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*A descriptive study of the factors that impact upon occupational performance and engagement for people living with spina bifida and/or hydrocephalus in the Mid-West of Ireland*

## **Abstract**

**Background:** Ireland has one of the highest prevalence of spina bifida (SB) worldwide. Between 2000 and 2012 there were 664 documented cases of SB, or a form of neural tube defect, per 10,000 live births, in the registries of Cork and Kerry, Dublin, Galway and the South East of Ireland. Furthermore, in the same time frame, and within the same registries, 113 cases of hydrocephalus were reported per 10,000 live births (EUROCAT, 2012).

**Objectives:** This study investigated the factors that impact occupational performance and engagement among people with SB and/or hydrocephalus, living in the Mid-West of Ireland.

**Methods:** Quantitative research was used. Data collected by the Health Research Board, by means of questionnaires with 77 people with SB and/or hydrocephalus living in the Mid-West of Ireland, informed this research project.

**Results:** The main factors that impacted upon occupational performance and engagement among participants in the Mid-West of Ireland were: 1) restrictions in body functions and structures, and limitations in performance skills, 2) external factors such as the physical environment, 3) limited access to health/therapeutic and support services.

**Conclusion:** There are many complex features associated with SB and/or hydrocephalus that can impact upon occupational performance and engagement. Despite these complexities it is vital for people with these conditions to engage in their chosen and meaningful occupations in order to promote their over health and wellbeing.

## **Introduction**

SB is a complex congenital birth defect that results in the failure of the caudal neural tube to fuse and is one of the most prevalent malformations of the human composition (Liptak & El Samra, 2010). Areas that SB can impact upon include; mobility (Dicianno *et al.*, 2009) executive function (Burmester *et al.*, 2005), attention (Roach *et al.*, 2011; Dyhr Caspersen & Habekost, 2013), social participation (Barf *et al.*, 2009) and over all neuropsychological functioning (Snow *et al.*, 1994).

Hydrocephalus is a common condition that occurs when the ventricles of the brain accumulate an abnormal amount of cerebrospinal fluid (Corns & Martin, 2012) and is present in approximately 90% of people presenting with SB (SBHI, 2015). The requirement of a shunt in hydrocephalus can compromise a person's cognitive abilities and result in complex complications to the spine (West *et al.*, 2011).

The chronic disabilities of SB and hydrocephalus place illness-specific demands on the person (Roach *et al.*, 2011) and can result in “activity limitation” or occupational restriction in the areas of work, activities of daily living (ADLs), instrumental activities of daily living (IADLs), social relationships and community involvement as indicated by the International Classification of Function (World Health Organisation (WHO), 2001). Therefore, it is important to investigate the occupational performance and engagement of people with SB and/or hydrocephalus in Ireland, as occupation provides value and meaning in life (Yerxa, 1998).

## **Research Objectives**

1. To investigate if people with SB and/or hydrocephalus are restricted in their occupational performance and engagement as a result of their condition, namely through client factors and performance skills.
2. To investigate if external factors impact upon occupational performance and engagement for people with SB and/or hydrocephalus.

## **Research Question**

*What are the factors that impact upon occupational performance and engagement among people with spina bifida and/or hydrocephalus living in the Mid-West of Ireland?*

This study describes the factors impacting upon occupational performance and engagement for participants living with SB and/or hydrocephalus in the Mid-West of Ireland. The research aims to form part of a larger study investigating support services for people with SB

and hydrocephalus in this region. Gaining a better understanding of the restrictions or limitations facing this population in their bid to undertake meaningful and chosen occupations may inform service provision to better accommodate people with SB and/or hydrocephalus.

## Literature Review

SB and hydrocephalus can significantly restrict occupational performance and engagement due to associated limitations in body structures and body functions (AOTA, 2008), namely, lower limb paresis/paralysis (West *et al.*, 2011), with upper extremity paresis causing further occupational constraints (Dennis *et al.*, 2009). This results in deficits to motor and praxis skills, including: motor weakness, poor manual and fine motor dexterity and poor bimanual co-ordination (Dennis *et al.*, 2009). These deficits significantly impact upon occupational engagement, making ADLs, such as dressing, a difficult chore. Cognitive deficits also impact upon occupational performance and engagement for people with SB and hydrocephalus, as memory, numeracy, literacy and language functioning are typically affected (Dennis & Barnes, 2010; West *et al.*, 2011). Furthermore, approximately 95% of people with SB present with neurogenic bladder and bowel (Mitchell *et al.*, 2004), with bladder and bowel management for incontinence consequently being a major concern.

Ireland has one of the highest prevalence of SB worldwide, occurring in 1.17 per 1,000 live births (McDonnell *et al.*, 2014). Recent research on children with SB, carried out by Temple Street Children's Hospital, identified that these children presented with complex needs. These complexities affected multiple body structures and body functions, which in turn impacted upon their occupational performance and engagement (Governey *et al.*, 2015). This research also identified the importance of access to specialist services for people with SB, and found occupational therapy to be among the most important and beneficial of these specialised services.

There are many factors associated with the conditions of SB and hydrocephalus that can impact upon a person's ability to perform and engage in his/her chosen occupations, that is, "the ordinary and familiar things that people do every day" (Christiansen *et al.*, 2015:4). Essentially, occupations are the building blocks in life which contribute to a person's overall health and wellbeing (McKenna *et al.*, 2007; Law, 1998), as well as providing a sense of purpose through "doing" (Wilcock, 2006). It is when we detach from this "doing" that we risk losing the sense of who we are (Urban Wilson, 2004).

## Methods

A quantitative study design was incorporated into this research project in order to identify many of the factors that impact upon occupational performance and engagement amongst people with SB and hydrocephalus in the Mid-West region of Ireland. A quantitative approach explains “phenomena by collecting numerical data that are analysed using mathematically based methods” (Aliaga & Gunderson, 2002: 21) and corroborates a hypothesis by means of statistical analysis.

### Data Collection

The sole method of collecting data was through the Health Research Board (HRB). The researcher, along with her research supervisor, applied to the HRB to access data they had collected and analysed from the National Physical and Sensory Disability Database (NPSDD), which depicts specialised health services being used or sought by people with physical/sensory disabilities. This database was established in 2002 and informs regional and national planning regarding these specialised services in relation to current and future service need. Currently, there are over 27,000 people registered on the NPSDD (Health Research Board, 2016).

Approval from the HRB provided me with data based on 1,111 people living throughout Ireland who were registered on the NPSDD, as of December 2013. This data was collected by the HRB through the use of questionnaires administered to people who reported SB, hydrocephalus or SB and hydrocephalus as either their primary or secondary diagnosis. This sample was chosen by means of purposive selection methods (Cresswell, 2013). A significant advantage of the quantitative approach employed by the HRB was that it enabled the research to be conducted with a large sample size, and provided a vast quantity of information in relation to statistics and value (Gerring, 2008). Other advantages of this quantitative research include;

- **Data collection:** surveys enabled an easier method of collecting data relating to different variables.
- **Bias:** researcher bias was not a factor that impacted upon the results.
- **Anonymity:** surveys enabled participants to remain anonymous and possibly afforded the provision of more accurate data, as participants may have provided more forthright responses due to the anonymous nature

(Fowler, 2013).

This convenient method of utilising data collected and analysed by the HRB was employed in order to gain an understanding of SB and hydrocephalus in Ireland, but specifically in the Mid-West region. The quality of the research is guaranteed, as the data was compiled by specialists, namely in the HRB (Cresswell, 2013). The validity of the research is guaranteed by the use of established data collection and analysis methods, as well as the fact that it was based on a large representative sample size (Joppe, 2000).

## **Interpreting the Data**

There were two main considerations to make when interpreting the data;

1. Participation in the research was voluntary, and furthermore not every individual in Ireland who has been diagnosed with a physical, sensory or neurological disability is registered with the NPSDD. Therefore, this data is not representative of all people in the Mid-West of Ireland living with SB and/or hydrocephalus; nor is claiming that 77 is the total amount of people living with these conditions in the Mid-West.
2. The NPSDD captured information only for those aged up to 66. Therefore, people living with SB and/or hydrocephalus over this age might not have been included as they were not registered on the NPSDD.

## **Data Analysis**

In order to filter the initial data pertaining to 1,111 people, a further application was made to the HRB to refine the data to participants living in the Mid-West of Ireland. This research aims to inform a larger study investigating the provision of services to people with SB and/or hydrocephalus in the Mid-West of Ireland, hence the decision to focus on this geographical location. This resulted in the receipt of data from 77 participants who had completed the questionnaire. This raw data was then analysed by the HRB, compiled into data sets and presented in excel spreadsheets (see Table 1).

**Table 1: Description of Data Categories**

| <b>Category</b>                  | <b>Description</b>  |
|----------------------------------|---|
| <b>Demographics</b>              | This included: geographical location of participants' residence; primary and secondary diagnosis; age; living arrangements; whether or not participants had a primary carer; and relationship with primary carer.   |
| <b>WHODAS II</b>                 | <p>The World Health Organisation Disability Assessment Schedule II (WHODAS II) is a self-evaluated assessment tool used to assess the limitations and difficulties experienced by an individual, independently from his/her medical diagnosis (WHO, 2004). This 36-item assessment tool evaluated individuals' functioning within six occupational domains:</p> <ol style="list-style-type: none"> <li>1. Understanding and communicating</li> <li>2. Getting around</li> <li>3. Self-care</li> <li>4. Getting along with people</li> <li>5. Life activities</li> <li>6. Societal Participation</li> </ol> <p>(WHO, 2004)</p> <p>Participants responded to this multiple choice question with either "None", "Mild", "Moderate", "Severe" or "Extreme" to portray the level of difficulty they experienced within each occupational domain.</p> |
| <b>Barriers and Challenges</b>   | This data identified if participants faced barriers and challenges due to external factors, such as the physical environment. Participants responded to this closed-ended question with "Yes" or "No".  |
| <b>Participation Restriction</b> | The data depicted the level of restriction the sample reported to face when participating with various services. Participants responded to this multiple-choice question with either "Not applicable", "Not at all", "Mildly", "Moderately", "Severely" or "Completely".  |
| <b>Services</b>                  | This data highlighted the provision of support and therapeutic services being received by participants at the time of completing the questionnaire.   |

## Ethical Considerations

In order to access this data, a written application was made to the HRB and a declaration of confidentiality was signed by the researcher. Confidentiality and protecting the identity of participants is a core component in any research project (Kielhofner, 2006). However, the researcher did not have any contact with participants, as the research had already been carried out by the HRB, therefore the identity of participants was entirely unknown and could not be compromised. Ethical considerations underpinned the process of collecting and analysing this data for the HRB, and permission to carry out same was granted by the Ethics Committee of the HRB (Stein *et al.*, 2013). Permission to use data collected by the HRB imparts a privilege on this researcher, and utilising this data for the sole purpose outlined in the application form is the only acceptable manner of data employment.

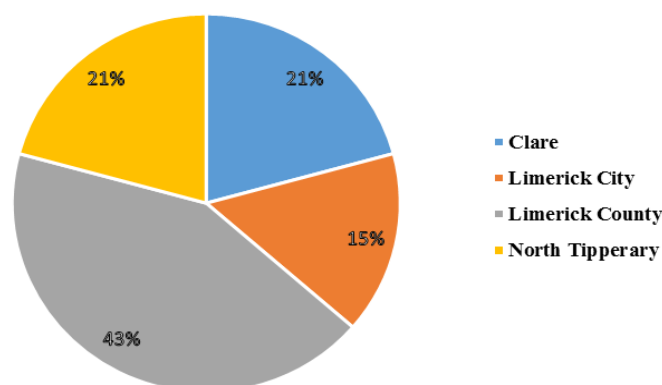
## Results

The section will detail the results of the datasets formulated by the HRB.

### Demographics

#### Geographical Location

There was a total of 77 participants from the Mid-West region of Ireland. A good representation from each area of the Mid-West was found in the data. However, the majority of participants were localised to Limerick County ( $n=33$ , 43%). Clare and North Tipperary provided an equal amount of participants ( $n=16$ , 21%), with Limerick City being represented by the least amount of participants ( $n=12$ , 15%).

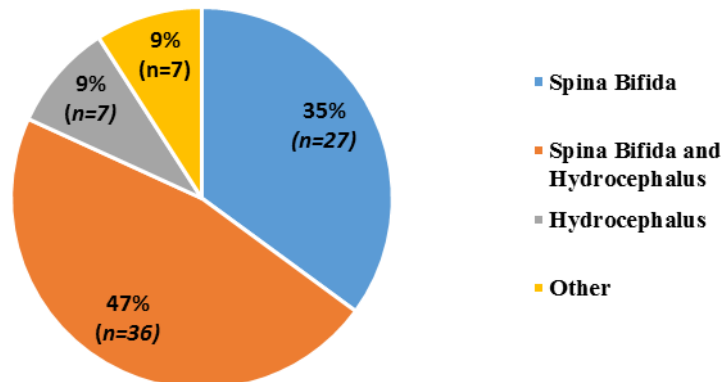


*Figure 1: Geographical Location of Participants*



### Primary Diagnosis

Based on the 77 participants from the Mid-West, 91% reported having SB ( $n=27$ , 35%), hydrocephalus ( $n=7$ , 9%), or both SB and hydrocephalus ( $n=36$ , 47%) as their primary diagnosis (see Figure 2). The remaining 9% ( $n=7$ ) of respondents reported conditions that have similar effects on client factors and performance skills which can result in barriers to occupational performance/engagement (such as cerebral palsy).



*Figure 2: Primary Diagnosis of Participants*

### Age

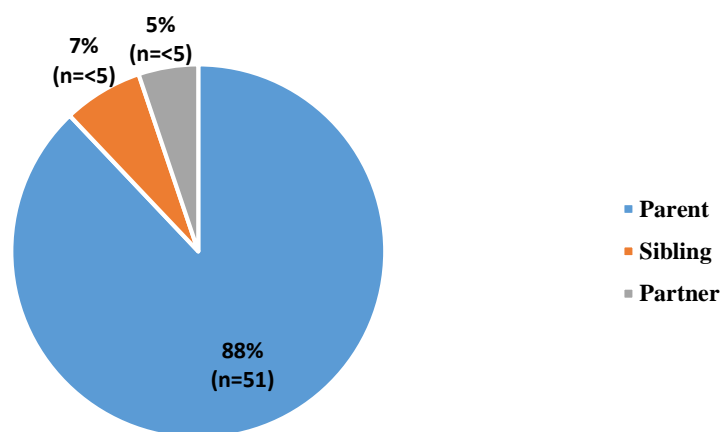
The ages of participants were diverse and spanned from 0-65 years (see Table 2). The age category with the largest number of participants was 25-39, ( $n=31$ , 40.3%). Age was an important factor to consider when interpreting the data, as the WHODAS II, Barriers and Challenges and Participation Restriction sections were not permitted to be answered by participants under the age of 18. This resulted in 29.9% ( $n=27$ ) of the Mid-West participants being ineligible to participate in these sections.

**Table 2: Ages of Participants**

| Age (years) | Percentage (%) |
|-------------|----------------|
| 0-4         | 1.3            |
| 5-12        | 18.2           |
| 13-17       | 10.4           |
| 18-24       | 9.1            |
| 25-39       | 40.3           |
| 40-59       | 16.9           |
| 60-65       | 3.9            |

### Primary Carer

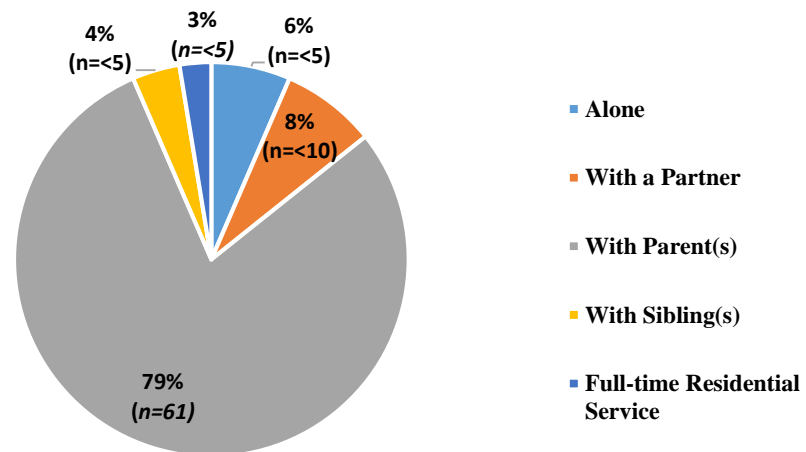
People with SB and/or hydrocephalus often require care givers to support/facilitate occupational performance and engagement. Of the 77 participants, 75% ( $n=58$ ) reported having a primary carer, of whom 88% ( $n=51$ ) reported their primary carer to be a parent.



**Figure 3: Relation of Participant to Primary Carer**

## Living Arrangements

While 88% ( $n=51$ ) of participants reported their primary carer to be a parent, this parental dependence is further reflected by the fact that 79% ( $n=61$ ) were living with their parents. Very few participants reported living alone ( $n=5$ , 6%).



*Figure 4: Living Arrangement of Participants*

## WHODAS II

The WHODAS II is designed specifically for adults, leaving just under 30% of the Mid-West participants ineligible to answer this section and a further 9% failed to complete the WHODAS II section. This means that 39% of the participants did not provide answers to the WHODAS II, resulting in a response rate of ( $n=47$ ). The WHODAS II data identified the self-reported results of participants' ability to successfully perform tasks that require physical, cognitive and social skills.

### WHODAS II-Physical Tasks

Physical tasks were reported to cause the most difficulty among participants ( $n=47$ ) (see Figure 5). A total of; 89% ( $n=40$ ) found "extreme" difficulty in standing for long periods, while 82% ( $n=37$ ) reported "extreme" difficulty walking long distances. ADLs in the area of bathing and dressing caused varied levels of difficulty for participants which ranged from "mild" to "extreme". A total of 53% ( $n=24$ ) highlighted a degree of difficulty with bathing and 49% ( $n=22$ ) with dressing. Further examination of these statistics highlighted that 22% ( $n=10$ ) of

those participants experienced “extreme” difficulty with bathing and 16% ( $n=7$ ) reported “extreme” difficulty with dressing. IADLs in the area of household responsibilities, presented further challenges to participants with 54% ( $n=24$ ) reporting mixed levels of difficulty tending to same.

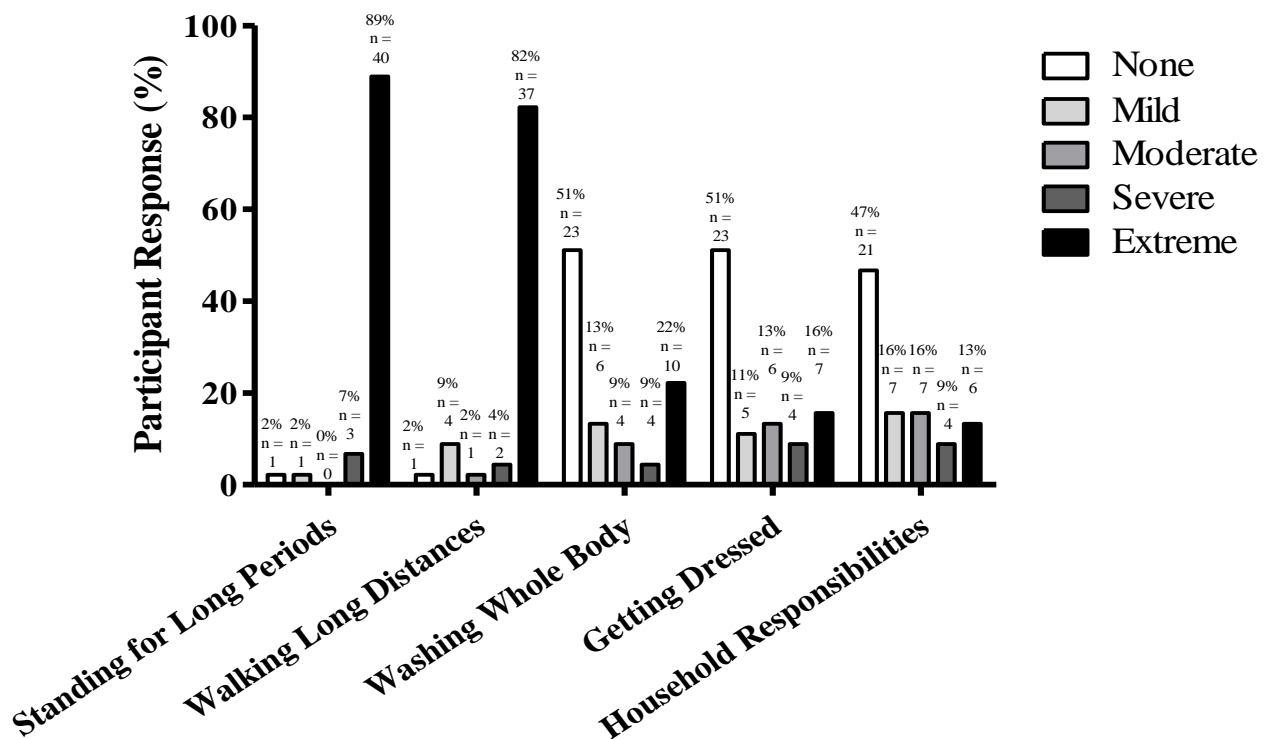
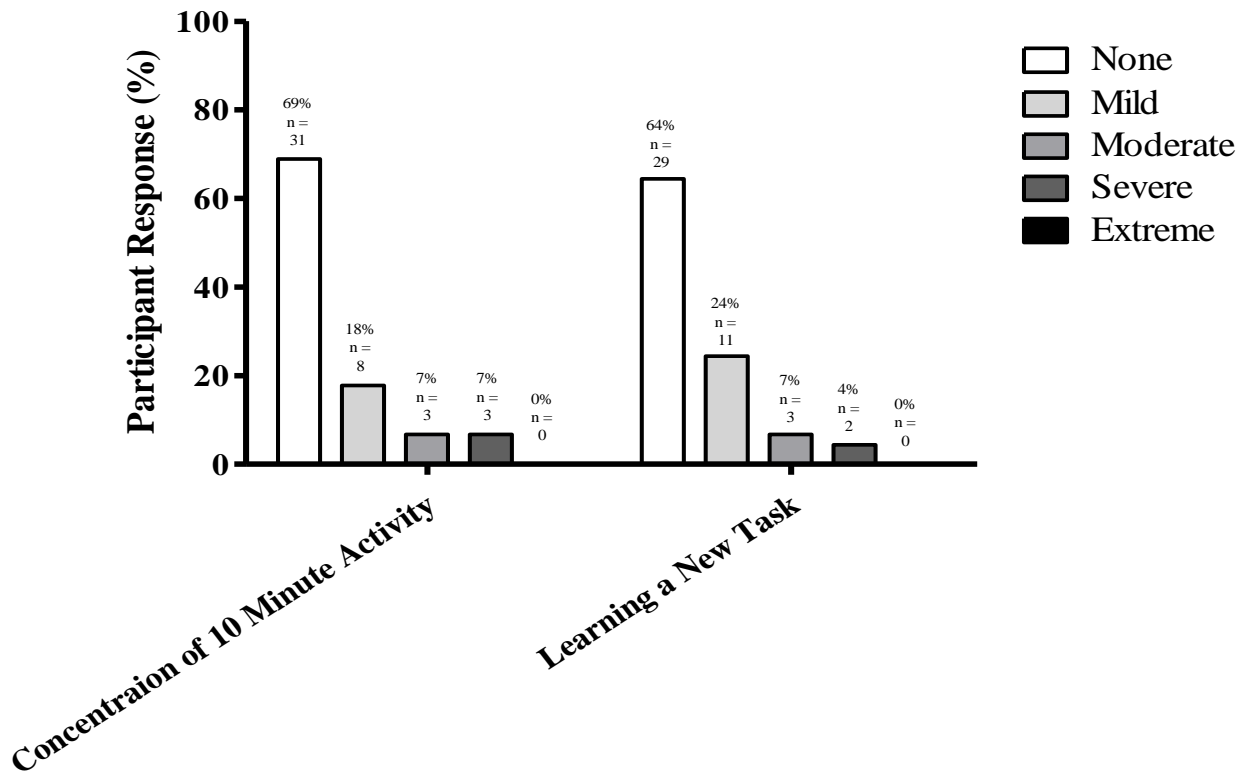


Figure 5: Difficulty Performing Physical Tasks

### WHODAS II-Cognitive Tasks

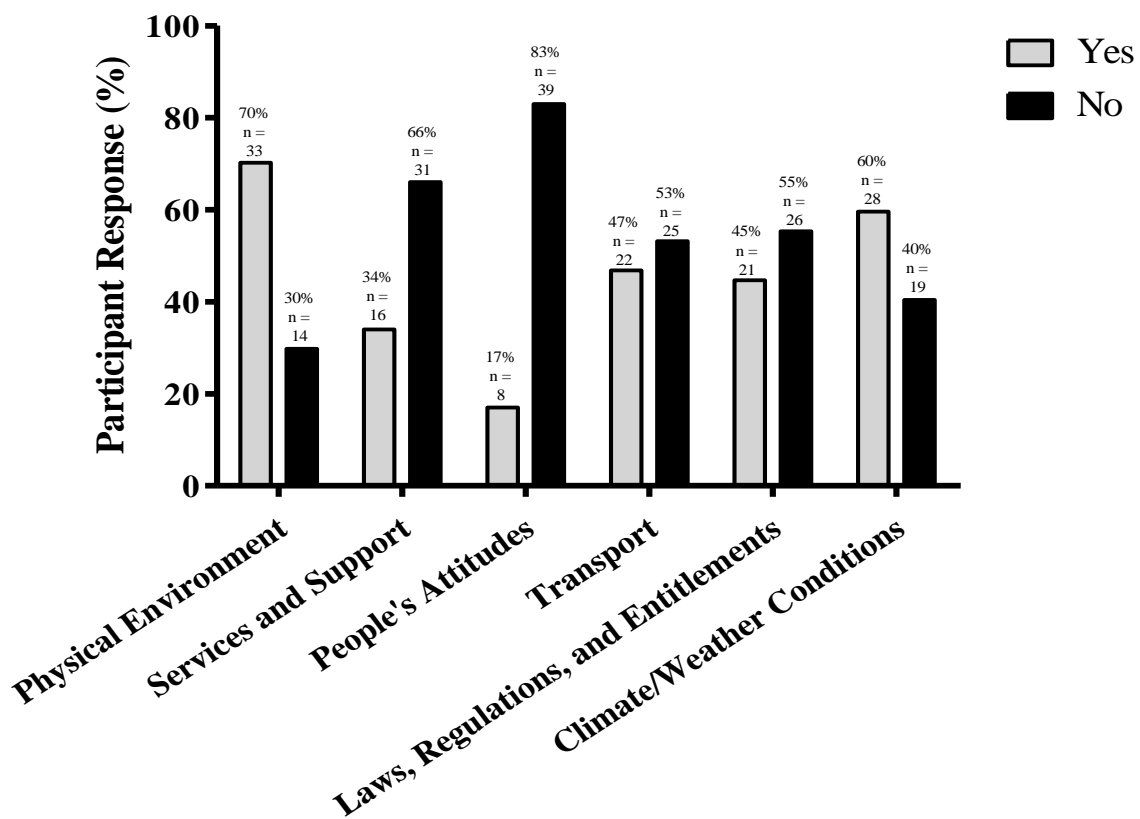
Participants ( $n=47$ ) were asked to report the level of difficulty they experienced in performing cognitive related tasks. A total of 35% ( $n=16$ ) had varying degrees of difficulty in concentrating on a task for 10 minutes, while 32% ( $n=14$ ) had problems learning a new task. However, the majority of participants found no difficulty at all in this area (see Figure 6).



*Figure 6: Difficulty Successfully Performing Cognitive Tasks*

### **Barriers & Challenges to Participation**

A response rate of (n=47) was achieved relating to different barriers that participants identified as interfering with their engagement and performance in meaningful occupations. According to the data, participants found that the external factors of the “Physical Environment” (n=33, 70%) and “Climate/Weather Conditions” (n=28, 60%) were the greatest barriers to overcome in a bid to tend to their chosen occupations (see Figure 7).



*Figure 7: Barriers and Challenges to Occupational Participation and Engagement*

### Participation Restriction

A response rate of ( $n=47$ ) was achieved, whereby participants stated the level of difficulty they experienced when attempting to participate in: 1) Educational/Employment Occupations and 2) Health Services (see Figures 8 and 9). “Education/Training” ( $n= 14$ , 30%) and “Employment/Job Seeking” ( $n=16$ , 34%) were reported as the most difficult occupations to participate in with participants experiencing mixed levels of difficulty with each (see Figure 8). Engagment with various health services was deemed by the majority of participants as being ‘not at all’ restricted with 66% ( $n=31$ ) reporting no restriction in engaging with ‘Hospital Services’ and 57% ( $n=26$ ) experienced no restriction participating with ‘Community Based Health Services’ (see Figure 9).

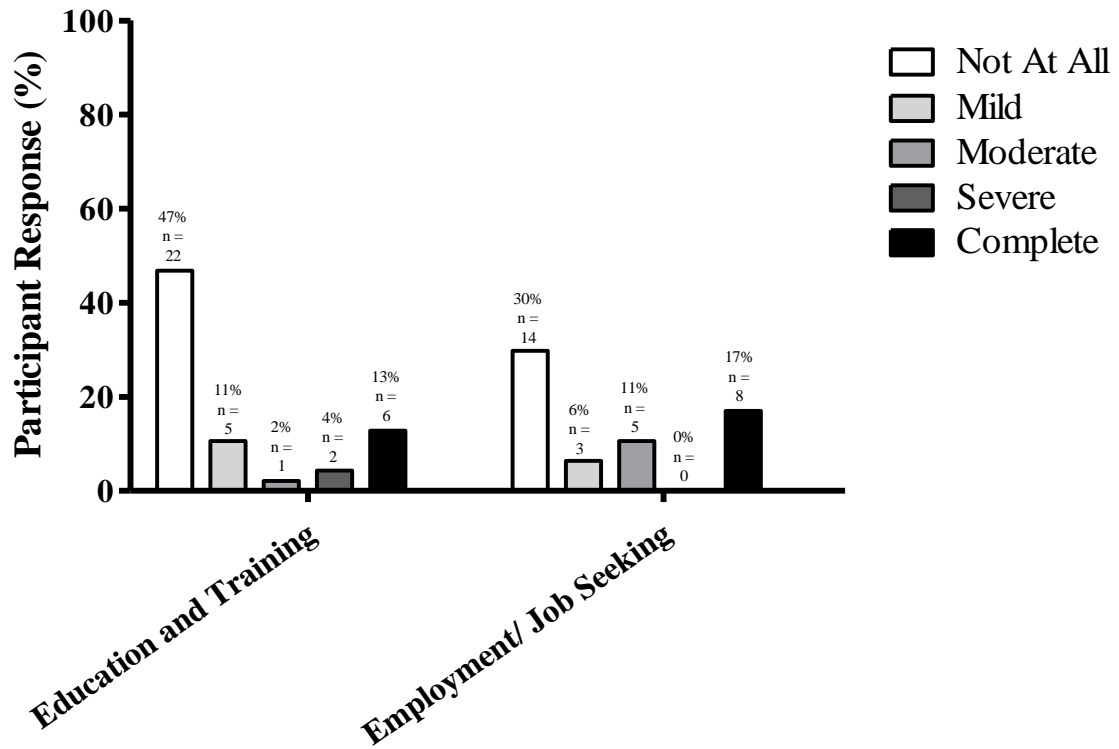


Figure 8: Difficulty Participating in Education/Training and Employment/Job Seeking

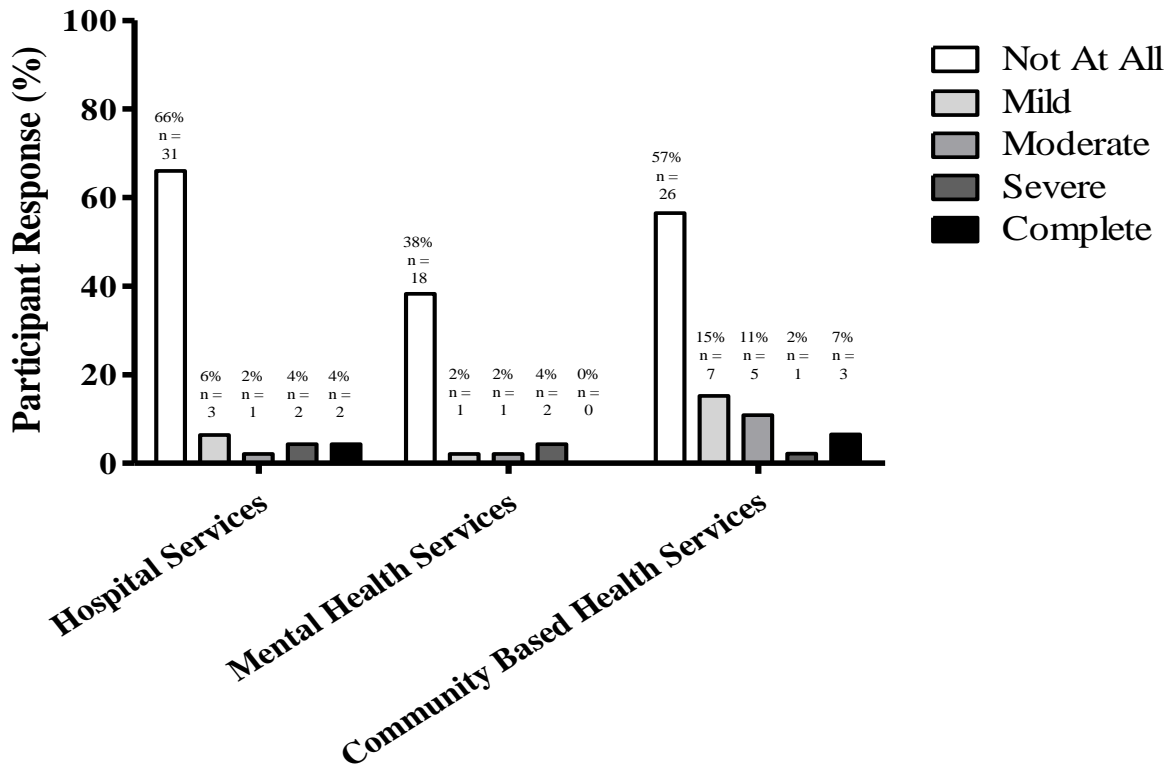


Figure 9: Difficulty Engaging with Health Services

## Services

### Therapeutic & Health Services

The data indicates that both therapeutic and support services were not being accessed by the majority of participants (see Table 3). Evidently, the number of participants accessing health and therapeutic services was quite low, yet participation with health services was not deemed by the majority of participants as being affected/impacted (see Figure 9).

*Table 3: Engagement with Health and Therapeutic Services*

| <b>Service</b>               | <b>Participation (%)</b> | <b>(n=77)</b> |
|------------------------------|--------------------------|---------------|
| <b>Physiotherapy</b>         | 57.1                     | 44            |
| <b>Occupational Therapy</b>  | 53.2                     | 41            |
| <b>Orthotist</b>             | 39                       | 30            |
| <b>Clinical Nutritionist</b> | 3.9                      | <5            |
| <b>Psychology</b>            | 13.0                     | 10            |
| <b>Continence Advisor</b>    | 13.0                     | 10            |
| <b>Counsellor</b>            | 3.9                      | <5            |

### Support Services

The data revealed that only 23.4% of the participants had personal assistants, while 93.5% were not in receipt of home help, and 96.1% were not availing of a home care assistant.

*Table 4: Engagement with Support Services*

| <b>Service</b>             | <b>Participation (%)</b> | <b>(n=77)</b> |
|----------------------------|--------------------------|---------------|
| <b>Personal Assistant</b>  | 23.4                     | 18            |
| <b>Home Help</b>           | 6.5                      | 5             |
| <b>Home Care Assistant</b> | 3.9                      | <5            |

### Educational Services

The typical age of school goes ranges from 5-18 years. This age range is applicable to 28.6% of participants and the results indicate that 26% are in education, thus signifying that a high percentage is engaging in primary and secondary education. However, engagement in further education is very low among participants with (n=<5) engaging in third-level education (see Table 5).



*Table 5: Participation with Educational Services*

| <b>Educational/Training Services</b>   | <b>Participation (n=77)</b> |    |
|--|-----------------------------|----|
|  | <b>(%)</b>                  |    |
| <b>Mainstream Primary School</b>   | 10.4                        | 8  |
| <b>Specialist Day Primary School</b><br><b>(Physical and Sensory Disability)</b> | 1.3                         | <5 |
| <b>Mainstream Secondary School</b>   | 14.3                        | 11 |
| <b>Third-level Education</b>   | 3.9                         | <5 |

## **Employment**

The employment statistics are quite low, highlighting that only 16.9% of participants from a sample of 70.2% between the ages of 18 and 65 are engaging in some form of employment.

*Table 6: Participation with Employment Services*

| <b>Employment Services</b>  | <b>Participation (%) (n=77)</b> |    |
|-----------------------------|---------------------------------|----|
| <b>Sheltered Employment</b> | 2.6                             | <5 |
| <b>Supported Employment</b> | 1.3                             | <5 |
| <b>Sheltered Work</b>       | 1.3                             | <5 |
| <b>Open Employment</b>      | 11.7                            | 9  |

## **Key Results**

- Over 70% of participants were over the age of 18 with 88% ( $n=51$ ) of the entire sample reporting a parent to be their primary carer. Furthermore, a substantial amount of participants reported living with their parents (79%,  $n=61$ ) and only 6% ( $n=5$ ) were living alone.
- Physical tasks posed the greatest level of difficulty for participants, with the mobility activities of walking long distances (82%,  $n=37$ ) and standing for long periods (89%,  $n=40$ ) causing “extreme” difficulty. The ADLs of bathing and dressing, as well as IADLs caused varied levels of difficulty (ranging from “mild” to “severe”) for participants, at a respective percentage of 53 ( $n=24$ ), 49 ( $n=22$ ) and 54 ( $n=24$ ).

- The greatest barriers and challenges to participation were reported to be the physical environment ( $n=33$ , 70%) and the climate/weather conditions ( $n=28$ , 60%).
- Engagement with health services was deemed to be “not at all” restricted by the majority of participants.
- A large number of participants were not accessing or engaging with therapeutic and support services.
- Third-level education was being attended by 3.9% (<5) of participants.

## Discussion

### Occupational Performance and Engagement

The occupational performance and engagement of participants was primarily restricted because of deficits/limitations in client factors and performance skills typically associated with SB and hydrocephalus. Movement is a core deficit that is present from birth in people with SB (Edelstein *et al.*, 2004) with the majority requiring mobility aids such as crutches, wheelchairs and/or orthotics due to limited gross motor skills (Hetherington *et al.*, 2005). Limited mobility and dependence on assistive mobility devices can result in people with SB finding it difficult to attend to their chosen and meaningful occupations. In the same way, mobility proved to be a significant difficulty for participants of this study, with 82% ( $n=37$ ) reporting “extreme” difficulty walking long distances, and 89% ( $n=40$ ) of participants reporting the same for standing for long periods.

Functional use of the upper extremities is needed to engage in occupations that require coordination, strength, grasping and manipulation (Cekmece *et al.*, 2013). However, these motor and praxis skills are typically limited for people with SB (Dennis *et al.*, 2009). Participants reported difficulty performing upper limb occupations; 49% ( $n=22$ ) identified varied levels of difficulty with dressing tasks; and 54% ( $n=24$ ) highlighted diverse ranges of difficulty with bathing (see Figure 5). Furthermore, 54% ( $n=24$ ) of participants experienced difficulties in domestic tasks. Cekmece *et al.* (2013) articulated the importance of functional upper extremity use for people with neurological conditions leading to paralysis/paresis of the lower extremities, in order to maintain as much independence as possible in everyday occupations.

The cognitive skills of people with SB and/or hydrocephalus are typically in the low range, and the majority have difficulty with various aspects of executive functioning which can

impact on everyday occupational performance and engagement (Friedman *et al.*, 2009). Interestingly, however, the results of this research indicated that 32% ( $n=14$ ) of participants had varying degrees of difficulty in concentrating on a 10-minute task, while 35% ( $n=16$ ) struggled with learning a new task (see Figure 6). However based on the literature one would have envisaged those results to be higher. Therefore, while cognitive deficits play a small role in occupation interruption for participants, the main associated difficulties that arise when performing and engaging in occupations stem from limitations in body structures, body functions and deficits in motor and praxis skills.

## **Barriers to Occupational Engagement**

A number of external factors were reported by participants as barriers/challenges to occupational engagement, with the “Physical Environment” posing the greatest difficulty (70%,  $n=33$ ). The Social Model of Disability proposes that disability is a socially constructed phenomenon that does not result from the limited bodily functions of individuals, but rather from the social and material situations that disable the full participation of people whom the remainder of society deem “atypical” (Oliver, 1991; Ginsburg & Rapp, 2013). This model and several authors in this field of study identify inaccessible environments as a significant entity of the disablement of people with disabilities (PWD) (Friedner & Osborne, 2013; Crews & Zavotka, 2006; Bickenbach *et al.*, 1999). Hughes and Paterson (1997: 328) encapsulated this impact of environmental disablement by stating that the “norms of construction are such that those with impairments may, and often do, find themselves excluded from a whole range of social spaces that non-disabled people take for granted.” The research carried out through Temple Street Children’s Hospital called for improvements in physical accessibility to be made to schools and community environments to promote participation and independence (Governey *et al.*, 2015).

The “Climate/Weather” was also identified as a barrier to occupational engagement for participants (60%,  $n=28$ ). This is likely as a result of prolonged ambulation time due to mobility issues which can result in lengthy time in unsavoury weather conditions.

Furthermore, the wet climate associated with Ireland may make it unsafe for participants to mobilise outdoors at times which would have significant impacts upon occupational engagement.

Irish Laws/Regulations were deemed by 45% ( $n=21$ ) of participants as creating a barrier to occupational engagement. Current laws and regulations do not provide for PWD to be

supported as best as possible. Ireland is yet to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) which would provide for better support services, housing choices, accessibility and foster overall independence for PWD.

## **Access to Services**

### **Health/Therapeutic Services**

Access to a variety of health and therapeutic services has the potential to promote and facilitate occupational performance and engagement for people with SB and/or hydrocephalus. However, the data indicates that very few participants are availing of these services (see Table 3). The occupational performance and engagement of these participants is evidently restricted due to an array of external and condition related factors. Despite this and the fact that occupational therapy was identified by Governey *et al.* (2015) as a key profession in the management of SB, 46.8% ( $n=36$ ) of participants were not engaging with occupational therapy.

Mobility issues are a prevalent factor impacting upon occupational performance and engagement, particularly for people with SB (West *et al.*, 2011; Hetherington *et al.*, 2006), yet 42.9% ( $n=33$ ) of participants were not attending physiotherapy and 61% ( $n=47$ ) were not accessing an orthotist. Neurogenic bowel and bladder among people with SB results in the need for bladder and bowel management due to this incontinence (Mitchell *et al.*, 2004). Nevertheless, 87% ( $n=66$ ) of participants did not have a continence advisor. Interestingly, obesity in people with SB is five times higher than the rest of the population (Governey *et al.*, 2015), but 96.1% ( $n=>72$ ) were not seeking the service of a clinical nutritionist.

People with SB are more likely to experience mental health difficulties such as depression due both to the severity of the condition and the functional limitations that the condition imparts on the person (Wallander & Varni, 1998). Limited independence and community integration was linked with the mental health difficulties challenging adults with SB in a sample of 97 Australians (Hayter & Dorstyn, 2014). Similarly, this study identified that 30% of the Mid-West participants were emotionally affected by their disability. Despite this figure, and the literature identifying this group as at risk of developing mental health difficulties, only 13% ( $n=10$ ) of participants were accessing a psychologist, while 3.9% ( $n=<5$ ) were attending a counsellor.

These complex characteristics associated with SB and/or hydrocephalus can have a significant impact on occupational performance and engagement. However, this impact is increased if those living with the conditions do not attend the relevant professionals for

support. Notably, very few participants indicated difficulty in engaging with health related services (see Figure 9).

### **Support Services**

People with SB and/or hydrocephalus have comprehensive healthcare needs and typically experience delays in skill development in the areas of independence and self-management (Bellin *et al.* 2011). This can impact upon occupational performance and engagement which in turn can impact upon their ability to live an independent life (Sawin *et al.*, 2009). This is reflected in the data as a significantly large number of participants were living with their parents (79%,  $n=61$ ) and only 6% ( $n<5$ ) reported living alone (see Figure 4). While it is unclear if these living arrangements are by choice or by necessity, it is reasonable to assume that participants would strive to live independently. What is clear however, is that participants are receiving very little support services to enable them live independently from their parents. Only 23.4% ( $n=18$ ) of the participants had personal assistants, while 93.5% ( $n=72$ ) were not in receipt of home help, and 96.1% ( $n>72$ ) were not availing of a home care assistant (see Table 4). If Ireland is to ratify its legislation to be compliant with the UNCRPD, home support services must be readily available for people with disabilities, as per Article 19(b).

### **Educational Engagement**

Education does not inherently manifest as a factor that impacts upon occupational performance and engagement for participants as education itself, is an occupation. However, it is interesting that only 3.9% ( $n<5$ ) of participants were engaging in third-level education despite cognitive skills not being reported as a significant factor affecting occupation performance for the majority of participants. Remarkably, however, only 30% of participants (over 18 years) found restrictions to participating in education/training, yet the number participating in third-level education is very low. Therefore, it is relevant to question if a lack of support services hinders participants' ability to engage in third-level education or possibly inaccessible environments play a role in this. Lack of engagement in third-level education can in a way be seen as a factor that limits occupational capacities in relation to future employment opportunities, this may explain why very little participants engaged in employment. Therefore it is crucial to understand exactly why participants are not attending third-level education in order to determine how these restricting factors can be overcome.

## **Implications for Practice**

The findings indicated that occupational performance and engagement for people with SB and/or hydrocephalus is impacted upon primarily by their condition, that is, by means of body functions and body structures and by means of performance skills. This highlights that there is a significant role for occupational therapists to work with people with SB and/or hydrocephalus to promote engagement in meaningful occupations. Occupational Therapists can work with people with SB and/or hydrocephalus to enhance their health and wellbeing through occupational engagement and increase their participation in everyday activities (WFOT, 2013). This can be done through adaptive or assistive equipment such as that which aid independent dressing, or by improving executive function through occupation engagement, e.g., developing planning skills through shopping. Furthermore, advocating for clients is a significant part of the OT role (Sachs & Linn, 1997; Smith, 2004; Swedlove & Brown, 1997). Therefore, we must advocate for laws/regulations that promote further inclusion of PWD to enable maximum occupational engagement. One significant aspect of occupational therapy is adapting environments to promote participation on a personal level, within the home. We must now move beyond this and further advocate for environmental adaptations on a societal level, so that PWD are no longer disabled by their environments.

## **Limitations of the Study**

This study is purely descriptive, based on the data provided by the HRB, thus limiting the conclusions. Future research should focus on making specific comparisons between the participants, their demographics and the datasets. This could include comparing the specific physical difficulties experienced by participants, and the provision or lack thereof, of home help/home care assistant to facilitate overcoming these difficulties. Also, there should be comparisons made between the number of people with SB and/or hydrocephalus who reside with their parents and those with other neurological disorders, to determine whether remaining in the parental home is due to the complexities of the condition or a lack of support services. Another limitation was that many of the questions were not fully answered, for unknown reasons. This means that the findings could have been distorted by those who were unwilling to answer the questions, and thus rendered somewhat unrepresentative of the sample.

## Conclusion

The conditions of SB and/or hydrocephalus are associated with many complex features which can greatly impact upon the individual's occupational performance and engagement. Based on this research, it is clear that these complexities manifested as client factors (body functions and body structures) and performance skills (namely motor and praxis skills and cognitive skills). These constraints associated with client factors and performance skills can be viewed as the predominant factors affecting occupational performance and engagement among people with SB and/or hydrocephalus. External elements also proved to be a factor that hindered engagement for these individuals, with the physical environment presenting the greatest challenge to attending to occupations. Engagement or lack thereof with health/therapeutic and support services was also found to be a factor contributing to reduced occupational performance and engagement. Highlighting these factors enables occupational therapists to promote occupational engagement despite these dynamics, in order to foster overall health and wellbeing (Law *et al.*, 1998) as what people 'do' can influence their health (Wilcock, 1998).

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