profound ID in relation to 'myself' as a barrier. However, there were key differences in other potential barriers. Service users with severe-profound ID had substantially higher rates for barriers related to familiar staff (+22.6%,  $p<0.01$ ), staffing levels (+24.5%,  $p<0.01$ ), the

Stewarts organisation (+17.4%,  $p < 0.05$ ) and their health (+9.2%,  $p = ns$ ). Apart from health, which showed the smallest difference of these, the biggest differences related to PATH barriers between service users with mild-moderate and severe-profound levels of ID appeared to structural/organisational rather than personal.

Figure 5: PATH Barriers by Type of Residence

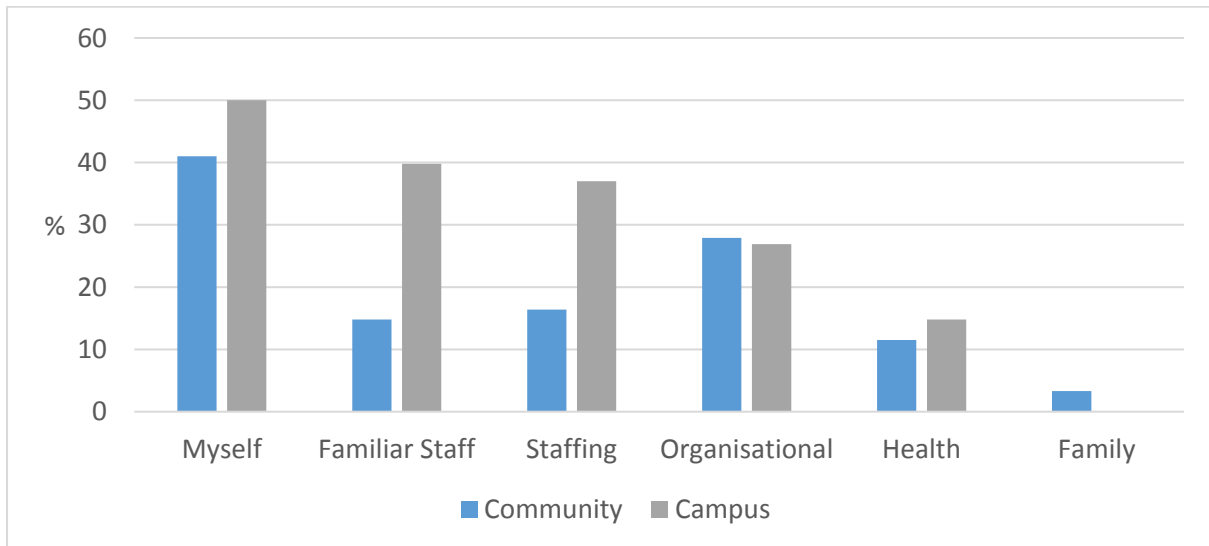
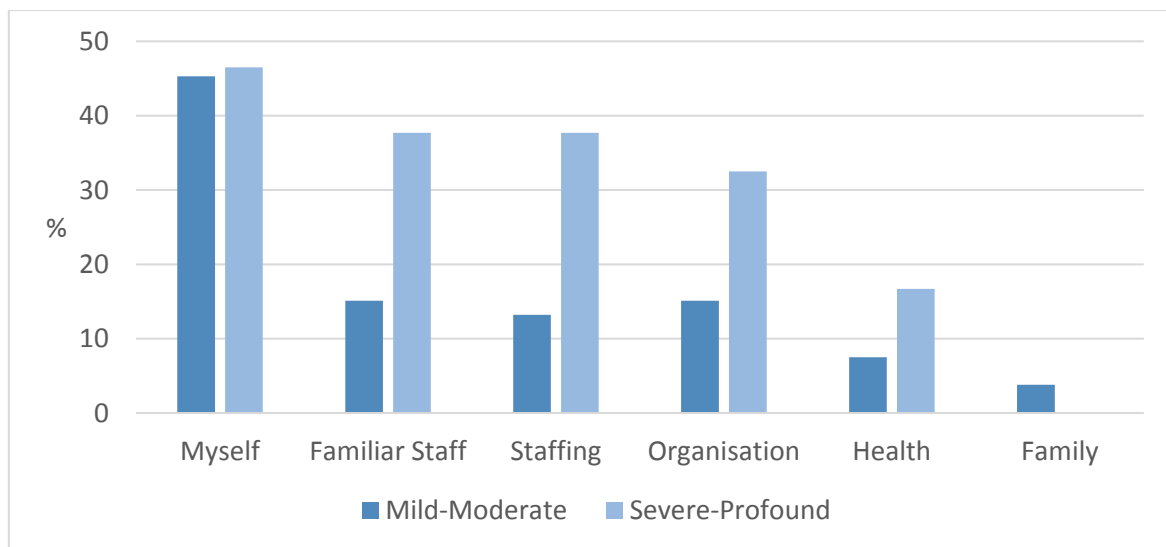


Figure 6: PATH Barriers by Level of ID



### Family Involvement in PATH

Overall, family took part in a quarter of PATH meetings (24.9%,  $n=42$ ), and just under half of completed PATHs (47.6%,  $n=80$ ) were viewed by the individual's family afterwards. It is not known how many participants no longer had family able to attend. Figures 7 and 8 show the differences in family involvement between groups based on type of residence and level of ID (See also Tables A.7 and A.8 in Appendix

A). With regard to residence, Figure 7 shows that, while more families of community residents attended PATH meetings (+12.4%,  $p=ns$ ), more families of campus residents viewed their completed PATH afterwards (+9.2%,  $p=ns$ ).

Figure 7: Family Involvement in PATH by Type of Residence

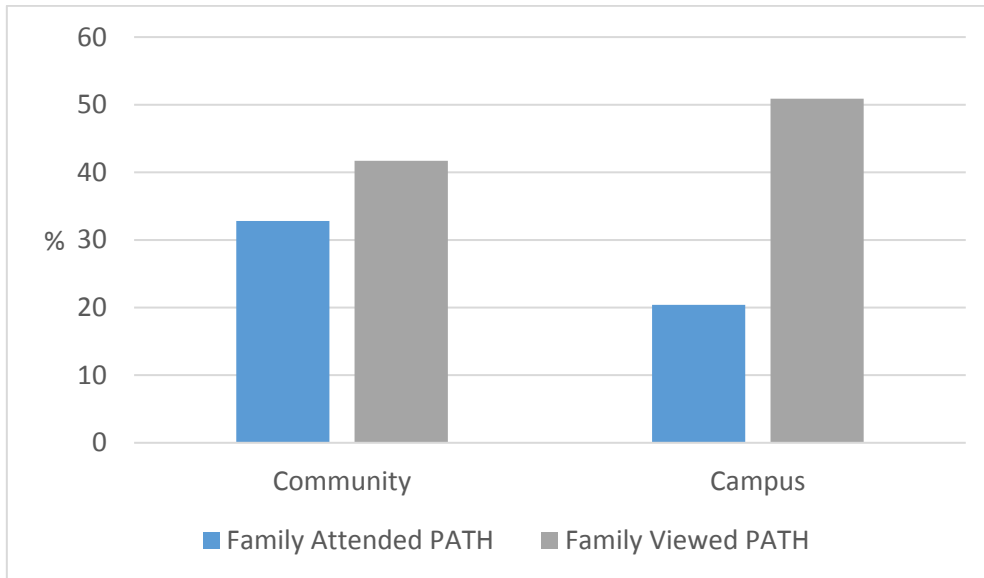
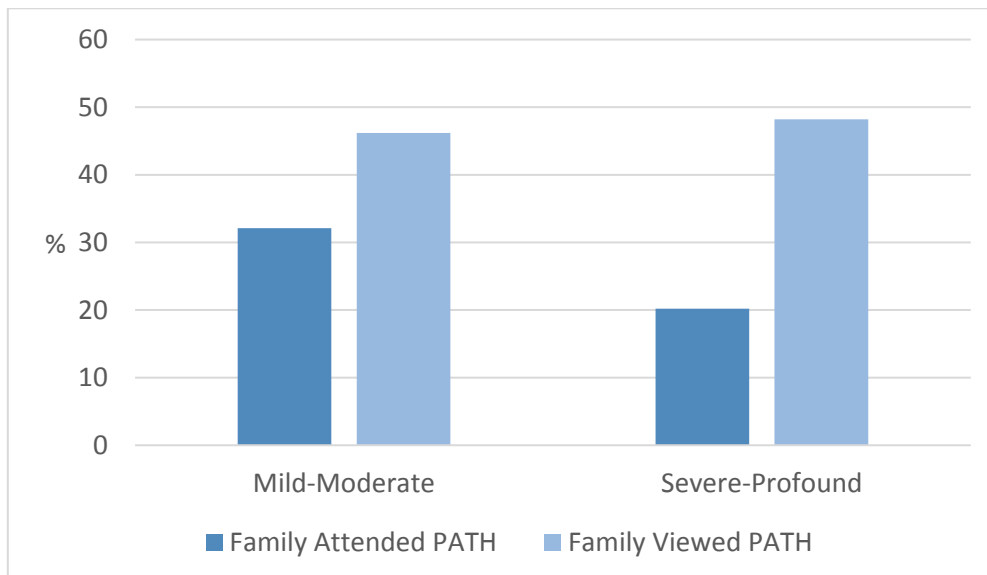


Figure 8: Family Involvement in PATH by Level of ID



In relation to level of ID, Figure 8 illustrates that the families of service users with mild-moderate ID were substantially more likely to attend their PATH meeting (+11.9%,  $p=ns$ ). There was little difference between groups with regard to family viewing completed PATHs, with just under half doing so in each case.

## PATH Outcomes

Table 2 below outlines a number of outcomes from the PATH process for the sample as a whole, including the mean number of goals identified, goals achieved, goals not achieved and actual barriers encountered during implementation (as opposed to barriers predicted during PATH development). This shows that the average number of goals developed in each PATH was 8.55, and that the majority of these had been completed by the time of review. However, the data available did not permit examining which specific goals, including community integration goals, were achieved; this is explored in more detail in the case studies that were created. Table 2 also shows that, while the vast majority of PATHs had identified potential barriers at the outset (84.6%, n=143), the actual number of barriers encountered during implementation was relatively low at a mean of 1.32. The nature, degree or impact of barriers encountered was explored in the case studies.

Table 2: PATH Outcomes

Outcomes	Mean	SD	n
No. of Goals	8.55	4.059	168
Goals Achieved	6.32	3.863	168
Goals Not Achieved	2.09	1.784	168
Actual Barriers	1.32	1.137	167

Figures 9 and 10 show the association between these PATH outcomes and the different categories of residence and level of ID (see also Tables A.9 and A.10 in Appendix A). In Figure 9 we can see that there was little difference in either the number of goals included in plans or the number of barriers encountered in implementation. There were, however, more substantial differences with regard to the number of goals achieved and not achieved. People in community residences achieved on average one goal more than people in campus residences (+1.17 goals,  $p=ns$ ), while those in campus residences had a higher average for goals not achieved (+0.58 goals,  $p<0.05$ ).

Figure 10 shows that there was a greater degree of difference in outcomes amongst PATH participants with regard to level of ID. Service users with mild-moderate ID had on average 1.5 more goals in their PATH than those with severe-profound ID ( $p<0.05$ ), and achieved almost two goals more in implementation (+1.92,  $p<0.01$ ). There was a smaller difference with regard to barriers encountered, with service users with severe-profound ID having a slightly higher average (+0.11,  $p=ns$ ).

Figure 9: PATH Outcomes by Type of Residence

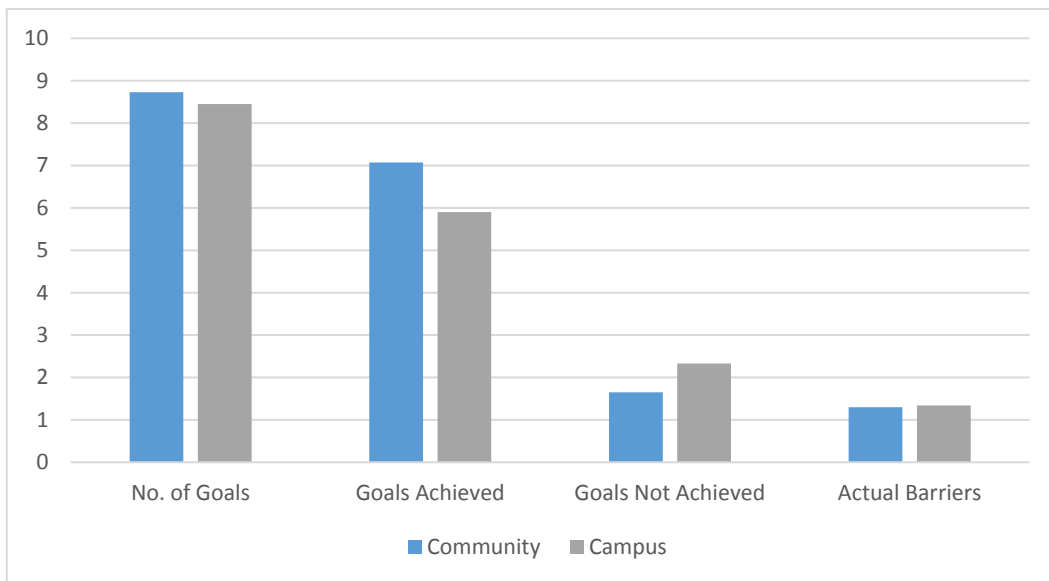
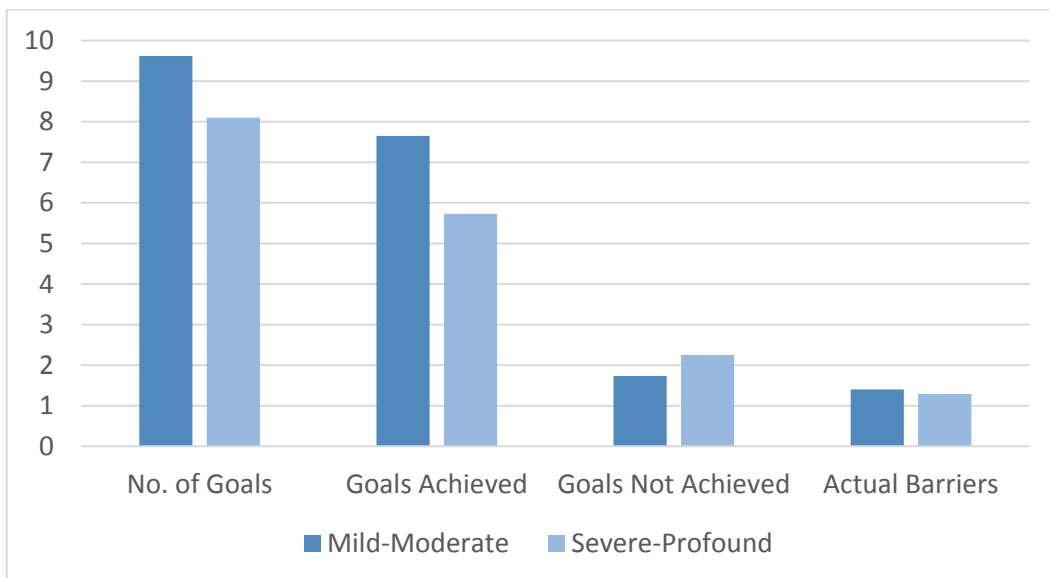


Figure 10: PATH Outcomes by Level of ID (Mild-Moderate vs Severe-Profound)



### Summary of Secondary Data Analysis

Overall, the analysis of secondary PATH data has identified that community integration is one of the key focuses for person-centred planning by service users in Stewarts, identified by two-thirds of service users. While goals that relate directly to improved integration within the wider community (i.e. ‘social community’ and ‘holiday’) were not the primary focus of PATH for many, the broader range of goals identified placed community integration amongst the top six goals identified in plans and was included by a majority of service users. Other goals were also related to greater integration, including personal independence and development, employment

and relationships. As such, we can conclude from this analysis that community integration is a key feature of person-centred planning for individuals with ID using PATH.

However, the data also revealed that social participation goals, including social activities and holidays that took place within the Stewart's environment and satellite locations, were also common in the PATHs of service users,. This emerged especially when we examined differences between groups based on type of residence and level of ID, when the data showed that people living in residences on campus and those with severe-profound ID were more likely to include these segregated goals in their PATHs.

With regard to implementation of PATH and the achievement of goals, the data shows that the large majority of PATH goals were achieved. The analysis revealed that there were again key differences in relation to residence type and level of ID; where people living in community residence and those with mild-moderate ID (regardless of setting) achieved more PATH goals than those living in campus settings and those with severe-profound ID. However, the available data did not allow for an analysis of what types of goals were and were not achieved, so it is not possible to comment here on the achievement of community integration goals of PATH. This is something that will be explored in depth in the case studies in the section which follows.

## Findings: Case Studies

This chapter presents the seven case studies that were developed during the study. All participant names have been replaced with pseudonyms.

### Case Study 1: Harry

#### Background

Harry is in his mid-fifties and has an intellectual disability. He has been living all of his adult life in Stewart's services. He shares a house with three other men on campus where he is supported by his key worker and another support worker. While he has achieved increased independence he requires individual support to achieve his social integration goals. He is supported to maintain a part time job at a local supermarket, a job which he thoroughly enjoys. His case study was developed from interviews with Harry and his sister and with his support worker who has been supporting him for three years.

#### PATH

Harry's PATH meeting included his family and staff that know him very well. While this member of staff was not present at Harry's PATH, he is very familiar with Harry and along with his key worker he supported him to identify his goals. Social integration goals in his PATH included maintaining his work routine, socialising in restaurants and hobbies such as bowling in the community and holidays with his family. His support worker reports that his family and staff felt that his PATH meeting had been a positive experience: "I know that everyone seemed to enjoy the experience."

Harry's support worker recalls the positive impact of having a good lead-in to the formal meeting, to allow the time to draw out Harry's interests and liaise with his family for input: "...it took me and my colleague probably about three weeks to get to the bulk of information from Harry's perspective. What he wanted. Once we had done that we gave that same information to the family to see what else did they think".

Harry has good verbal communication and the staff at his house know him very well. Consequently, Harry's staff have learnt the optimum time to talk with Harry about his PATH goals to ensure they gain the most meaningful input from him: "Harry is vocal so he can tell us what he wants, just wait for the right times when he's able to concentrate on your questions, you get the answers."

His staff are therefore confident that the PATH process was a genuinely person-centred plan led by Harry: "it was there from him...we are not trying to lead them in one direction... he can tell you directly what he wants to do. He came up with it himself... it was led from him."

As a result, his support worker believes that Harry's PATH goals are achievable: "perfectly attainable. Sometimes it takes a bit of will to do it but it's just being



organised.”

### Implementing PATH

From Harry’s support worker’s perspective, family involvement helps staff gain a deeper understanding of the service user interests: “I love having the families involved because they come up with ideas even from the past ...a much wider picture. Harry’s family have always been heavily involved... they have great ideas and willing enthusiasm from them.”

In Harry’s case his family have led the achievement of the majority of his PATH social goals including regular family holidays, as his support worker notes: “They have done most of the goals with Harry, a lot of them involved family going to Donegal, where they have a holiday home. Going to a live show, going to things, the family have taken care of all that.”

Harry’s support worker is quick to commend their involvement, while also acknowledging that this level of family involvement is not commonplace: “They are regular visitors, Harry goes home every weekend. And here every Wednesday she drops off his uniform and lunch for work on Friday. So it’s great family contact. It’s fantastic.”

Harry’s family also acknowledge the strong collaboration with their brother’s familiar staff at his home as very helpful to ensuring Harry can participate as much as possible in the community. A positive outcome from carrying out his PATH has been that Harry is gaining increased independence, as his support worker notes: “Harry is now more independent and walking down to catch the (Stewarts) bus at the main building.” This practice has been well supported and encouraged by his familiar staff as previously they accompanied him to the main building he now walks there by himself. From Monday to Thursday Harry travels with other service users on the Stewarts services bus to work at Stewarts Equestrian Centre in Kilcloon. On Fridays with the aid of his key worker he is driven to work either in Stewarts transport or the staff’s own car.

Harry has a very active life, both in Stewart’s and in the community. He enjoys a variety of activities including swimming and bowling. Working at a local supermarket is a central focus in Harry’s life. He enjoys his work; in fact he said “I love it”. This was a key component of his PATH which both his family through regular lifts to work and familiar staff support him to maintain.

While Harry is getting on well with his PATH goals he has encountered some challenges in meeting some of his goals. For example, Harry’s support worker and his sister and Harry himself acknowledge that due to unwanted weight gain, he has discontinued one of his key social and sports activities, horse riding, as his support worker notes: “[something] he hasn’t done is continuing to horse ride...weight limit on the horse.” Harry’s sister also acknowledges that Harry is missing this activity. She believes there could be more support for service users to keep fit and maintain a healthy weight. She suggested that her brother could join other service users in a slimming-down regime.

A lack of regular available transport has presented a challenge for Harry. For example, Harry enjoys going out to restaurants in the community. However, given the challenge with organising transport for social outings he has been restricted in meeting this goal. It is a frustrating situation for Harry, his family and staff, as his key worker explains: “Transport... of course that has an impact... it’s frustrating.”

Another challenge for Harry in meeting his social goals is the difficulty he is having with changes in the behaviour of one of his peers. Previously as a group they enjoyed going once a month on a Sunday to a restaurant in the community. While this activity is fulfilled as a group, this social outing to a local restaurant in the community was a goal shared by service users in Harry’s house. And given transport and staff limitations it made practical sense to arrange this as a group activity rather than on a one to one basis. Recently due to a behaviour change in one of Harry’s house mates this activity has been stopped: “The behaviour of one of his peers has changed. The activity was going out to a restaurant and socialising, so I used to go out once a month on Sunday... because the behaviour of one of the peers has changed I can’t plan these things... now stopped doing it...nothing to do with Harry or myself. It’s just the circumstances has changed. Until they deem it serious enough to give me some more support it’s not going to change.”

Managing living with this individual who has extremely challenging behaviour is stressful for Harry, as he says himself: “he’s always screaming, he won’t stop...” When asked how this makes Harry feel he simply says “angry”.

Currently, as mentioned by Harry’s support worker, they are seeking additional support to address the impact of this housemate’s behaviours that challenge on Harry and other service users. This may result in a change of accommodation for this housemate.

Harry’s sister praises the care and support that her brother receives from staff. However, she acknowledges that there is a challenge with staffing resources. This can impact Harry’s capacity to fulfil his PATH goals, as she remarks: “You could not fault the staff in this house, they’re absolutely fantastic. They’re just seriously out on their own... Harry is, yea he is active, but he does need to be watched... The others would be like 100% one on one. So one client moved and one staff moved. So you were left with three clients, two who were definitely one on one... The staff are completely tied, so if he wants activities, they can’t do that because the other two are physically not capable... It’s very frustrating.”

Harry had always wanted to learn to read and write. Within the services it was not feasible to support him achieve this goal. Therefore, Harry’s sister stepped in to seek a solution herself: “In terms of the reading and writing that was Harry’s goal...So there wasn’t really anything happening here. So I rang NALA myself... So we got Harry into college and he’s done his first year in college.” The crucial role that Harry’s sister played in enabling him to achieve his goal cannot be underestimated.

Harry’s sister is also keenly aware that having adequate but also familiar staff is instrumental to Harry’s well-being: “She was here the other day, you weren’t mad on her?” “No, no,” (Harry says). “You see it’s familiarity, you know. If he’s not familiar

with the person... Let's say X or Y (referring to his support workers) took holidays and the agency were going to bring you instead. Which would you prefer? Stay in, I'd prefer to (Harry says)... has an impact because if there was a change of staff during the week it upsets him and it goes on and on all weekend."

Harry's sister points out that Harry participates in some activities that are not Stewart's led, that are out in the community. For example, he really enjoys bowling, this is a community activity as she says: "I usually pick him up at half four, he goes to bowling on a Friday night... not part of Stewarts now... love it (Harry says)... it's only for an hour and fifteen minutes and then go back to my Mum's... it's not run by Stewarts so they don't take him up and drop him home ... I love it ... I have a few friends (Harry says)". Having his sister's support is enabling Harry live a more socially integrated life in the community.

### Next steps

Despite some challenges Harry's PATH is going well. Due to the support from his family and familiar staff he is achieving his community integration goals, such as enjoying his job at the local supermarket, regular family holidays and weekly activities such as bowling. Harry is thoroughly enjoying all of these activities. Given Harry has successfully achieved these PATH goals both his sister and his support worker recognise it may be time to set new ambitions, as his support worker notes: "We should probably redo the PATH from scratch again... a lot of the goals have been done, some of the ones that haven't been done are probably now unrealistic, rather than you haven't done them."

An ongoing review of Harry's PATH as part of good practice of person-centred planning would benefit Harry. A review of the PATH was undertaken with key workers. Both Harry's sister and his support worker were not part of this review.

## Case Study 2: Liam

### Background

Liam is in his sixties and has been living in Stewart's services since he was a child. Liam has severe to profound intellectual disability. Liam has been described as a lively outgoing individual. Until recently he enjoyed a range of activities in the community. However, in recent years Liam has developed dementia which has significantly impaired his capacity to participate in social activities. When his PATH was developed Liam was in the early onset stages of dementia. His PATH meeting was attended by his brother and sister and his core staff who knew him well, including a staff member from day services who has contributed to this study. This case study was developed from interviews with a familiar staff member and another interview with Liam's sister and brother. Unfortunately Liam was not well enough to join them.

### PATH

At the time, three years ago, Liam very much led the creation of his own PATH. He is described as an individual who was clear on the goals and related activities he wished to include in his PATH. Throughout his life Liam's family have been a steadfast support. The staff recognise the key role that his family have played in his PATH: "we would get family involved into the pre-PATH you see the whole thing is that everybody is involved, has a say and that there is...Liam was in the community when we done this. So yes, his sister and his brother have massive impact in his life...they are fabulous."

This member of staff reports that in the beginning she was hesitant about the PATH process and the capacity for it to make a real difference to service users' lives. Nevertheless, once she received the pre-PATH training with the PATH coordinator she gained practical insights into how the programme worked in reality and is much more open to the positive impact it can have for service users, as she remarks: "I came in for training with the PATH coordinator here and he explained the whole process because I wasn't sure...when it's explained to you properly it's good. I still was a little bit sceptical about maybe some of the long term goals and ensuring that we help people reach them... I was afraid that it would be pie in the sky maybe and that is always a worry because we all have dreams and aspirations but I don't know how our lads would understand that sometimes how they come to pass."

Despite her initial scepticism about the process this staff member was pleasantly surprised that it all went very well. Breaking goals into smaller manageable steps she found especially helpful as she says: "they were very manageable very they are really good way of getting things to happen it was a lovely way of sitting down... kind of made it concrete...It was good and it was a good way to get kind of future goals out".

Before the onset of dementia, Liam was someone who thoroughly enjoyed social activities and this was translated into his PATH. In particular he enjoyed attending social activities in the community, such as tea parties as his staff recall: "life and soul of the party...There used to be tea parties run in Palmerston for senior citizens. ...a

group of them went and they just had a ball, sure it was all old time waltzing dancing. He loved it sure he would entertain all the old people.”

### PATH implementation

Two key challenges that inhibit Liam completing his PATH are undeniably his recent severe health changes with the onset of dementia and when familiar staff are unavailable to support him. His family recognise that while Liam used to love many activities such as gardening, bowling, music and dancing, his capacity to engage in social integration activities have diminished significantly: “When Liam’s PATH was done, Liam was in the early stages of dementia at that stage...it was just at the beginning...he’s wheelchair-bound now. Liam wouldn’t have been able to tell us...beginning to change at that stage you know, he was beginning to get forgetful and he was getting a bit cross...you see he likes going to concerts and things, he likes going on the tram or the Luas or the train or whichever. I know those things were fulfilled by Stewarts...he was very good at it, he sort of interacted on that but with dementia ...it would be very hard to bring him...”

Prior to the onset of Liam’s dementia his family used to bring him home every Christmas for two weeks. Given his changing health circumstances they found that they now struggle for more than two days: “I had Liam at Christmas, I brought him home. I would always have him home for nearly two weeks at Christmas. And [brother] took Liam home for two nights. We weren’t able to look after him, he’s very you know; it takes three or four in Stewarts to look after Liam as in changing his nappy and everything. But he was so bad at home with me at Christmas he never had his foot inside the bedroom door.”

In particular family and staff noticed the major impact unfamiliar staff can have upon Liam’s behaviour. For example, his brother recalls a recent incident when an unfamiliar staff approached him and unfortunately the situation turned dangerous: “If strangers go in near him or somebody he doesn’t like he just lashed out. A young girl had to go to hospital...they bring in agency staff there’s at least one agency staff there every day. So they try and keep the agency staff working with somebody else rather than with Liam...it’s not always possible but they do the best they can. ...he wouldn’t have anything got to do with them... he’s more cooperative with the girls in the house, the regular staff, the Stewarts staff.”

Liam’s family continue to try to take him to events in the community; for instance they recently brought him to a concert which he enjoyed without incident. At the same time they are acutely aware that should they try the same activity next week it may not be as successful; as his family remark:

“Bring him to a restaurant, whatever, they’d have to have at least two or three people, you know. And having said that even if they did go to the shopping centre, Liam could get very cross and just say, I don’t want to go there....create a rumpus where you’d just have to turn around and bring him back... it’s the dementia...you could be sitting beside Liam and talking to him and he would be in great form or laughing and joking, and just by the time you snap your fingers you could put your hand on Liam’s hand and he’d just shout at you... taking him to a concert which he

was fine with the last time, last week, you could do the same thing this week and it could be a totally different situation. It could be a total disaster.”

### Next Steps

Liam’s family recognise that when Liam’s PATH was developed, the staff all had his best interests in mind and realistic goals were identified: “they were facilitating in any way they could, anything he wanted to do it was all written down, it’s all actually up in the house over there the PATH... a picture of it on a big huge 4x3...I have to say the staff now do what was said there they will do their best of their ability.”

In planning for Liam’s future social inclusion activities, his family feel that a flexible approach to Liam’s PATH is needed to recognise his changed health circumstances: “...need to decide how to deal with....as it (dementia) develops rather than acting according to plans made earlier”.

The staff member who supported him in day services prior to his dementia feels that Liam may benefit from his previous staff engaging with his current staff. She feels that this may help bring out some of the activities Liam enjoyed prior to his dementia. She also believes that his current PATH is not suitable and now needs to be revisited as part of best practice of person-centered planning:

“Definitely he knew it was all about him. There was so much going on his PATH...he was in the clubs the social club every Wednesday...obviously they would not be suitable a lot of them (goals); there is probably still some that he could do... we look at with people with dementia it’s like reminiscent therapy so if you are going to bring him somewhere where it’s going to be music of his youth and stuff that...there might be other things that bring him to a concert maybe... I don’t think anything is ever off the cards but you are looking at it in a different way...input from people who knew him before because I don’t know maybe the staff he’s working with now might not know the old Liam.”

Developing a new PATH for Liam that considers his changed health circumstances, and especially given the specific challenges of dementia, would be in line with recommended good practice for people with ID who develop this condition.

## Case Study 3: Yvonne

### Background

Yvonne is in her early thirties and has been using Stewart's services since she was a child. Currently she is living in a shared house with support care in the community. Once a week she stays at her family home with her parents. For Yvonne, her PATH meeting involved participation from all of the staff who support her at the service and her mother. This case study is based on interviews with Yvonne and her mother, and with Yvonne's key worker and another staff member who knows her very well and supports her with her activities. Yvonne communicates through Lámh (sign language) and is prone to behaviours that challenge.

Yvonne's key worker has worked with her for five years, while the other staff member has been working with her for nearly two years. Both her mother and her staff believe that Yvonne has made significant progress since completing her PATH almost three years ago, as her mother remarks: "[She has] come on so much, I just find that they're absolutely brilliant. Anything that happens in here I'm told about."

Her key worker also reports that improvement in Yvonne's behaviour have been noted: "Over the years ... people have kind of said how well she has come on from the time...where she had major behaviour...she has come on amazing...would see that kind of transformation."

### PATH

In advance of the PATH meeting, her key worker attended pre-PATH training with the PATH coordinator which she found helpful: "Basically what the PATH was and like the process of what it would be you know we did an hour or two training prior to the PATH. You know it was quite new to us all then...we kind of learnt from the PATH what kind of goals we can bring in."

Despite Yvonne not having verbal skills she is capable of communicating through sign and her mother felt the experience was authentically person-centred as decisions were made based on what her daughter wanted: "We were all involved in it ...she is asked for everything you know, nothing is decided without her. She's included in everything. So like they don't decide that she's going to do this, she going to do that without her... she's not just left behind because she can't speak...everything is what she wants."

Her key worker and the other member of staff acknowledge how important it is that individuals who support service users at their PATH are extremely familiar with the person. For example, her key worker says; "I will be her key worker for a long time and I would know her really well so I'm lucky in a way, her mam, the other staff member and myself we are all on the same page." The other member of staff agrees: "You have to be able to read her."

Her key worker believes it is critical for anybody supporting Yvonne to learn her signs, to ensure clear communication and that her real needs are being met. "You have to learn her signs and let her be part of it, she wants to know the signs you



know, it's reassuring really for ourselves. She will do this with her fingers, she wants to know the exact plan of what's happening. It gives her reassurance and she's happy then like once she knows exactly."

### PATH Implementation

The key worker believes the success of Yvonne's PATH is linked directly to the fact that everyone at her PATH meeting was well known to Yvonne, as she states: "I think because of the people that were at the PATH knew her really well...she very much is in charge of her own routine and her timetable...nobody would influence Yvonne at all, she's amazing."

Problems can arise when unfamiliar staff try to introduce new activities to Yvonne's timetable without prior planning, as her key worker says: "People coming in...I can take her off to restaurants or concerts and I have had people coming in...that wouldn't know her too well but we have to look at the whole picture then and look at Yvonne not to put her in a situation that she's...she's on her own and they can't cope with it."

Routine is particularly important for Yvonne. She enjoys activities such as, swimming, walking and in terms of social activities in the community she enjoys watching horse racing and going to restaurants. To ensure that she can enjoy these activities it is critical that she is supported by familiar staff and/or her family as staff note: "She loves routine, so you come in on a Monday and it's swimming, multi-sensory... She communicates very well and then going out for her picnics and her social, going to restaurants and that, we are following Yvonne, she's got one favourite restaurant...got to be with people that know her very well."

Yvonne's mother also knows how important routine and familiarity are for her daughter. She also confirms that Yvonne can act out when with unfamiliar staff which can mean she drops her activities: "She goes out for lunch, she loves that and she loves watching horse racing. Anything she likes she gets to do. She really likes her swimming and her walking and her one-to-one. Everything that was set out for her she has achieved. Sometimes on a Sunday she goes out for her dinner and she could go to the Lord Lucan, she goes where staff know her... she can play up a lot if there's more. She's better with one-to-one...not familiar staff she plays up on the staff to get what she wants. ...she wouldn't go for them and she wouldn't walk for them."

An outcome of the PATH meeting was identifying that Yvonne would benefit from one-to-one support. Currently, however, due to funding difficulties Yvonne cannot access this type of resource to support her travel to and from community activities. As her key worker says: "Here she [doesn't have] one-to-one, she's not allocated... she's part of the group of five. That's the only drawback we do have... that is a big thing... so then she has an episode of challenging behaviour...there's no funding at the moment".

Both staff members acknowledge the absence of one-to-one for Yvonne impacts herself and the rest of the group, as her support worker says: "Going out still it's



two staff for her to get her into the community for social integration... when we go out it's usually she'd have another staff around."

An especially encouraging factor for Yvonne successfully meeting her PATH goals is the solid working relationship that has been nurtured over the years between everyone who supports her; from her mother and the staff, and between the staff members themselves. Her mother is pleased that staff keep her up to date with everything that is happening in her daughter's life, as she says: "They are always in contact with me, you know, the least thing, something is changing or if there's a change with her I'll hear from them straight away...there is great communication...it's brilliant...they are very good." From the staffs' perspective they acknowledge the benefit of regular contact to develop open communication with Yvonne's mother and the team, as her key worker reports: "With Yvonne's mum like really good communication, because I pick up Yvonne in the morning and we have great rapport and familiarity of people... it's when we have unfamiliar is when we have a couple of challenges...also communication handover for Yvonne is very important... it's important to have good communication with staff."

### Next Steps

Currently staff are working towards achieving a new goal to facilitate Yvonne enjoying a new restaurant in the community. Her staff member described the plan they are putting in place: "She loves Chinese and we want to bring her to a Chinese restaurant. So we are going to do a little story, you know take a picture of the restaurant where we are going and step by step to build her up to it."

In planning for Yvonne's future her key worker and her other staff member believe that a move to living in her own apartment would improve her quality of life. When her PATH is next reviewed she wants to include this as a goal, as her staff note: "She wants her own apartment for the next PATH...that should be good." Her staff think that with the appropriate support and choice of location this is an achievable goal for Yvonne: "Think long term that would be maybe living not too far away you know, they would have amenities around even though that's totally different; one thing moving out but for Yvonne you know...connected, not a big journey going to the pool at the weekend... that would be my recommendation if I had to for next year for her".

Reflecting on the PATH process her key worker believes that the implementation of Yvonne's PATH has been overall successful, because her goals were developed and led by Yvonne and supported by staff and family. Her key worker believes a critical downfall in some service users' PATH is not following the individuals' interests and including goals that may be perceived as beyond their reach and not supported by familiar staff, as she reports: "Not putting goals that are not realistic, like putting goals that kind of have people that know her well, having people that wouldn't know them is pointless. We are lucky with Yvonne's PATH; people that knew her really well were at the PATH. So having somebody coming into you tomorrow and going into the PATH meeting wouldn't be realistic."

## Case Study 4: Jim

### Background

Jim is in his mid-60s and has been living in Stewarts since he was an infant. Jim has no family involvement at the moment nor at any time during his life.

### PATH

Jim's PATH process and meeting was completed almost two years ago. He has been living in a community house for the last twenty years. Here he has been supported by the same staff member for almost eighteen years and his current key worker has been with him for the last ten years.

Jim was supported at his PATH meeting by both of these staff members who are extremely familiar with Jim. This case study is based on an interview with the manager of his community house who Jim is very familiar with. Jim also participated in this interview.

The manager of Jim's house, explains that Jim is an individual who is clear about his interests and particularly benefits from one-to-one support as she says: "We know what he likes, what he doesn't like...he loves one-to-one."

While Jim is clear about his interests he struggles with people who are unfamiliar to him. For this reason during the PATH process staff found the pre-PATH stage of the process especially helpful as it encourages a one-to-one session with a familiar staff member. The opportunity to sit with Jim on a one-to-one basis alleviated anxiety that he experiences in larger groups with people that are less familiar to him. His house manager explains the benefit of the pre-PATH process for Jim:

"I mean Jim would've done the pre-PATH with his key worker...it's basically they ask you, you know your interests. What you'd like short term, long term. They ask you all about your friends, your family things like that. Things you like to do, things you want to do. So Jim would be a lot, you know, calmer when he's just on a one-to-one, with people he knows. He knows this is about him, he knows we're talking about him."

### PATH implementation

During this pre-PATH one-to-one time Jim's key worker identified with him his interests such as his affection for animals, especially horses. His house manager explains that through identifying this interest they were able to plan a horse riding activity for him which has become a regular outing for him:

"People would've advocated strongly for him because they'd know his interests. He has a lot of interests in animals...horses and horse riding...he loves horses, he goes to Clonfert for his horse riding... he used to do a day with us from the house and then they started it... that was, that's a big, big thing in his PATH. Like he got his riding boots, his hat, his gear and all that so that was a big, big draw and that's still ongoing."

Another interest of Jim's is music and socialising in the pub with his friends, as she

reports:

“I think he went to maybe a musical, he likes music...pubs, he likes like the Guinness Store House.” “They do all sorts of things; they bring them out for meals...pint, he loves a pint of Guinness...that puts a smile on your face. He goes to the local, the Court Yard or the GAA Club...they know him like you know that they are local.”

A key element of Jim’s PATH is ensuring his one-to-one support to participate in goals specific to his PATH are sustained. For instance, recently he went to the Zoo and Sea Life. These community based outings were arranged especially for Jim because of his love of animals as she explains:

“I think a lot of it was around animals, the Zoo and one-to-ones. He went to Sealife; he loves anything to do with animals... Sealife in Bray that was another big thing. Just going on public transport, trains, buses, all of that to try and integrate him into the community.”

### Next Steps

Looking to the future, Jim’s house manager believes the key to ensuring Jim participates in the community activities he enjoys is ensuring his one-to-one support is sustained for activities specific to his PATH goals. As Jim lives in the community his house manager believes overall his capacity to participate in community activities is better than for people who live on-campus as there are less staff and transport related barriers.

## Case Study 5: Jane

### Background

Jane has been living in Stewart's since she was a young adult. She is now in her late fifties and she shares a bungalow on campus with eight ladies. Jane has a profound intellectual disability and can have episodes of challenging behaviour. She is supported by her key worker who has known her for many years. Jane's family have been a constant support in her life, in particular her brothers; and previously she was supported primarily by her mother until she passed away a number of years ago. This case study is based on interviews with Jane, her key worker and Jane's brother.

### PATH

Both Jane's brother and her key worker believe her PATH meeting was a positive experience. Initially her key worker was reticent that the PATH process would not be applicable for Jane due to the level of ID: "I'd heard of other PATH experiences and I thought this was not going to be relevant to Jane at all...you know with her capacity". However, the pre-PATH stage helped her better understand the process and gave her time to prepare:

"We had an introduction to it with the PATH coordinator, to tell us exactly what the process was going to be. And then we were given an invitation to come over to a meeting, a date for the meeting...gave us time to prepare... we came over then to the meeting and it was, and Jane's brother was there...other girl that supports her was there...we think we did very well."

Jane's brother was satisfied that Jane's interests were taken into account, as he describes:

"We touched on some of her interests along the way, we tried to, we had a kind of brainstorming session to see what does Jane actually really like and what are the simple things in life that makes her happy."

In particular Jane's brother recognises the role he could play in generating ideas about Jane's interests that she enjoyed as a child:

"We did discover a few things and I spoke about her past as I remember home as a child. And then we kind of plotted out her objective for the next couple of years...certainly the simple things that she enjoys doing we should encourage that."

Jane's brother also acknowledges the importance of the pre-PATH process in allowing himself and his family reflect on what would be best for their sister in advance of the formal PATH meeting, as he says:

"I had a brief outline of what was going to [happen] so I was trying to think about it when I was coming up...how I could contribute to it. Overall it was good...one guy he was the leader he was very good...we did draft a kind of PATH card...we touched on some of the interests, how she didn't participate at all but she sat here...she was there, she was present and we were observing her behaviour."

Jane's brother remarks that while his sister was present, she did not play an active

role. Nevertheless, he views her presence as a positive sign. He recognised that she was at ease in the meeting: “She was quite comfortable and normally she wouldn't be able to sit for that period of time, an hour and a half...I were saying Jane do you remember what we did when you were small and she'd say yeah you went swimming in the lake, yeah simple stuff like that.”

Jane's brother recognises the significance of Jane being supported by staff who are very familiar with her:

“They are familiar...the staff that was there that day and she would know Jane inside out...I think it's important those key people are there.”

Similarly, Jane's staff recognise the importance of familiar staff for Jane and how her family in particular are very good at supporting her PATH goals such as visiting the family home: “They were very good with Jane bringing her up and down to the house, so one of the goals was to go down to visit the house only not to stay and we weren't sure how that was going to go but it was okay.”

### PATH Implementation

Some activities that Jane enjoys are visiting the horses in Kilcloon. Her key worker acknowledges the role that the PATH process played in identifying this interest. She especially credits the way in which the questions were asked during the PATH meeting as helpful to tease out simple ways to realise her goals:

“Then when we sat down and actually did it you could see where there were things that you know are relevant to her and to make her life a bit better...you think back the horse riding it's not going to work but the question would be does Jane like horse riding...she likes horses...she likes to see horses and she had been up to Kilcloon so maybe the next step would be will we try and see if she'll sit on a horse...the way the questions were put to us.”

Jane's key worker also mentions Jane's interest in beauty treatments and activities, such as going to a salon, are part of her PATH. Essential to enabling this activity for Jane is for her to be supported by two familiar staff members to reduce the risk of an episode of behaviours that challenge: “She had things like beauty...she used to go to the hairdressers, that had stopped because of her behaviour so that was a goal that we said we'd try with two staff...put on a happier face.”

Due to Jane's challenging behaviour two staff are required to support her in community activities. This is often not possible as sufficient staff resources are not always available, as Jane's key worker explains:

“Trying to get other people and its two staff that have to go with Jane to do things...we definitely need more staff because it's not just Jane, it's everybody is trying to do the same thing. Everybody is on the same path of trying to do PATH, to try to get you know goals achieved or even to start them off so you just need staff. And we are always going around saying are you on that day, or are you on that day, so that you can help out or if they have to go somewhere.”

Jane's key worker believes that this challenge of restrictions to staff numbers could

be addressed by having the support of a dedicated staff member to take responsibility for supporting service users complete their PATH goals:

“If we were given the staff to do something with everybody...socialise...if they gave us another, an actual staff to focus in on the PATH well it would be great, like a PATH staff...that person is there just to focus in on Jane say this week or another girl next week...it can be actually planned well in advance.”

Jane’s key worker believes that having a dedicated staff member to support service users complete their PATH goals would have a direct impact on enabling service users engage in more activities: “We definitely would have more activities.”

Jane’s key worker reported that even when a social activity has been planned well in advance and the staff are available to support the service user, a reoccurring organisational challenge is the availability and communication about transport. She describes several times when she had organised transport for an outing for Jane and other service users and at the time it was unavailable:

“In the end we’ve no transport and we can’t get buses, trying to book buses in advance is a disaster...well when you go to book them and somebody else has gone off with the bus or it’s off the road... just silly things...we could have got so much more done with the bus because I had to cancel.”

### Next Steps

Planning for Jane’s future, her key worker would like for Jane to have more opportunities to socialise and to go to the Stewart’s holiday home in the west of Ireland. As she says: “Getting out and a bit of socialising and we want to do a holiday to Kinvara that’s going to be one of the ones (PATH goals) before the end of the year...Jane hasn’t been there yet so we are going to try and bring Jane...on holiday.”

From Jane’s brother’s perspective he acknowledges that Jane’s challenging behaviour can be a barrier for staff and family to involve Jane in community activities. As he explains: “her mood can be a bit erratic now so they said they’ve tried to bring her to Liffey Valley but she’s just been too difficult and bringing her to the cinema has proved difficult too.”

Jane’s brother acknowledges the importance he feels of revisiting Jane’s PATH to assess whether certain aspects are still appropriate. Looking to the future, Jane’s key worker notes that one of her goals identified in the PATH meeting was for Jane to live in her own house with support in the community: “We could see her living in a house, not on her own but I mean outside of here...with lots of support...that is a goal on her PATH.”

## Case Study 6: John

### Background

John is in his late 50s, and has been in Stewarts services since he was a child. John's PATH was supported by his sister and his residence staff. John lives with six other men in a two-storey house in Stewart's campus. He has profound intellectual disability and does not have verbal communication skills. The staff member who participated in this study has known John for many years. However, she was not present at his PATH meeting.

### PATH

Due to staff turnover John was not at ease during the meeting and his key worker neither knew him well nor was familiar with the PATH process as he had not received pre-PATH training. This meant that John did not partake in the pre-PATH process. The PATH meeting was attended by his new key worker who had only known him two weeks at that time and his sister. His PATH took place over eighteen months ago. In the last two years John has had several different key workers supporting him. John is a person who has significant challenging behaviours. John typically is more at ease within his own environment in the house. On the day of the PATH meeting his sister described how John became uncomfortable and agitated out of this familiar environment. While his family are regular visitors they do not bring John home as they believe he is more at ease at his house in Stewarts.

For John leaving his house to participate in the PATH meeting in the main building was in itself a challenge, as his sister described:

"I got a call from Stewarts to say that John was part of the PATH programme...he had to be present and a family member to draw up a kind of plan for him...I met him in the house and we went over, I can't remember the name of the staff...in the house were with him. Basically they explained what PATH was and aims of it, you know, and objectives of it. But for the whole duration of it John was agitated. I understand as the plan was for him that is why they wanted him there but it just didn't work out like that. To be honest he was extremely agitated so we kind of stopped it."

John's staff confirmed that the PATH meeting posed a difficulty for John as his key worker had barely started supporting him and was unfamiliar with the best means to ensure he was at ease, as she explains:

"...he was only here two weeks when he got him, and then he left. So he didn't know him at all when he brought him over for the PATH meeting... he only knew him a couple of weeks... he brought him over, he didn't bring any tea with him and he was smacking his head off the table, we had to stop the PATH and they had to stop, it had to be finished off over here."

His sister agrees that her brother's behaviour and quality of life is impacted by changing staff and he requires consistent familiar staff, otherwise activities such as bus outings that were identified in his PATH are not feasible for him: "There seems to be



a lot of agency staff as well this weather and that makes life more difficult for John...I suppose he can't communicate and if John is upset the only way I suppose he communicates is he bangs his head or he just gets upset and that is more obvious and a regular team, a consistent team will tell you that...they are not familiar faces...he is really upset... if he's upset there's no way and there aren't regular staff you know, he is not going to get out in the wheelchair, they are not probably going to bring him on a bus if there's a bus trip if the full-time staff are not there, probably have to cancel...I know when you are dealing with vulnerable you have to have consistent people."

### PATH Implementation

Given John's difficulty with unfamiliar staff, going on bus outings have been curtailed. The reason for stopping these outings is connected to John's challenging behaviour which involves knocking his head against the bus window when he is anxious. Recently there had been a decision by HIQA to withhold using protective headgear as it was perceived a violation of his human rights. Nevertheless, both his family, his sister and her siblings and his staff believe John would benefit from using this protective headgear. Firstly as a safety measure to reduce the impact of the knocks he is taking to his head and also to enable him to resume social activities. Currently the family are awaiting the decision on whether the protective headgear can be used again. His sister felt that the PATH meeting facilitated an opportunity to voice her concerns about this measure. She praises the support from staff and appreciates the strong communication both between herself and her siblings and the team at Stewarts as she remarks:

"I'm really lucky my sister and brother are just great and the three of us are on the same kind of mind when it comes to John, so like if there is something annoying one it will filter through to the other two...like the headgear HIQA rule...in fairness I have to say the team they are great...they have been fantastic, like if we have a problem...there's no difficulty in ringing one of them now."

John's sister believes the PATH meeting was a good opportunity to think of activities based on John's abilities that he could enjoy as she describes:

"We were trying to think over the years myself and his key worker things that we knew he liked. I know he likes getting his hands, he used to always like getting hand cream on and stuff like that and a massage. ...and decorated for his own things and personal belongings... ...it was an opportunity I felt to voice that."

Other goals that were included in his PATH involved having his own bedroom and decorating it. These goals have been achieved with the support of staff. With regards to the goal to decorate his room his sister was very pleased as she felt that it was a tangible outcome of the PATH meeting, as initially she was hesitant that it would be a tick-box exercise as she describes:

"I just had a feeling at the time it was going to be a paper exercise; it was another you know box ticked. I wasn't sure or to be honest; I wasn't even that optimistic about anything tangible coming out of it... John liked his feet being rubbed and his



hands and I know that his current keyworker does that with the oils. And he has a foot spa...he has his own bedroom...it is fantastic and he has his family photographs, we have been able to then you know I suppose feel part of it because it's always they are letting us, not that we haven't...we could then all of a sudden buy stuff or maybe the lights went on in our head I don't know as a family."

His staff members also acknowledged some positive outcomes from his PATH. "We have foot spas, he likes that. He'll let you do a hand massage as well and all that."

Recently John has got a wheelchair. This has meant that he can now be taken for walks around the campus and sometimes down to the Palmerstown House and out shopping. His sister is pleased that he is having the opportunity to leave the residence:

"I know from the team that they tell me John goes, I think they go down is it the Palmerstown House; John has got a wheelchair in recent years which means he was never great at the walking...when the wheelchair came in here that has improved the mobility. So he gets down there, they bring him to the cinema, he gets over to Liffey Valley and they bring him for his clothes and that. So to me that is out of those four walls...it's something else for him to see...how much of it he takes in I don't know but it has to be better than four walls at the end of the day."

The staff member believes the PATH process would benefit from a handover procedure where new key workers receive the PATH training with the PATH coordinator prior to supporting the individual:

"There's been so many people taking over his PATH that should be clarified...the girl who is doing it with him now has never met the PATH coordinator and has never done anything, where she came in and she really is blind... I don't think there's understanding...when it was passed onto the next person... say okay you are his key worker now you are to look after the plan but that was it...somebody should have sat down and said well okay so what's been done, well then okay why don't you try and do the next one and the next few weeks with John we can come back and we'll see, that support isn't there...if anybody leaves the person that should be able to come in and sit down in front of the progress notes."

She believes it would instil a full understanding of the process and enthusiasm to support the individual. Otherwise understanding the significance of the individual's goals are likely to be lost on staff:

"They are asking him about what does he like, and as you are saying it she's drawing it in, so you really feel you are a part of it...she missed that so she just sees a chair, an arm chair but she doesn't understand that if somebody said well it would be great if I had his own recliner in his room...if she was never there with the PATH coordinator in the beginning and explained.. it was brilliant...so I think that's what would help...he would have had a better quality if he had the one or if the information had of been passed on better or something like that...should be an assurance around...it all...when people leave a new person takes over. They don't understand the importance of it really...they should go over and do a little course for an hour or two..."

At the house where John lives the team organise music entertainment on a regular basis at their house. The staff notice that John enjoys this activity; however, they also recognise that he may benefit from living in a bungalow which may facilitate access to more social activities.

Looking to the future, both John's family and staff believe the most critical factor to support John with his PATH is having support from familiar staff as much as possible, to avoid triggering the challenging behaviour which severely limits his capacity to participate in any types of social activities.

## Case Study 7: Maeve

### Background

Maeve is in her mid-forties. She has Down syndrome. She has been using Stewarts services since she was a child. She currently lives in a shared house in the community and attends day services. This case study about Maeve's PATH experience has been developed from an interview with Maeve and her brother and sister, and a separate interview with her day service key worker. While Maeve has limited verbal communication skills she can let people know her likes and dislikes by non-verbal actions and occasional words.

### PATH

Maeve's PATH was created two years ago. Both her family and staff who participated in this interview believe her PATH was a positive experience for all involved. From her family's perspective it was carried out in a professional way. All staff who support Maeve were present, this included staff from her house and staff from the day services and the PATH coordinator; as her sister describes:

"It was all very professional. Anyone that was involved with Maeve was there ..., her key worker, the girl from the house... the coordinator of PATH...it was sitting around a table and Maeve was there and they talked about what they felt would benefit Maeve... loves to do all her activities like her swimming, her dancing is a big thing. Music, anything to do with music and she's always been like that."

From her key worker's perspective, the PATH programme provides a structure to guide setting and achieving service users' goals: "We do follow the PATH as in weekly you know goals...we try to adhere to a structure that would be PATH based... it helps with that".

As she has been supporting Maeve for many years, her key worker is very familiar with Maeve's interests and her nature. She believes that the process was as person-centred as it could be for Maeve given her communication capabilities:

"I can tell you about Maeve's plan...we say before her PATH like she was a service user who you know would know what she liked, although she's non-verbal from her records we know she's verbal but she chooses not to speak...Maeve is very much an individual who likes what she likes and...what she doesn't like. So she's not difficult to communicate with because she won't do what she doesn't like... she can understand you when you are talking to her, she just responds in whatever way she chooses it might be. A one word or it might be whatever way, but you will understand."

### PATH Implementation

At her PATH meeting both Maeve's staff and her family cooperated in identifying activities that interested her. Maeve could let the group know whether these activities were genuinely of interest to her. Since her PATH meeting her staff recognise that life has improved for Maeve, as her key worker comments: "Since she

did her PATH things have kind of improved an awful lot for Maeve. Like what she loves is sports; she loves swimming, she loves basketball, she loves any contact sports. She is very coordinated...when she came to us first she used to cry a lot, she has actually become much more content.”

During the PATH meeting the family felt that they were included and that staff were particularly interested in their views about Maeve’s childhood interests, as her sister comments:

“They welcome any comments ... I suppose the thing they wanted to emphasise really was what she was like from a child...what she liked or interested ...and music was always a thing in her life... she always liked to dance all that sort of thing.”

At her PATH meeting Maeve’s staff suggested that she would enjoy opportunities to participate in more social activities and her family were encouraged to support Maeve achieve these goals. A particular outcome from the meeting was the decision to try to organise more community outings and family holidays that were specifically tailored to what Maeve would enjoy as her keyworker describes:

“We suggested at the PATH...she has a load of activities now but she hadn’t as many at that stage, and what we came up with was as people talked, and as her sister I kind of looked at her family a bit, you know just being one you can bring Maeve loves going to the shops ...somebody who would be ecstatic if they got small things...she just wants you know to be going out more regularly. So the suggestion was made at her PATH that she go to Euro Disney.”

Maeve’s family found collaborating with Maeve’s staff to identify the specific activities that she could enjoy and making a concrete plan to action these goals most helpful. For example as a result of the PATH meeting they planned a special family holiday which they all enjoyed, as they comment:

“There was the thing about Disneyland. Now my brother has actually taken her to Disneyland...so she had a lovely weekend (Sister)...we had a fabulous time (Brother)...that was one of her goals. (Sister)”

While the holiday was a great success, Maeve’s family recognise that they could play a more significant role in enabling Maeve to participate in activities in the community. This view is also supported by Maeve’s key worker, who comments: “At the PATH so what we wanted for Maeve was to get out more.... ...I mean she is a pleasure, I wish she would kind of get out more... it’s a very sensitive area because you can’t suggest...people will automatically get defensive.”

From the family’s perspective, her brother acknowledges that they could potentially do more to enable their sister’s social engagement outside of the services:

“Maybe we need to push as a family now and again. I’d say it’s probably fair to say just go along to things, we rarely do, but we tend to just pick her up at the house take her out for the day and bring her back again. Sometimes a half day...what we do at the moment....I feel sometimes I should be doing more...going out she loves.”

## Next Steps

Planning for the individual's future is a component of the PATH process. Maeve's family were impressed with how this was carefully considered within the PATH meeting, as her sister comments:

"I thought it was all very well done, very well thought out you know, they were really telling us you know what their plan, like why they do this. It's kind of so they have something to work on you know, I suppose it's like everything else if you have a strategy in place it's easier to work towards something...if you are given something to work forward, planning for their lives."

In terms of future plans, their family appreciate the staffs' proactiveness in coming up with ideas for social activities, as her brother says: "The lady in her house is her special...she'd be very definite about things...which is good. I mean we probably need that...some new ideas perhaps... because you might like to go to a show or something, a musical show...the Bord Gais or something...she loves music, she knew many of the songs...that would be fantastic. Andrea Rieu, she loves him...yeah we should do something like that for her birthday...see what's coming up and book it."

Her brother and sister are acutely aware that they could support Maeve enjoy activities outside Stewarts more frequently and try different activities and they welcome staff suggestions, as they both say: "Maybe I could be doing a bit more...I certainly think I could do more... if the house had ideas of where she would like to go for a day or something that we could take her or something like that, and just give us a ring and say Maeve would love to go...so we could take her with the family or something... because we don't do an awful lot we tend to just do the normal regular...it only happens every six, four or five weeks it's not great...if they had ideas in the house...a concert or a show or something like that... we could probably do better."

It is clear that her family are keen to enable Maeve participate more in the community. They are however looking to the service for direction in this regard. From the staff perspective, her key worker sees it is for her family to think of a goal for her, which is in contrast to their thinking to look to staff for suggestions, as her key worker says: "I was just saying if we had one big goal on like her last big goal was Euro Disney and it was achieved, you know; so maybe for her family to think of a goal for her...let's do it again."

Overall the PATH process has resulted in positive outcomes for Maeve. For her family it has also prompted them to consider and create, in cooperation with her staff, new opportunities for Maeve to participate in social activities in the community.

## Interpretation of Case Studies

Following from the seven individual case studies presented in the preceding sections, here we will synthesise findings from these individual cases to identify key findings and overarching themes that have emerged as important to PATH within Stewarts. These are organised under the broad headings of:

1. Enablers – what helps person-centred planning/PATH, and
2. Challenges – what hinders person-centred planning/PATH.

### Enablers: What helps person-centred planning (PATH)

Analysis of the case studies reveals five key facilitators that support a successful PATH process from development through to implementation.

#### (i) Familiar staff

The most important factor in the success of PATH was having familiar staff. All seven case studies illustrated this as the vital factor in the PATH process and in success with community integration goal attainment. At the heart of PATH is facilitating service users to voice their own views, thoughts and feelings about the goals they have for their own lives. An authentic person-centred process was achieved when staff who were familiar with and to the service user were involved in the process, including facilitating better communication of the service user's views and wishes, as evidenced in the experiences presented in six out of the seven case studies including Harry, Maeve, Yvonne, Jane, Jim and Liam.

Support from familiar staff is key throughout all stages in person-centred planning. From the initial pre PATH pathing, as illustrated in Harry's PATH where his support worker knew his temperament and routine so well he identified the most suitable time to discuss the process and identify his goals. For the PATH meeting itself, John's case study demonstrated poorer outcomes when an unfamiliar staff is present who is unaware of the individual. The huge importance of knowing the person over a long period of time was best illustrated in Yvonne's PATH process where she was supported throughout her PATH process from the pre PATH goal identification stage, to the official meeting to reviewing her progress by a key worker who has supported her for several years. As a result, progress in Yvonne's behaviours that challenge was reported and achievements in her social integration goals such as going to local restaurants.

#### (ii) Preparation for PATH

The case studies demonstrated that the pre-PATH process was essential in adequately preparing the planning itself. As outlined in the introductory section of this report it involved sending a pre-PATH questionnaire to the individual's key worker and family. Staff participants noted that training provided useful insights into practical ways of working with service users and preparing individuals for the process. Training is not offered to families but this may be something to consider for the future. The practical and accessible approach taken in the training session also

helped to dispel many doubts and reservations that staff may have had about the process. The lead-in time allowed time for staff to learn about the process, including how they could best support service users to identify their goals and to map how they could achieve them, in particular community integration goals, with support from family and familiar staff. This was demonstrated in six out of seven cases including Harry, Liam, Jane, Maeve, Yvonne and Jim. A good lead-in to the PATH meeting was seen as important in giving adequate time (i.e. weeks and months) to discuss the process with service users, which was helped by staff being familiar with the individual including important factors such as their personality, their routine, or any behavioural issues. The case studies also highlighted the collaborative role that family could potentially play in this preparation phase, which may ultimately support better understanding and fulfilment of service users' goals.

### (iii) Communication and sharing information

The case studies demonstrated that good communication between the person, staff and families was important to success in the PATH process, and that the recording and sharing of information was central. The PATH process encourages support staff to record daily activities with services users and goals as they are met. For example, in Yvonne's case, her key worker and other members of staff noted that recording activities and achievements in this manner is a valuable activity to document the PATH goals as they are achieved. It is critical that this information is then shared with and communicated to the individual, other staff and the individual's family. Evidence of good communication and sharing information practices were noted in all case studies.

### (iv) Family involvement

Strong communication between staff and family (where available and/or present) was shown throughout the case studies to help with every aspect of the PATH process, but was especially important in supporting the achievement of community integration goals. Only one participant (Jim) had no family support at all as he had been brought to Stewarts as a baby. Varying degrees of family involvement were reported, but better community integration and social inclusion outcomes were achieved when family assumed more responsibility in supporting their loved one to participate in social activities outside services. For example, in Harry's case, his sister was heavily involved with him and was very proactive (e.g. literacy class); with the majority of Harry's social goals being enabled through her involvement (e.g. bowling, regular holidays). While Maeve's family were involved in her PATH they were less proactive in supporting her community participation, but expressed an awareness of their own responsibility to support new social activities for their sister with guidance from staff. In Jane's case, her brothers were involved but more remotely, relying more on the staff to facilitate social inclusion activities where possible. While John's support worker reported good relationships with his family and this was corroborated by his family, it was noted that they have never brought John out socially. Liam's family have provided steadfast support to him throughout his life and were actively involved in supporting his social goals and PATH development. With the onset of his dementia they feel less equipped to maintain these activities and home visits have been

reduced. For Jim, who was brought into Stewarts Care services, his very familiar long standing support staff expressed feeling like family to Jim. In the absence of family, Jim's key worker supported him to develop his PATH plan, and his love for animals was identified and his person-centred social integration goals such as visits to the zoo and SeaWorld were developed and achieved.

#### (v) Activity planning

The case studies highlighted the importance of preparation and planning specifically with regard to new activities identified as goals within the PATH process. A number of key factors were identified as important in this including adequate lead-in time for introducing any new activity. The example of Yvonne's new activity of going to a new restaurant illustrates what may be required – where she was prepared for her new activity by first being familiarised with the restaurant using a photograph and was incrementally built up to the new activity through smaller, more manageable steps. This was also seen in the cases of Liam and Harry. Setting realistic and achievable goals was also identified as an important factor in planning new activities and setting PATH goals. For this, again, it was seen as critical to have staff who were familiar with the service user and knew what may or may not be achievable for the individual. In cases where activities were not carefully planned, and/or carried out with unfamiliar staff, service users were more vulnerable to episodes of challenging behaviour, as reported in the cases of Jane, John and Yvonne. Evidence of careful planning in advance of social activities was present in six out of the seven case studies.

### Challenges: What hinders person-centred planning (PATH)

The case studies illustrated many positive examples of PATH achieving community integration goals, and a positive impact overall. At the same time, some important challenges or potential barriers to the achievement of PATH goals were also identified, some of which represent the flip-side to enablers mentioned above.

#### (i) Unfamiliar staff

Whereas familiar staff was identified in the case studies as the most important enabler of PATH success, a difficulty arises in this regard when staff without an adequate knowledge and familiarity of the service user play a central role in the PATH process. This was a particular concern when there was turnover of key workers. Participants suggested that the more the staff know the person, the better the chance of developing attainable community goals and sticking with them. Unfamiliar staff in some cases appeared to be a trigger for behaviour that challenges, curtailing social and community activities particularly when agency staff were used.

#### (ii) Staffing resources

From the evidence of the case studies lack of staffing resources may become a barrier to implementing PATH social and community goals. Examples of this were seen in the case studies of Harry, whose restaurant activity was stopped, and Jane,



where her keyworker believed that having a dedicated staff member with the sole remit to support service users complete their PATH social inclusion goals would enable service users engage in more activities. No data was gathered on the availability of additional staffing to meet these goals but families and staff themselves reported that this was usually because there was not funding available for such additional resources.

Lack of funding specifically for one-to-one support for individuals was raised by staff and families as impacting the achievement of some community integration PATH goals. For example, in Yvonne's case, she needed access to one-to-one support to utilize transport to participate in community activities. Similarly, for Jane some social activities were cancelled because of the need for one-to-one support.

### (iii) [Access to transport](#)

The practical issue of access to transport was also identified in the case studies as a barrier to achieving PATH community access goals. For example, Jane had difficulties when a booking issue arose despite support staff being in place. Change in health circumstances (e.g. dementia)

Finally, health was identified in the data analysis as a potential barrier to PATH implementation for a minority of service users. The case studies demonstrated how this may occur in practice, specifically where the changing health of service users may seriously impair their capacity particularly for social and community activities – as illustrated in the case with Liam.

Although there were barriers and challenges, it is important to note again the high levels found of goal achievement and satisfaction among individuals, their families and staff.

## Discussion of Findings

Policy developments relating to people with intellectual disabilities in recent years in Ireland have prioritised community living and integration alongside a support service infrastructure that places the individual at the centre. These recent developments have aligned Ireland more with the intent of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), particularly with regard to deinstitutionalisation policy (Health Service Executive 2011) and a shift towards more individualised and integrated service provision (Department of Health, 2012; Health Service Executive, 2012). In this context, person-centred planning has been recognised as a potential mechanism for advancing community integration (Bigby and Knox 2009; Beadle-Brown, 2006; Robertson et al., 2006).

This study aimed to assess the impact that person-centred planning has had on the community integration of adults with an intellectual disability by examining the experiences of implementing the PATH approach to PCP at Stewarts Care. A particular focus for the study was the experiences and outcomes of PATH in this regard for people with severe-profound ID. The study approach to this included analysis of secondary data from Stewarts on the PATH process of 169 of their service users, and qualitative case studies compiled for seven individuals with severe-profound ID within the service.

## Community Integration and Segregated Activities

The statistical analysis of PATH data presented in chapter 3 of the report highlighted a number of key findings. Principally, the analysis identified that community integration is a strong focus of individuals engaged in person-centred planning within Stewarts, with goals of this nature included in the majority of service users' PATHs. Among these goals were a range of social activities planned in the integrated environment of individuals' local communities. They also included holidays that were planned in integrated destinations including mainstream hotels and locations and activities amongst the general community. And there were also a range of other PATH goals which had potential for community integration; these included goals of personal independence and development, employment and relationships. These aims of community integration were also reflected in the case studies presented in chapter 4, many of which included PATH goals of activities planned for the individual's local community. So we can say from the analysis of both PATH and case study data that community integration is certainly an aim which is embedded in the PATH goals of service users in Stewarts. This reflects previous studies where social and community inclusion goals were a key aspect of person-centred planning (Claes et al., 2010; McConkey and Collins, 2010; Mirza and Hammel, 2009; Robertson et al., 2006).

The statistical analysis also showed that the PATHs of many service users also included a range of social participation goals being planned within the environs of the organisation and its satellite facilities including the service's holiday home. The data revealed that more people in the sample had on-campus social participation goals

than had social goals within a community context. When we examined differences within the sample, we found that people with severe-profound ID were more likely to plan on-campus social activities than integrated community activities; were more likely to plan a segregated holiday than an integrated holiday; and were less likely than people with mild-moderate ID to plan either an integrated community activity or holiday.

This finding may reflect a tendency by support staff to plan activities for people with more complex needs including behavioural issues in a more controlled and predictable environment, such as that offered within the service's own facilities. This is supported in case studies where challenges and difficulties involved in implementing even simple goals of community integration for individuals with severe-profound ID and complex support needs, were reported by some staff.

### Integration Challenges for People with Complex Needs

There is perhaps a natural inclination to limit community activities based on safety considerations and practicalities of logistics including transport and other facilities, lack of one-to-one support, and lack of involvement by family in both planning and implementing PATH goals. These are all issues that were highlighted in some case studies as real challenges and barriers to implementing PATH goals of community integration. This experience is one that is reflected in the literature which consistently shows that people with greater and more complex support needs such as those with severe-profound ID are less likely to be involved in community activities and less likely to be involved in the wider community in general (McCausland et al., 2017, Overmars-Marx et al., 2014, Verdonschot et al., 2009). Furthermore, it was also evident in the PCP literature which previously found particular challenges in person-centred planning for people with more severe ID and associated communication and behavioural difficulties (Claes et al., 2010). Nevertheless it is acknowledged that in the seven case studies developed here there were many examples of community integration goals achieved, such as regular family holidays, community employment goals and social activities. Some success was supported by families and in other cases staff were the primary supports. Often it is the smaller things in life that make a critical difference in the quality of life experienced and future work should look at the relationship between resources available, activities desired and the quality of life improvements experienced. The reality that some people with ID do not have family members to assist also encourages greater attention to increasing other informal supports and better understanding of how staff may advance engagement beyond their organization.

The literature also supports a specific finding from the current study that PATH barriers related to organisational or structural factors impact more on service users with severe-profound ID. In the quantitative findings, service users with severe-profound ID reported more than double the rate of organisational barriers as compared to service users with mild-moderate ID. This is supported by the literature which identifies that there is a multi-factorial basis to community

participation rather than simplistic explanations based solely on individual factors such as level of ID (Kozma et al., 2009; Mansell and Beadle-Brown, 2009; Chowdhury and Benson, 2011).

The findings from both the statistical analysis and the case studies here suggest that PATH/PCP goals of community integration for people with severe-profound ID require additional supports if this particular cohort of adults with ID are to improve their community integration through this person-centred approach. These additional supports should include adequate staffing levels to support activities, one-to-one supports to facilitate individual goals, consistent and familiar staff, and family involvement, if available, in implementing goals. More generally policy and funding decisions for ID services must be re-examined to determine if they are designed to support the resources that will best assure achievement of PATH/PCP goals

### The PATH Process

Another factor to emerge in the implementation also relates back to PATH goal development. There was a need expressed in several case studies, largely by support staff, for PATH goals for people with complex needs to be 'realistic' and 'achievable', and in this respect to reflect the capacity of the individual with ID and the knowledge that staff and family have who are familiar with the individual's capacity and available resources. This is an idea that is supported by some of the literature (Holburn and Cea, 2007). Conversely, the very goals of person-centred planning (including PATH), include 'dreaming big' and having a long-term 'vision' to aspire being at the heart of these approaches to individual planning. There appears to be a tension between ideal aspirations of person-centred planning on one hand, and the practical realities of trying to implement goals with limited resources and difficult support challenges. Yet rooting PATH goals in what is practical and achievable may also undermine the underlying ambition of person-centred planning by limiting the horizons of individuals to what others feel may be achieved. There was evidence here of staff and the organization being willing to support "dream big" despite challenges around the resources needed but some staff still struggled.

This raises a critical aspect of person-centred planning highlighted throughout the case studies; the importance of PATH training for staff including pre-PATH training, and in particular for new staff coming into the organisation to support individuals who may have already developed their PATH. Within Stewarts many staff praised the initial training and found this to be of great use, but there was less awareness of and a desire for ongoing training once this initial training was completed, and for continuing training of new staff. Building further on the good initial training that is in place would be of great benefit to the PATH process within the organisation, reminding service users and staff to 'dream big' while also managing the practical challenges inherent to implementing PATH goals of community integration.

### Family Involvement

Family involvement in the PATH process was voluntary. A wide disparity in levels of

engagement and capacities to create opportunities for social inclusion for their loved ones was reported in the case studies and probably reflected differential availability of family members and different histories of involvement. The research suggests that regular feedback to families about individuals' progress with their PATH goals, and suggestions for trying new activities, may help to motivate families to take a more proactive role in supporting more meaningful social participation in the community.

Other research also highlighted the benefits generally to social activity of regular contact with family (Bigby, 2008; McCausland, 2016). Families, themselves often challenged by other responsibilities may nevertheless be an especially important resource in a context of restricted resources following economic recession and cut-backs throughout the last decade (Department of Health, 2012, Dolan, 2016). The Study Advisory Group highlighted a local initiative in one part of the organisation designed to engage families more in PATH. The organisation has implemented six-monthly meetings with the available family of all service users; and one manager noted that the simple step of adding PATH to the agenda of these meetings has helped to bring PATH more to their attention. More and similar initiatives may better harness the potential resource of families for achieving better community integration through PATH.

## Conclusions & Recommendations

This study aimed to assess the impact of person-centred planning on the community integration of adults with an intellectual disability, and particularly for those with severe-profound levels of ID. From the preceding analysis of quantitative and qualitative data collected from individuals with ID, family members and Stewart's staff, we propose a number of conclusions and recommendations.

It is clear from the study that community integration is embedded in PATH planning and development within the organisation, being present as goals with the PATHs of a majority of service users. The analysis also shows that the vast majority of PATH goals are successfully achieved, which is very positive. However, further to the idea of 'dreaming big', achievement alone should be taken in the context of specific goals, and whether individuals are being supported to challenge themselves and expand their horizons through PCP, even if this runs the risk of falling short sometimes. The willingness of Stewarts Services and its staff to dream big may also explain why some of the challenges experienced occurred.

There is a lower rate of goal achievement for people with severe-profound ID than for those with less severe ID; but this group still achieved most of the person-centred goals that were planned in their PATHs. While the statistical data does not facilitate analysis of goal achievement by goal type (such as community integration goals achieved), the case studies confirmed that people with severe-profound ID largely had good outcomes and achieved community integration with PATH albeit in some cases this was infrequent and at a low participation level.

However, for some, challenges exist within the process of PATH goal development and implementation, particularly for the group with the most complex needs including significant behavioural and communication difficulties. The study found that these challenges act to restrict or inhibit the potential for community integration within PATH. Some of the challenges identified related to the individual but others related to organisational or structural factors including having familiar staff, adequate staffing levels and the organisation itself. A lack of family involvement in PATH planning and implementation was also highlighted, despite efforts to include family. Again it should be remembered that some individuals did not have family and no data was collected on the other responsibilities families were addressing. Given the benefits that accrued when family were involved, this is still a significant gap in the personal resources available to many individuals.

There is also a challenge that emerges as a consequence of the lack of resources, and the need identified by staff within the study for PATH goals to be realistic and achievable. While this is an understandable aim in the current circumstances, this may also act to inhibit the ambition for community integration within the PATH goals of service users, when person-centred planning should aspire to achieve great things for individuals. This is especially a risk for people with more complex needs including severe-profound ID, behavioural challenges and communication challenges. The tension between ideal aspirations of person-centred and the practical realities of supporting individuals with complex needs is a very difficult one for support staff to

resolve.

Based on these conclusions, this report makes the following recommendations for future implementation of PATH within Stewarts, and for the broader policy and practice of person-centred planning:

### Staff and Family Supports

- (i) More staffing, including where needed, one-on-one supports and maintenance of familiar staffing, may be needed to better support individualised goal achievement for individuals with severe-profound ID and complex support needs. Achievement of this goal will be further enhanced by organisational practices that may increase retention of familiar staff. A periodic review of organisational policies to maintain regular and familiar staff is recommended.

At a broader level, policy and practice needs to recognise that personalised or individualised approaches to support people with severe-profound ID and complex support needs is more costly than group-based activities. Additional staffing and other resources are needed to support community integration for this cohort of people using this person-centred approaches.

- (ii) Greater family outreach to increase involvement with their loved one where possible may be an important resource to support the development and achievement of person-centred goals of community integration.

Natural supports are recognised in policy as an important resource for people with an intellectual disability. In the current climate of funding restrictions, service providers must explore every possible avenue to opening up communication and involvement with families of the people they support.

### The PATH Process

- (iii) Periodic refresher training and embedding PATH within the orientation and induction programme for all new staff will better underpin person-centred planning throughout the organisation.

This is instructive to all service providers that person-centred planning should not be a one-off exercise, but should be integrated into the core business of every organisation, underpinned by ongoing training and development in the ethos and practical application of person-centred planning for the staff who are expected to implement it.

- (iv) Continuing attention is needed to how PATH goals and activities are communicated to all staff who work with an individual so they become embedded and integrated into the everyday support for each individual.

Again, all services should be aware that person-centred planning does not end after a plan has been written on paper. What happens to the plan afterwards,

and how that is incorporated into everyday business of supporting individuals, will in many ways determine the potential success of the initial exercise.

- (v) Periodic formal review of individuals' PATH goals and their implementation should be built into the PATH process, to assess the achievement of goals and to review and maintain their continued relevance for the individual. Reviews should involve the individual, their friends and family, advocates, and support staff. In addition, keyworkers should monitor the achievement and relevance of PATH goals for the individuals they support on an ongoing basis.

Again, Stewarts is to be commended for its continuing commitment to developing and implementing PATHs, seeking to involve families, encouraging and training staff to believe in and pursue with individuals with ID their desired lives, and for a thoughtfulness about the challenges and barriers that make implementation more difficult. More needs to be done and the resource challenges identified here particularly in support for persons with severe and profound ID need to be addressed. This includes work on the best allocation of existing resources as well as on policy and funding processes and mechanisms so that it becomes more possible for services to support individualised PATH specific staffing needs. For persons with severe and profound intellectual disability there is a particular need to examine how to best support both one-on-one staffing and transportation supports. However the benefits of a sustained commitment to person-centred planning are well documented in the experiences here. Given the demonstrated success for this particular cohort of people with more severe/profound level of ID, the potential to benefit for older adults with all levels of ID and in all services is well supported.



Table A.1: PATH Goals

<b>Goal Type</b>	<b>%</b>	<b>n</b>
<b>Personal interest</b>	82.2	139
<b>Social Stewarts</b>	74.6	126
<b>Family</b>	68.0	115
<b>Social community</b>	66.9	113
<b>Personal independence</b>	62.7	106
<b>Holiday</b>	62.1	105
<b>Personal possession</b>	52.7	89
<b>Stewarts holiday</b>	49.7	84
<b>Support</b>	33.7	57
<b>Living arrangements</b>	32.5	55
<b>Personal development</b>	31.4	53
<b>Self-care</b>	29.6	50
<b>Review</b>	28.4	48
<b>Social both</b>	17.8	30
<b>Religion</b>	11.8	20
<b>Employment</b>	11.2	19
<b>Day service</b>	10.7	18
<b>Health</b>	7.1	12
<b>Intimate Relationship</b>	3.6	6

Table A.2: Path Goals by Type of Residence

Type of Goal	Community % (n=61)	Campus % (n=108)	P-value
Personal Interest	77.0	85.2	<i>ns</i>
Social Stewarts	72.1	75.9	<i>ns</i>
Family	55.7	75.0	<i>p&lt;0.01</i>
Social Community	72.1	63.9	<i>ns</i>
Personal Independence	62.3	63.0	<i>ns</i>
Holiday	85.2	49.1	<i>p&lt;0.001</i>
Personal Possession	41.0	59.3	<i>p&lt;0.05</i>
Stewarts Holiday	16.4	68.5	<i>p&lt;0.001</i>
Support	11.5	46.3	<i>p&lt;0.001</i>
Living Arrangements	41.0	27.8	<i>ns</i>
Personal Development	60.7	14.8	<i>p&lt;0.001</i>
Self-care	21.3	34.3	<i>ns</i>
Review	23.0	31.5	<i>ns</i>
Social Both	18.0	17.6	<i>ns</i>
Religion	8.2	13.9	<i>ns</i>
Employment	26.2	2.8	<i>p&lt;0.001</i>
Day Service	14.8	8.3	<i>ns</i>
Health	8.2	6.5	<i>ns</i>
Relationship	8.2	0.9	<i>p&lt;0.05</i>

Table A.3: PATH Goals by Level of ID

Type of Goal	Mild- Moderate % (n=53)	Severe- Profound % (n=114)	P-value
Personal Interest	81.1	82.5	<i>ns</i>
Social Stewarts	66.0	78.1	<i>ns</i>
Family	56.6	73.4	$p < 0.05$
Social Community	71.7	64.9	<i>ns</i>
Personal Independence	56.6	64.9	<i>ns</i>
Holiday	79.2	53.5	$p < 0.01$
Personal Possession	45.3	57.0	
Stewarts Holiday	26.4	60.5	$p < 0.001$
Support	9.4	44.7	$p < 0.001$
Living Arrangements	35.8	30.7	<i>ns</i>
Personal Development	64.2	16.7	$p < 0.001$
Self-care	17.0	35.1	$p < 0.05$
Review	28.3	28.9	<i>ns</i>
Social Both	22.6	14.9	<i>ns</i>
Religion	11.3	12.3	<i>ns</i>
Employment	30.2	2.6	$p < 0.001$
Day Service	13.2	9.6	<i>ns</i>
Health	9.4	6.1	<i>ns</i>
Relationship	9.4	0.9	$p < 0.05$

Table A.4: PATH Barriers

Type of Barrier	%	n
<b>Myself</b>	46.7	79
<b>Familiar Staff</b>	30.8	52
<b>Staffing</b>	29.6	50
<b>Stewarts</b>	27.2	46
<b>Health</b>	13.6	23
<b>Family</b>	1.2	2

Table A.5: PATH Barriers by Type of Residence

Type of Barrier	Community % (n=61)	Campus % (n=108)	P-value
<b>Myself</b>	41.0	50.0	<i>ns</i>
<b>Familiar Staff</b>	14.8	39.8	$p < 0.001$
<b>Staffing</b>	16.4	37.0	$p < 0.01$
<b>Stewarts</b>	27.9	26.9	<i>ns</i>
<b>Health</b>	11.5	14.8	<i>ns</i>
<b>Family</b>	3.3	0.0	<i>ns</i>

NS = not statistically significant

Table A.6: PATH Barriers by Level of ID

Type of Barrier	Mild-Moderate % (n=53)	Severe-Profound % (n=114)	P-value
<b>Myself</b>	45.3	46.5	<i>ns</i>
<b>Familiar Staff</b>	15.1	37.7	p<0.01
<b>Staffing</b>	13.2	37.7	p<0.01
<b>Stewarts</b>	15.1	32.5	p<0.05
<b>Health</b>	7.5	16.7	<i>ns</i>
<b>Family</b>	3.8	0.0	<i>ns</i>

NS = not statistically significant

Table A.7: Family Involvement in PATH by Type of Residence

	Community % (n=61)	Campus % (n=108)	P-value
<b>Family Attended PATH</b>	32.8	20.4	<i>ns</i>
<b>Family Viewed PATH</b>	41.7	50.9	<i>ns</i>

NS = not statistically significant

Table A.8: Family Involvement in PATH by Level of ID

	Mild-Moderate % (n=53)	Severe-Profound % (n=114)	P-value
<b>Family Attended PATH</b>	32.1	20.2	<i>ns</i>
<b>Family Viewed PATH</b>	46.2	48.2	<i>ns</i>

NS = not statistically significant

Table A.9: PATH Outcomes by Type of Residence

<b>Outcome</b>	<b>Community μ (n)</b>	<b>Campus μ (n)</b>	<b>P-value</b>
<b>No. of Goals</b>	8.73	8.45	<i>ns</i>
<b>Goals Achieved</b>	7.07	5.90	<i>ns</i>
<b>Goals Not Achieved</b>	1.65	2.33	<i>P&lt;0.05</i>
<b>Actual Barriers</b>	1.30	1.34	<i>ns</i>

NS = not statistically significant

Table A.10: PATH Outcomes by Level of ID

<b>Outcome</b>	<b>Mild- Moderate μ (n=52)</b>	<b>Severe-Profound μ (n=114)</b>	<b>P-value</b>
<b>No. of Goals</b>	9.62	8.10	<i>P&lt;0.05</i>
<b>Goals Achieved</b>	7.65	5.73	<i>P&lt;0.01</i>
<b>Goals Not Achieved</b>	1.73	2.25	<i>ns</i>
<b>Actual Barriers</b>	1.40	1.29	<i>ns</i>

NS = not statistically significant

## Appendix B: Accessible Recruitment Materials



**Trinity  
College  
Dublin**

The University of Dublin



An Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing



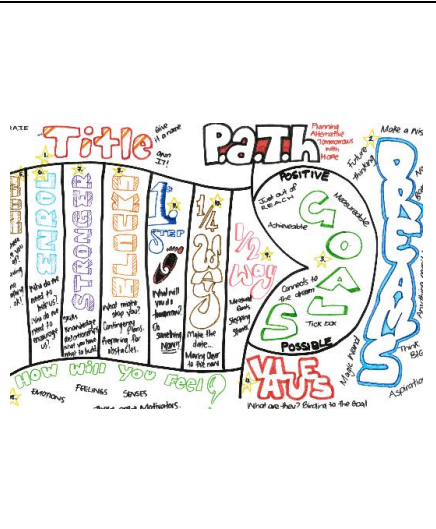
**A Study to Assess the Impact of Person-Centred  
Planning on the Community Integration of Adults  
with an Intellectual Disability**

### **INFORMATION BOOKLET**

Family

**This study is being carried out by the Trinity Centre for  
Ageing and Intellectual Disability (TCAID) at  
Trinity College Dublin**

# 1. What is this study about?



This study is about PATH.

It is about what you and your family did to make a PATH with your relative.

It is about the goals of PATH.

And what happened after the PATH was made.



The study will find out if PATH helps people to have a better life.

And if PATH helps people to be included more in their community.



It will help Stewarts to improve PATH and how they support people.



## 2. Who is taking part in the study?



People with an intellectual disability (ID) who are:

- ✓ Service users of Stewarts Care
- ✓ Aged 18 years and over
- ✓ Have made a PATH



Family members (and friends) of the person with ID who:

- ✓ Helped to make the person's PATH, OR
- ✓ Helped to carry out the person's PATH



Support staff of the person with ID at Stewarts who:

- ✓ Helped to make the person's PATH, OR
- ✓ Helped to carry out the person's PATH

### 3. Who is carrying out the study?



The study will be carried out by researchers from Trinity College Dublin.



The study is linked to the Trinity Centre for Ageing and Intellectual Disability (TCAID) and the IDS-TILDA study.

## 4. What will I be asked to do?



Your family members including your relative with ID will meet the researcher.

You will be asked about:

- ✓ What you did to help make the PATH
- ✓ What you did to help achieve the goals in the PATH
- ✓ What helped and what did not help to achieve the goals
- ✓ How PATH can improve



You will be asked to sign a consent form to say that:

- ✓ You know what the study is about
- ✓ You are happy to take part in the study
- ✓ You agree that we can use what you tell us in our reports.



We will record the meetings so we have a record of what was said.

We will use these recordings to help us write our study reports.

We will not use the recordings or what you tell us for anything else.

You can ask for a copy of the notes from the recording if you wish.

## 5. Where and when will the study take place?



If you agree to take part in the study, we will arrange to meet you in the next few weeks.

We will arrange a day that suits you.



Each meeting will last no more than one hour.

We will arrange a time that suit you.



Meetings may take place wherever is most convenient for you.

This may be:

- ✓ In your home
- ✓ In Stewarts
- ✓ Any other place you want to meet

## 6. Are there any risks involved?



We do not think there are any risks to you if you take part in the study.

If you become upset during the meeting we will:

- ✓ Stop the meeting if you wish
- ✓ Take a break if you wish
- ✓ Provide you with information about support if you need it



Taking part in the study will not guarantee future services.

Taking part in the study will not affect your current level of service provision.

The researchers have no control over services provided.



We will keep your information private, and we will not use it for anything else.

You will not be named in reports.

Nobody outside the meetings will know what you said.

But we will report any abuse or risk we hear about to the Garda.

## 7. What else do I need to think about?



You need to think about:

- ✓ Are you happy to talk about what you did for PATH?
- ✓ Are you happy to talk about some of the difficulties with PATH?
- ✓ Where would you like to meet the researcher?
- ✓ What day and time would you like to meet the researcher?

## 8. What happens next?



If you want to take part in the study, you can either:

- ✓ Tell the person who gave you this information booklet, OR
- ✓ Contact the researcher yourself



If you agree to take part in the study you will be asked to sign a consent form.

## 9. Who do I contact if I have any questions?



If you have any questions contact the researcher.

You can contact her by phone, email or post.

## 10. Contact details for the study

**Researcher Name**

Phone:

Email:

Write to: PATH Study,  
IDS-TILDA,  
2 Clare Street,  
Dublin 2



**This study is funded by the National Disability Authority**



Údarás Náisiúnta Míchumais  
National Disability Authority

## Appendix C: Case Study Interview Schedule

### 1. Preparation for PATH

- Were you involved in the preparation for [Service User Name] PATH?
  - Tell me about what you did to prepare for PATH
  - How much time/effort did you put into preparation?
  - Was the preparation adequate? Why?
  - Do you think preparation for PATH could be improved? How?

### 2. Creation of PATH / PATH meeting

- Were you involved in [Service User Name] PATH meeting?
  - How many people were at the meeting? Who was involved?
  - Tell me about the process used – how did it start/continue/end?
  - What was your role? What did you do during the meeting?
  - How were goals identified and developed for the PATH? Who proposed them? How were they finalised/agreed?
  - How was [Service User Name] included in the meeting? Do you think this was adequate?
  - Do you think the final PATH was representative of [Service User Name]? Why?
  - Do you think the PATH meeting could be improved? How?

### 3. Implementation of PATH

- Have you been involved in implementing [Service User Name] PATH?
  - What has been your role in implementing his/her PATH?
  - Has [Service User Name] achieved the goals set out in his/her PATH? None/some/all?
  - Tell me about the goals that were achieved.
  - Tell me about the goals that were not achieved.
  - What things helped to achieve the PATH goals?
  - What things hindered the achievement of PATH goals?
  - Have the goals set out in [Service User Name] been changed in any way since the PATH meeting? If yes, what was the process involved in these changes? Was there a formal review of the PATH? Who was involved in deciding these changes?
  - Do you think implementation of PATH could be improved? How?

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