Project Report

"Co-producing interactive engagement tools and crafting training content to support transition of young people with complex needs in community settings".

Burdett Trust
for Nursing

Spina Bifida
Hydrocephalus
Scotland

Contents

1 Introduction

1.1 Introduction to SBH Scotland

Spina Bifida and Hydrocephalus (SBH) are complex conditions leading, in some cases, to disabilities involving cognition, behaviour and neurological dysfunctions. The majority of people affected by these conditions will have been diagnosed before birth and have significant medical input in the early years of their life. The remarkable advances in health sciences and technology, over the past 20 years, see many more babies surviving and moving from being supported by paediatric and hospital-based teams onto adult health and care services, in community settings.

Many individuals who reside in Scotland with SBH, and their families, are supported by Spina Bifida and Hydrocephalus Scotland (SBH Scotland). The charity aims to provide specialist support and information to all touched by these lifelong, complex disabilities and a wide range of services are offered nationwide to over 4,000 individuals. These include a helpline, one-to-one support in homes and schools, combined outpatient clinics in hospitals and nurse led clinics in the community. Other services SBH Scotland offer include support groups, financial advice, play sessions, outings, and workshops.

1.2 Introduction to the Project: “Co-producing interactive engagement tools and crafting training content to support transition of young people with complex needs in community settings”

Service users have been sharing their experiences with SBH Scotland staff about the excellent support they are offered in paediatric healthcare facilities across Scotland. They tell us that the family centred care, which is offered from birth and throughout childhood, often ends abruptly when the individual progresses to adolescence. The young person and their family are told that in an emergency they should contact their local Emergency Department and that routine care will be delivered by a General Practitioner who may have not been in the involved delivery of their care previously. In 2014 the charity published a report highlighting that there is a lack of planning before moving from paediatric to adult healthcare (transition), loss of benefits gained whilst in paediatric care and significant burden being placed on unpaid carers (Levy et al 2014). The study also warned that leaving young people without the continued support they may need put them at risk of not reaching their full potential and contributing to civic society as integral members.

The project reported here aimed to combat these issues by co-producing interactive engagement tools to support transition of young people from paediatric to adult health and care services. The focus was on co-producing a boardgame, digital stories, for and by families and crafting supplementary educational content about transition of young people with complex needs for healthcare professionals. The intended outcomes of this project are as follows:

- A printable board game that can be repurposed to serve as an aid to understanding of a transition pathway for a young person with complex health and care needs, residing in a community setting.
- A few completed digital stories that outline a transition pathway of a young person with SBH in Scotland.
- An education portal dedicated for transition of young people with complex needs and aimed at healthcare professionals.
- A final report to highlight the learning and development efforts completed during the yearlong project, including recommendation for future and further developments.

This report will outline the process that enabled these outcomes to be achieved and to what extent. In addition, this report provides an updated overview of the transitioning process for people with SBH in Scotland. It reviews current research literature and highlights key challenges that still exist for our service users, young people, parents and caregivers. Literature for this review includes current UK legislation, policy briefs, best health and care practice guidance and academic research papers. In addition, this report also draws upon evidence from global research studies and other relevant literature, in order to achieve a thorough depiction of current issues affecting our members.

We are grateful for funding from the Burdett Trust for Nursing to support this nurse-led project. The Trust aims to make significant improvements to the care environment, through enhancing the work of those who are often described as closest to the patient. The Complex Needs in Primary Care Grant, awarded to SBH Scotland in January 2020, is building on research findings affirming that the continuity and quality of primary care can help prevent the development of more severe health and social problems, resulting in fewer hospital admissions and emergency care attendances. The Trust recognised that people living with complex needs benefit from a coordinated approach to their care, but that all too often they experience fragmentation between health and social care services, which leads to reduced outcomes and poor patient experience.

1.3 What is 'Transition'?

With advances in healthcare, more people with complex medical conditions such as SBH are living into adulthood and experiencing a move from paediatric onto adult healthcare services (Lewis, et al., 2016). 'Transition' refers to "the complex and continuous process of preparing Children and Young People (CYP) with long-term conditions to move from child-centred to adult-oriented healthcare systems" (Fortune, Murphy, et al., 2020: 3). Successful transition aims to maximise the potential of an individual and enhance their wellbeing and abilities within the constraints of disability. In general, the transition experience can "vary widely among individuals, families and organizations" (Kralik, Visentin, 2006: 321) with some Young People (YP) having a successful transition and many more expressing negative experiences of the process. Our project aims to capture the voices of those experiencing such a transition and support efforts to create a more holistic, person-centred transition process which is, to a certain extent, more predictable.

Transition of healthcare services should be a gradual process, which ideally starts when the young person is around fourteen to sixteen years old. It ends when there is a complete transfer of care responsibility to adult services and tends to happen very quickly once the process is initiated. For many YP and their families it can be an incredibly daunting process often described as "falling off a cliff" (Arc Scotland, 2020). It is common for families to receive a letter noting an end date of their time in child healthcare, which initiates the process. When it comes to the actual transfer, it can often take place very rapidly, with families attending paediatric clinics one day, to the next, when they are to attend larger hospitals which "often requires individuals with SB to make separate appointments with multiple specialists across multiple settings" (Holmbeck et al., 2020: 199).

Whilst the transition process should be “complex and continuous” (Fortune, Murphy, et al., 2020: 3), too often the case is that it is quick, confusing and at times, lacking in empathy. Our work aims to foster and encourage successful transitions through which the young person remains at the centre of the care planning process. Successful transition also means autonomy for young people with complex conditions and partnership in decision making so that they gain independence and the ability to thrive as an adult. This involves an appropriate level of support that empowers the YP to take control of their own care and wellbeing, whilst providing guidance where needed.

1.4 Fostering Successful Transition

For YP with long-term conditions, such as SBH, and their support networks, it is common for several transition elements to intersect and amalgamate into a unique experience for individuals. We acknowledge that negative experiences of transition exist in Scotland and our aim is to offer tools and education that support a good, or successful, transition for YP and their family.

There is a common consensus that for successful transition to be achieved, certain goals must be met. ARC Scotland (2020) produced seven principles of transition, which promote a holistic process that encourages resilience and independence. These principles are now backed by the Scottish government in their Neurological care and support: framework for action 2020-2025 and consist of:

1. **Planning and decision making should be carried out in a person-centred way**
2. **Support should be co-ordinated across all services**
3. **Planning should start early and continue up to age 25**
4. **Young people should get the support they need**
5. **Young people, parents and carers must have access to the information they need**
6. **Families and carers need support**
7. **A continued focus on transitions across Scotland**

Successful transition takes all these principles into account and allows for YP to thrive.

Fostering successful transitions is important for both the health and wellbeing of YP with complex conditions and their families/carers. There is clear evidence that negative experiences of transition have an impact on the health and wellbeing of YP who may become disconnected from services as adults (Levy, 2014: 211-212). Due to the complexity of conditions such as SBH, "health issues are further compromised by inadequate transitional care" (Lewis, et al., 2016: 973). Generally, there is a rhetoric that the transition process is still not good enough (Ibid).

In a recent study conducted by ARC Scotland, it was shown that YP and their support networks still feel not only dissatisfied with the transition process, but also overwhelmed, scared and anxious for the future. The study found that there were individuals who described the transition process as "a black hole" (ARC Scotland, 2020); words not synonymous with support and guidance. Furthermore, often forgotten about are the parents and carers who themselves feel let down by the system. In an earlier report, entitled 'Facing the Future Together', ARC Scotland, identify that "90% [of parents and carers] were effectively unaware of any formal plan for their child's transition. 61% were either 'fairly' or 'very unhappy' with this" (ARC Scotland, 2017: 33); These figures highlight much room for improvement and the lack of success in transition can be attributed to "inadequate preparation and education for the transition process" (Lewis, et al., 2016: 973) prior to it taking place.

In addition, some young people are kept on by their dedicated paediatric services up to and well past the age of 18, in an attempt to protect from and avoid hardship of transition for as long as possible (Holmbeck et al., 2020). Whilst the sentiment is understandable, it highlights two key issues in the transition process which need to be addressed. Firstly, this means that there is less encouragement of independence and self-efficacy in the young people. Secondly, it leaves their General Practitioner and other future medical interveners out of the loop; leading to a disjointed healthcare service when transition inevitably does take place (Ibid). To combat this, transition education must take place as early as possible, consistent support must be provided throughout and self-management must be encouraged, where possible, in early adolescence. Successful transition must be empowering, supportive and organised so that YP don't suffer at the expense of a faulty system.

What we want to witness is improved transition with YP and their voices at the centre. Our project outlined in this report encourages YP and adults who have been through transition, and their families, to reengage with their journey, and amplifies their voices on what is working in healthcare transitions and what areas need improvements. We, in turn, have shaped a package of educational resources which support healthcare professionals involved in transition. These resources include digital stories about transition, a transition card game and an online learning course aimed at healthcare professionals about transition. These elements will be further discussed in chapter's three, four and five to highlight what we have learnt and what we have achieved.

Continues on the next page

2 Wider Context to Transition

2.1 Person-centred and rights-based approaches

Our project is underpinned by a movement towards person-centred care which allows for young people to have more of a voice in their healthcare journey. A person-centred transition plan would empower YP and their families to take on self-management roles without detriment to the young person's health and wellbeing. Taken from standard for care from one Scottish Health Board;

"Person-centred care is providing care that is responsive to individual personal preferences, needs and values and assuring that people's values guide all clinical decisions and where their experience of care meets or exceeds their expectations" (NHSGGC, 2020: 1)

This approach to care encourages and supports people in gaining independence and self-management skills by placing the individual at the centre of all decisions about their health and care. This is extremely important practice for transition as it ensures not only that the young person is ready to transition, but also ensures that they are fully aware of all stages of the process. Person-centred care encourages better health-literacy in individuals with complex conditions such as SBH and fosters resilience so that their overall wellbeing does not suffer as a result of a negative event taking place.

A person-centred approach also ensures that the rights of young people and people with disabilities are not only upheld, but respected. Recently, the United Nations Convention on the Rights of the Child (UNCRC) came into law in Scotland, therefore, it is now more important than ever that healthcare professionals understand how their practice interacts with YP's wellbeing and rights. In our online course on transition (outlined in chapter five) there is a full module dedicated to legislation, rights, and responsibilities, which encourages learners to reflect on how their practice and the healthcare system as a whole is equipped to uphold the rights of YP. This new legislation is extremely important when attempting to improve the transition process because this is a key period in young people's lives when they are gaining more independence and therefore can be even more vulnerable to the faults of a non-person-centred healthcare system. However, it is also a period which, if successful, can set them up for a future where they can 'take on' the world with confidence.

2.2 'Transition' in Scotland

The Scottish Parliament, through consideration of the ARC Scotland's "Facing the Future Together" study, have concluded that improvements to the transition process must be "person-focused" and include improved collaboration between services. This will be achieved by ensuring young people and their parents having a single point of contact and providing the environment where young people can be actively involved in their own care (The Scottish Parliament, 2019). It has been proven that "suboptimal transition to adult health care is associated with diminished treatment adherence and interruption or loss to follow-up" (Hopson, Alford, et al., 2019: 3). Therefore, it is necessary for individuals with SBH and their support network to have a well-established and pre-emptive transition process available to them.

There is evidence of political and societal shifts towards improving the transition process in Scotland. Former MSP, Johann Lamont, put forward a bill in the last session of parliament, known as the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill (Scottish Parliament, 2020), that would enable improvement of transition in accordance to the Scottish Government's 'Getting it Right for Every Child (GIRFEC)' approach (Scottish Government, 2021). It focused on rights and wellbeing of children, requiring "local authorities to introduce a transitions plan for each disabled child and young person to ensure that each disabled child and young person receives appropriate care and support before, and during, the transition to adulthood" (Ibid: 2). Unfortunately, the bill was not passed, however, its existence does suggest there are aspirations at government level to ensure the rights and wellbeing of children and young people with disabilities, such as SBH, are protected and supported in their journey to adulthood. Nonetheless, the lack of such a bill continues to leave YP going through transition vulnerable to a system where their rights, should be, but are not always, put first.

Generally, there is a lack of specific legislation dedicated to transition in Scotland which leaves gaps of understanding in the system leading to what the Quality Care Commission (England) refers to as "significant shortfall between policy and practice" (Quality Care Commission, 2020: 2). There is certainly no lack of healthcare professionals who care deeply about the rights, health, and wellbeing of the individuals they work with. However, their role is made more difficult by a system that often offers confusing answers on how to best cater for YP going through transition. One key shortcoming is the blurred lines in the legal parameters around when a young person is to be considered an adult in the context of transition and therefore, leaving them vulnerable to a system acting on principles rather than law.

The Law Society of Scotland problematised the proposed bill, highlighting that even a bill focused on transitions from children and young people fell short of full protection under the law;

"The Bill must be clearer regarding the definitions of "child" and "young person". We note that section 19 defines a child as a person under 18 years of age, and a young person as a person aged 18 to 26 years. We would suggest that the Bill must take into account the fact that a person over 16 years of age is treated as an adult for many legal purposes, including the Adults with Incapacity (Scotland) Act 2000. The Bill should address the fact that once a "child" turns 16, they are considered an adult for purposes including the 2000 Act and thus to specific extent subject to both the child and adult regimes" (Law Society of Scotland, 2021: 2)

The lack of distinct definition across Scotland for ages of child, young people and adults is a cause for concern which must be addressed. This lack of continuity can be seen in the ***Neurological care and support: framework for action 2020-2025***. The framework, which endorses ARC Scotland's ***Principles for Good Transitions 3***, states;

"The Framework is focused on adults (16 years and older, although we recognise transition for young people into adult services can occur at different ages depending on circumstances). There is separate work ongoing within the Scottish Government considering how best to support children and young people." (Scottish Government, 2019: 7)

"Separate work" (Ibid) refers the Getting it Right for Every Child (GIRFEC) principles which when "working well can ensure that all children and young people have the right to expect the same high-quality consideration and service wherever they live" (Health and Social Care Alliance, 2018). However, they do not refer to transition directly; despite it being a process that every young person with a complex condition or health needs will have to experience at some point in their adolescence or early adulthood. Furthermore, there is no guarantee that these principles are always used and understood in healthcare practice (Health and Social Care Alliance, 2020). In a review of the current legislation relating to children, YP and YP with complex needs, we found that there is a whole web of principles, guidance, legislation, and policy which add up to the protection of children. However, the lack of legislation which deals directly leaves opportunity for gaps through which YP can fall. In addition, young people are also left vulnerable to not understanding their rights and knowing how to use their voice to steer their own transition journey.

Our aim is to support healthcare professionals to learn more about the gaps in legislation, not only to improve their practice, but also push for long term change in protecting YP from loopholes in bureaucracy. Following the course, learners should demonstrate critical awareness of current legislation concerning transition and apply new knowledge to their practice. This, we hope, in the long term will provide YP with opportunities to use their rights for gaining autonomy and empowerment in steering their own transition journey.

2.3 What developments have been made, globally and locally?

In a study done by Department of Neurosurgery and Division of Paediatric Neurosurgery at University of Alabama it was found that there was a need for transition support for improving wellbeing and therefore established the "lifetime care model" (LCM) which provided support to their patients and families when the adolescent reached nineteen years old. It was found that "patients and their families were not prepared for either transition or the adult healthcare model" (Hopson, Alford, et al., 2019: 2) and therefore this age was changed to fourteen. This is echoed by Fortune, et al., who believes the optimum age for embarking on the transition process is thirteen to fourteen years of age with care spanning into adulthood when most responsibility for a person's health rests upon the individual (Fortune, Murphy, et al.: 2020: 3), along with the necessary level of support. This is a key development which acknowledges the enormous shift that adolescents experience as they move through their teenage years and into adulthood.

The Neurological care and support: framework for action 2020-2025, despite its pitfalls, does encourage for more focus on "kindness, dignity and compassion" and the creation of person-centred care plans for all individuals with a neurological condition through which they "live well, on their own terms" (Scottish Government, 2019: 6). This strategy consists of nine health and well-being outcomes (Ibid) and seventeen commitments which aim to ensure co-ordination between services, "equitable and timely access to care"(Ibid), person-centred support and the existence of "a sustainable neurological workforce fit for the future" (Ibid). There is acknowledgement in commitment four that transition processes in care are a particularly challenging time and can leave people vulnerable to "increased risk"(Ibid).

Organisations such as SBH Scotland also play an integral role in not only providing services which aid YP and their support network, but also embark on research to better understand where gaps exist in the framework. This research also includes investigation into how to provide more holistic services which take into account YP's overall wellbeing and delivers these discoveries in a succinct course for healthcare professionals. The role of organisations such as SBH Scotland plugs the holes in a system which can often leave service users, their parents and other caregivers overwhelmed and not knowing where to turn.

In addition, The University of Alabama (mentioned above) also developed five key goal categories for those moving onto adult care; maximised education, a working bowel program, independence and autonomy, parent set goals and self-administered goals (Hopson, Alford, et al., 2019: 3). These sentiments are echoed by Bogossian, Gorter, et al., who undertook a longitudinal study in Canada between 2009 and 2013. The study followed adolescents with various conditions through their transition to adult care. The aim of their study was to find out how their two interventions improved the wellbeing of participants. The two interventions were a Youth KIT organisational tool which focused on promoting organisation, goal setting, and self-management (Bogossian, Gorter, 2015) and the Trace Online Transition Monitor, an online transition mentor (occupational therapist with expertise in transition) who facilitated discussion of various transition issues that were of interest to participants through group chats, individual chat and via email. The overall goal was to involve YP in their own transition process and not only provide support, but empowerment (Ibid). This is certainly a move forward and links closely to our aim to amplify the voices of people who are going through the transition process.

2.4 Where is improvement needed?

Despite the transition process being a progression from the "single-event" (Ibid) transfer system of the past, there is still a plethora of challenges which face those going through transition to adult-healthcare services. As stated by Fortune and Murphy, et al. (2020), there are "obstacles to successfully implementing transition [which] include funding limitations, lack of continuity and coordination between child and adult services and limited training opportunities and specialist expertise in the adult system. In addition, there are significant changes to healthcare provider relationship and reduced support levels in the adult environment” (Fortune, Murphy, et al.: 2020: 3). The Scottish Government also acknowledges similar problems; “barriers to successful transitions, reported in evidence, include lack of support from adult services, poor co-ordination between services, inadequate planning and confusion around who is responsible for planning, lack of information on available options, and young people’s voices not being heard” (Hall, 2019: 5). The shortfalls of this system are felt keenly by YP and their support network who express anxiety, frustration, and fear about the next stages of their child’s lives. We hope that our project gives a voice to YP who have been through or are going through the journey of transition. Their voices are valuable in supporting healthcare professionals and wider audiences about the realities of the gaps between policy and practice for transition and the impact this has on the health and wellbeing of YP.

2.5 Summary of Chapter

To conclude this second chapter, there have been noted improvements to the transitions process in Scotland, over the last 5 years, which affirms the potential of providing YP with more clarity and autonomy throughout the process. However, more progress is needed to ensure that YP are empowered in their journey onto adulthood by person-centred care and a rights framework which is robust and accessible. The remainder of the report will offer an overview and an evaluation of the different segments of the project.

Continues on the next page

3 Digital Storytelling, ‘Our Voices’

3.1 Introduction to ‘Our Voices’

As outlined in the articulated intended outcomes, we aimed to create ‘digital stories’ to chart a current transition pathway of a young person with SBH in Scotland. In collaboration with **RealTalk** and the **Scottish Storytelling Centre**, SBH Scotland has coproduced five digital stories with which to offer healthcare professionals a unique gaze to comprehending the nuanced lived experience of transition with SBH. During the story crafting process, we found that a more holistic approach to transition has a direct impact on improving the wellbeing of YP with long-term conditions such as SBH.

SBH Scotland aimed to use storytelling as a qualitative method for eliciting data from participants that can then be used to aid the learning of healthcare professionals. This ‘data’ is the stories and lived experience of YP and their support network, regarding the ups and downs of transition with SBH. These stories have been digitalised and uploaded to an online educational platform, which accompany the learning content we created for healthcare professionals. The stories have also been uploaded to our **Youtube channel**, so that others, including our service users, can review and use them as they see fit.

SBH Scotland, along with RealTalk, is part of a wider movement which aims to enable service users’ voices not only to be heard, but also to have their experiences used to inform practice and improve the healthcare system.

3.2 Storytelling as Qualitative Method for Research

For human beings, storytelling comes naturally. We spend our days telling stories of all kinds and in many cultures across the globe it is a traditional process which has been handed down through the generations. The art of storytelling can be honed in specific ways to impart certain knowledge and to engage with one’s own experience and history. There is an element of catharsis that comes with honing our personal stories and engaging with the emotions which surface throughout the process. There is also an empowerment to be found in the telling of personal experiences how we wish them to be told and for our own voice to be heard. Therefore, we hoped that through our storytelling process, participants could reengage closely with the raw emotions of their personal stories and in doing so present an insightful resource which not only provides the participants themselves with catharsis and empowerment, but also reveals the realities of transitioning with SBH for healthcare professionals, students and the wider public.

Storytelling presents a useful qualitative method in which we can gain true insight into personal experiences of transition. This process means that we gain useful data through testimonials, yet participants can deliver these on their own terms. Storytelling is now a recognised research method which “captures our imagination about the life history of individuals in which we become interested, and it vividly portrays the lived experience” (Liamputtong, 2020: 237). This ‘lived experience’ is the corner stone of our project and links to our aim of placing service users’ voices at the centre of the educational healthcare rhetoric.

An insightful case study can be found in the origin story of **Patient Voices**, the brainchild of Pip Hardy and Tony Summer. In 2003, Summer and Hardy established Patient Voices “in response to the urgent need for better communication and understanding of all healthcare stakeholders’ experiences of care” (Patient Voices, 2020). They facilitate creation of digital stories which use sound and images in tandem to create digital stories of individual experience. Their project aims to empower people to use their voices to discuss their experiences of “health and illness, tragic losses and miraculous recoveries” (Ibid). Creation of the stories is a three-part process which involves participants at every stage; they are responsible for choosing the images and sound included in the story.

This inspired SBH Scotland to teamed up with RealTalk, who predominantly focus on mental health stories, to initiate a similar project; ‘Our Voices’. This process involved three virtual workshops in which participants moulded and shaped their stories about transitioning with SBH, using the RealTalk Storytelling Workbook (see appendix 1). These stories have been digitised by the SBH Scotland team through a co-production process with participants. The end result is stories which reflect transition and life with SBH and convey the true emotions of people who have experienced and overcome the challenges of transition. We hope that this will not only be useful to healthcare professionals and students, but also to families who are soon to go and are going through transition, making sure that they know they are not the only ones. Chapter three will outline what exactly went on in the workshops, how these stories were built and honed and reveal to what extent this outcome was achieved.

3.3 Personal Stories as Educational Online Tools

We gathered digital stories as qualitative resources for learning which hold a space in our online course on transition. This was developed with the help of **Digital Bricks** and is available from Autumn 2021. The resource includes educational resources such as links to important websites and articles centred around transition. Also included are interactive features for individuals to assess and reflect upon their learning. To steer learning, we have developed a set of learning outcomes. People will complete the course with heightened critical awareness of practice when working with those experiencing the transition from paediatric to adult healthcare. We hope that this will instil empathy, knowledge and understanding of transition which healthcare professionals can implement in their workplace and help to build towards more person-centred practice. This will be discussed further in chapter five.

Hardy and Summer claim that advances in technology, within healthcare education, and open learning "...was (still) regarded by many academics as a threat to their expertise and centrality in the learning process" (Hardy, Summer, 2018: 7). This legacy, it may be argued, still stands; the voice of doctors often absolute as they are "unquestioned in their knowledge and their position in health services... the voice of the patient was largely heard with scepticism at best and mistrust at worst" (Hardy, Summer, 2018: 5-6). This process has resulted in systematic "scientific oppression" (Halpin, 1989); doctors and researchers are often treated as the "knowing party" (Hesse- Biber, 2017: 103), tending to act on behalf of, rather than with, individuals. We hope that our project can promote change so that our service users' voices can be heard. Technology has afforded us the opportunity to share the stories of our service users as part of an online educational resource, which could be accessed from anywhere in the world.

With the help of technology, universities and educational groups are now offering online learning, which has made education much more accessible. Availability of open and free online courses also mean that learning does not need to stop once students leave their university. We want to harness this lifelong learning ethos and provide robust resources, which can help encourage better person-centred practice. Covid-19 has put another spin on this; for SBH Scotland, what was planned to be a process of digitised stories collected through face-to-face interaction has shifted into a wholly online process, with workshops taking place through Zoom and participants never actually meeting face to face. Harnessing technology means that our project did not have to be abandoned. As Rieger, et al., point out; "given digital media's vast and nearly instantaneous impact, the use of digital storytelling as an innovative knowledge translation approach has the potential to significantly decrease the time between knowledge generation and knowledge implementation." (Rieger, K.L, West, C.H, 2018:

2) and SBH Scotland, along with RealTalk, took full advantage of this. Stories are no longer limited to real time face-to-face interactions, but now hold a place within the digital sphere. And with larger servers and all our data existing online, a new level of posterity has been achieved. We can now hear the stories of someone living on the other side of the world at the click of a button.

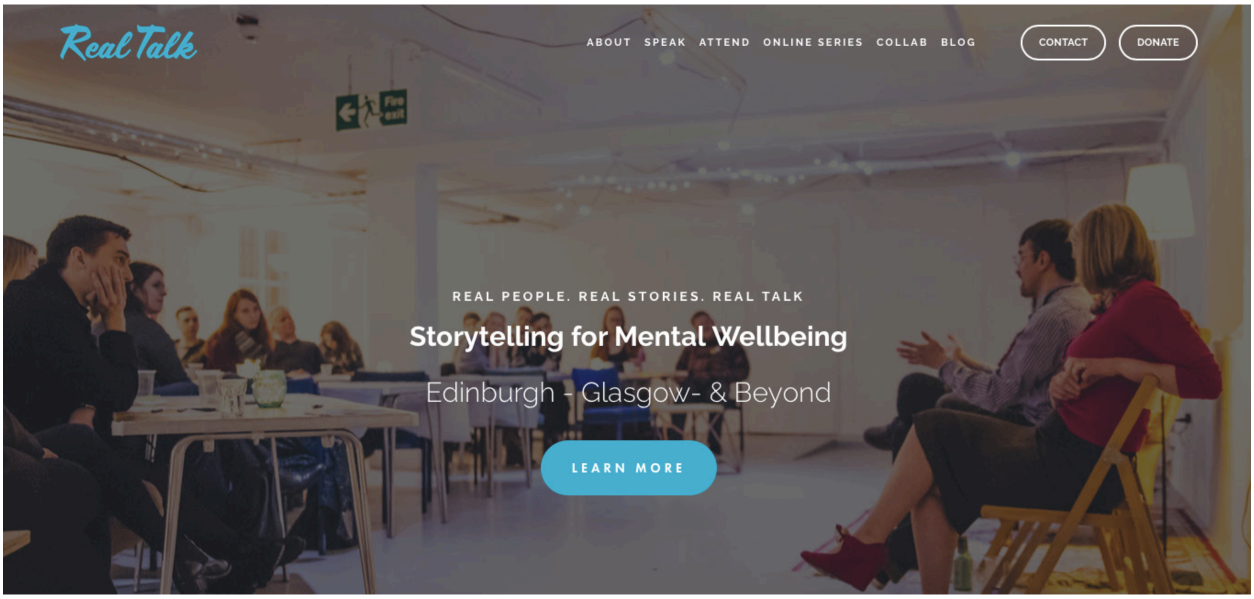
These advances have provided an exciting opportunity for people with SBH, who have been through transition, to actively contribute to education about the process. By equipping healthcare students and professionals with the educational framework to improve transition for YP and their families, we hope to see real change. Those who partake in the course, will have gained from a structured learning framework which will aid them to identify key areas where improvement of practice and legislation is needed. We hope that learners will act as change agents within their practice and share resources with peers in and out of the workplace. This will be outlined further in chapter five.

3.4 Our Storytelling Journey

In collaboration with RealTalk, SBH Scotland has been creating digital stories, known as ‘Our Voices’, which aim to break down the barrier between our service users and healthcare professionals. As discussed in chapter one and two there is often a disconnect between users’ experience and tacit knowledge and understanding that healthcare professionals have about transitioning with SBH, and other complex conditions. With these stories we aim to empower YP and their support network to build their own narrative which can then be used to inform healthcare professionals and practice. In this chapter we will have a look at the three workshops, which were both fun and challenging, then follow up with some reflections of the process. We hope this this project will enable more people going through transition to speak up and use their voice to receive the healthcare that they deserve.

Continues on the next page

3.4.1 Who are RealTalk?



REAL PEOPLE. REAL STORIES. REAL TALK

Storytelling for Mental Wellbeing

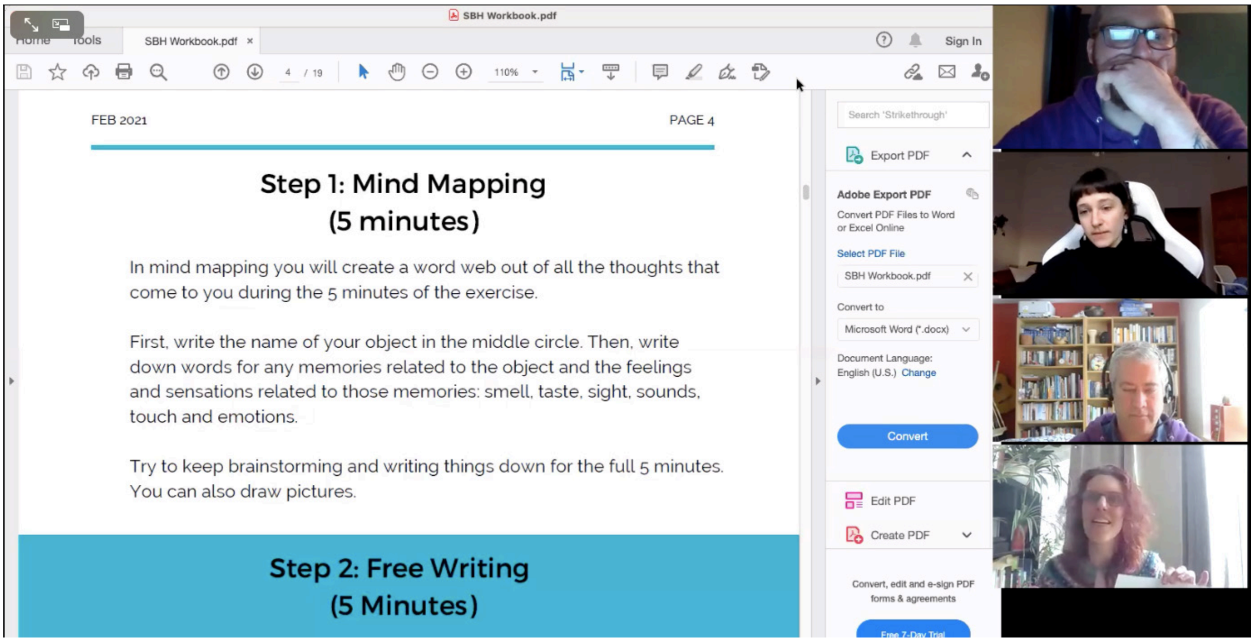
Edinburgh - Glasgow- & Beyond

Figure 1: Real Talk Website (RealTalk, 2021)

RealTalk is a mental health storytelling social enterprise, which was launched in 2015. It was following involvement in a Talk for TEDxUniversityofEdinburgh that founder, Lily Asch, discovered the cathartic and empowering benefits of talking about her personal mental health story (RealTalk, 2020). Together with Dr Alette Willis they have created successful mental health storytelling workshops, where people craft and engage with their own stories of mental health and mental illness. Collaboration with RealTalk has proven to be beneficial to elicit stories with a clear understanding of the complexities that exist within an individual's story. The empathy displayed during the virtual sessions was necessary for discussing transition, which is a frustrating, and at times, incredibly challenging process. Below is an outline of what we got up to in the workshops that Lily and Alette led us through.

3.4.2 Workshop One: Working with Memory Objects (one hour)

Our first workshop with young people and parents was a chance for everyone to get to know each other, albeit over Zoom, and learn more about the overall aims of the project. We hoped to also build confidence in participants and therefore the given exercises acted as warm-ups for the following workshops. To kick off Lily got everyone to share their favourite books and films to get everyone thinking about stories. Although this almost led to war over the best film, it was a good chance for everyone to have a relaxed chat and learn how to navigate the Zoom environment. Lily and Alette then introduced the RealTalk workbook, which would guide the storytelling experience for the next three sessions, and the first task; a creative writing warm up exercise to set everyone's inner storyteller alight. This task involved mind mapping and free writing of memories, with encouragement to draw pictures and focus on the senses; sight, smell, taste, sounds, touch and emotions.



FEB 2021 PAGE 4

Step 1: Mind Mapping
(5 minutes)

In mind mapping you will create a word web out of all the thoughts that come to you during the 5 minutes of the exercise.

First, write the name of your object in the middle circle. Then, write down words for any memories related to the object and the feelings and sensations related to those memories: smell, taste, sight, sounds, touch and emotions.

Try to keep brainstorming and writing things down for the full 5 minutes. You can also draw pictures.

Step 2: Free Writing
(5 Minutes)

Figure 2 (SBH Scotland, 2021): Alette explains the first activities of mind mapping and free writing to the group which they then had 10 minutes to complete

It was an opportunity for everyone to delve into the emotional side of transition and connect to their own personal reality. Participants had also been encouraged to bring three objects or artifacts, which represented stages of transition that they could use as a prompt for these emotions. It was stressed that the objective of this part of this exercise was to "not censor anything"; that nothing would be right or wrong, or weird. Only the participant could see their own mind map and free writing so that any pressure was removed. Participants were encouraged to push past the rehearsed version of their story that they were used to telling and delve into their true experience.

Following this exercise, the group came back together to discuss how they feel it went. One participant told the group that they were surprised with some of the elements that appeared on their piece of paper, describing this as a release of a "supressed feeling". Another participant shared that they had had to go up to the loft to fetch objects down for the workshop and in a perfectly aligned metaphor they also found some emotions stored away in secret parts of their mind.

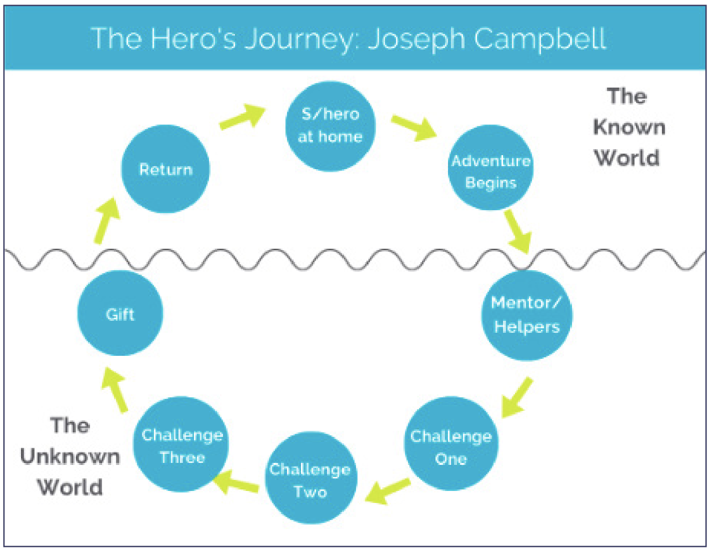
From here onwards, emotions were easier to access, and it looked as though these workshops, although challenging, would be effective in enabling people to grapple with their subconscious thoughts and feelings towards transition.

3.4.3 Workshop two: Learning About Story Structure (one hour)

"Humans are storytelling beings. Stories help us to communicate, to pass down histories, and to make sense of the world around us. From fairytales to our favourite films and books, stories are everywhere. And we have been sharing stories for thousands of years." (RealTalk, SBH Scotland, 2021)

This quote, taken from the RealTalk x SBH Scotland Storytelling Workbook, links closely into what was discussed in chapter two. Storytelling is intrinsic in humans and has become almost lost in the world of research. RealTalk aims to reclaim this, and it is an excellent technique for gaining qualitative understanding of individual's experiences, which provides the storyteller with an active role in how the story is told.

In the second workshop, Lily and Alette introduced our participants to the building blocks of storytelling which took the form of "The Hero Journey", which is broken down into eight steps. These steps formed important elements for digitising the stories at the later stage, therefore, it was important that even if participants did not create a full story that they at least had key steps which could be followed in the form of a storyboard. Figures 3a and 3b below, demonstrate the hero journey which was a useful tool for participants to see how a storyboard is usually set out.



Figures 3a

FEB 2021 PAGE 11

The Hero's Journey

1. Hero at Home

This is the beginning before the journey starts. It paints a picture of the setting, or the 'normal' world the hero comes from.

2. Adventure Begins

This is where the hero faces a problem that pushes them into the journey. It can be an external change or an internal desire. It normally represents a move from the known, into the unknown.

3. Helpers

The helpers or mentors show up to provide advice, assistance or items to help with the hero's journey. They may give crucial information or provide moral support.

4. Challenge One

On the journey to face their problem, the hero has challenges along the way. These might be outward feats of strength or inward reckonings with self.

5. Challenge Two

This is a second scene of a challenge the hero faces along the journey. Facing the challenges might not always be successful but show tests along the way.

6. Challenge Three & Succeed

This is the third and final challenge of the journey. It might be the most difficult to overcome but through it, the hero is able to meet their goal and solve their problem.

7. The Gift

The gift is the reward or lesson the hero takes from the journey. It is the fruit of their labour through all the challenges. It might be a physical thing or an internal understanding.

8. Return

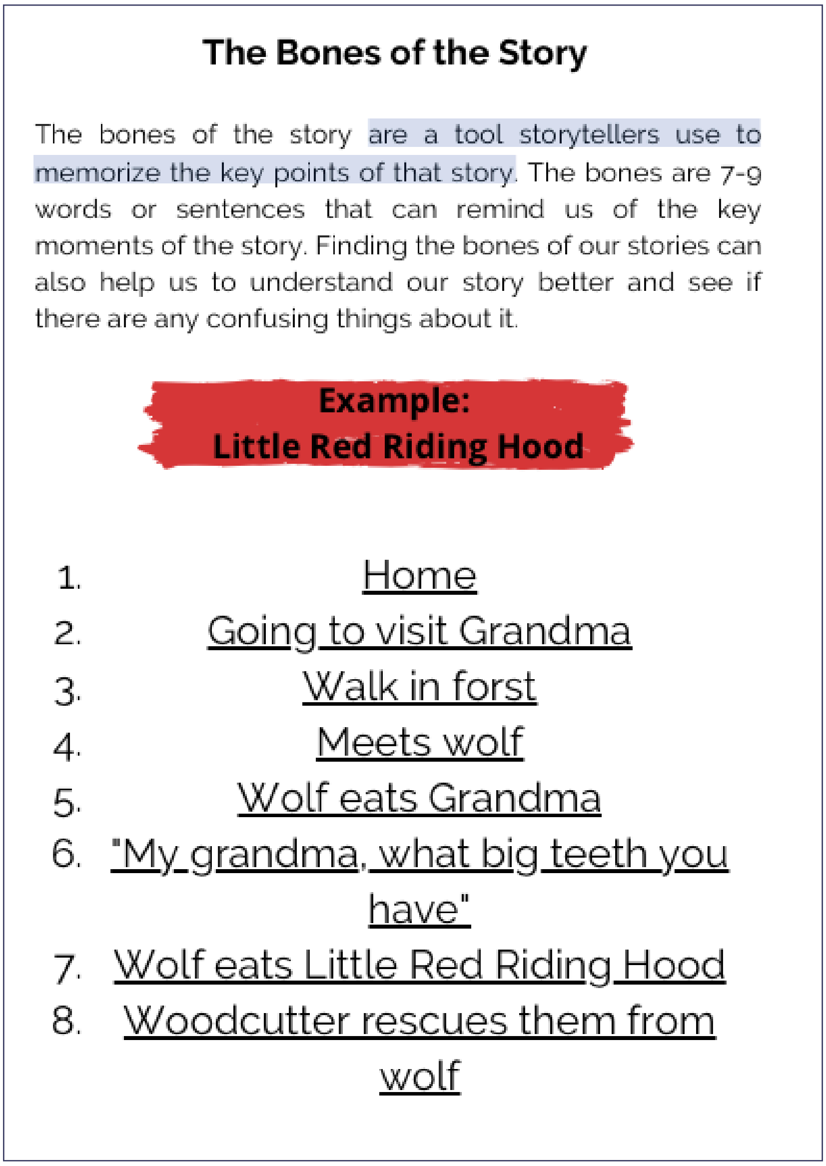
The return is when the hero returns home, to the start. They take all they have learn and can share this with others or use it to make changes for moving forward.

Figures 3b

Figures 3a + 3b (Real Talk, SBH Scotland, 2021): The Hero Journey Storyboard. This visual aided in seeing that sometimes we may have emotions, thoughts and feeling which run under the surface unnoticed. We wanted to tease these emotions out for an authentic story.

3.4.4 Workshop Three: Story Practice and Telling Techniques (one hour)

RealTalk's final workshop with participants was to work on storytelling techniques. The first exercise was to identify the "bones of the story" which are "a tool storytellers use to memorize the key points of that story" (RealTalk, SBH Scotland, 2021). The "bones of the story" were to be seven to nine words or phrases which form reminders to key parts of the story. It was emphasised here that if this stage contained more the seven to nine pointers, then the story would probably be too complex to fit within the allotted time for the digital recording (up to 4 minutes). We also wanted to ensure that participants had confidence in the structure of their story and ensuring that they knew the "bones of the story" was a way to do this.



The Bones of the Story

The bones of the story are a tool storytellers use to memorize the key points of that story. The bones are 7-9 words or sentences that can remind us of the key moments of the story. Finding the bones of our stories can also help us to understand our story better and see if there are any confusing things about it.

Example:
Little Red Riding Hood

1. Home
2. Going to visit Grandma
3. Walk in forst
4. Meets wolf
5. Wolf eats Grandma
6. "My grandma, what big teeth you have"
7. Wolf eats Little Red Riding Hood
8. Woodcutter rescues them from wolf

Figure 4 (RealTalk, SBH Scotland, 2021): The bones of the story section helped participants to have a clear storyboard in mind that they could follow when it came to the recording stage

The next exercise of this workshop was “gossiping the story”. This gave participants the chance to engage with their story in an informal way that allowed them to explore the ‘ins and outs’ from another perspective. Lily asked participants to imagine that they had run into a friend whom they hadn’t seen in a while and wanted to quickly catch them up on the ‘jist’ of their story. The aim was to get across the key points and key feelings of the story in a fun and interactive way. Lily also stressed that at every stage of the workshops the story can adjust and change, and that this stage was no different. People had come far in reengaging with their transition story and therefore it is to be expected that it may change along the way as both new and old emotions came to the surface.

In this final workshop we saw some true emotion come to the fore as one participant grappled with the frustration and confusion they have felt throughout transition. This participant and her daughter are currently in the throes of transition and had found it harder than the others in the group, who had been through transition already, to articulate their thoughts and emotions about the process. They had chosen a tennis ball as their object because it represented the day that the participant’s daughter was hit in the head with one at school. This sparked fear in her mother and upon dealing with healthcare professionals, they had found it extremely difficult to get a direct line to expertise and someone who understood what a ‘shunt’ was. This participant had been unsure of her story, but as it turns out when she had a chance to talk openly and ‘gossip’ her way through her story, it began to naturally form a structure. This is what is so incredible about the storytelling process: it enabled people to tell their narrative the way they saw fit and knowing that, in the intimate space of the workshop, they will be heard.

Another positive aspect of this was the interaction which then followed sharing this story with another mother, who had chosen running trainers as one of her objects. She said that this was a symbol of how her and her daughter had wanted to ‘run’ back to paediatric healthcare due to the uncertainty of transitioning to adult healthcare. This reveals that, not only had participants engaged with their own story, but also, they were given the chance to engage with others’ stories and see that they are not alone.

Continues on the next page

3.4.5 Digitising the Stories

Following the workshops, participants were encouraged to go away and write their stories. Some participants remained really engaged at this point and sent stories over within a couple weeks; others' struggled and needed extra support. By May 2021, we had only two stories recorded, but were determined to continue to engage with other participants to help with complete their stories. For a couple of people, a new approach was needed. Whilst some enjoyed the structure the storyboards had given them, others found this confusing and restrictive. We chose to contact participants who had had trouble engaging and encourage them to tell us their story over Zoom, however they wished to tell it. This had meant that they went outside of the timeframe of around four minutes, however, the content they provided was rich and, in our opinion, it would have been wasteful to cut them short or ask people to refilm. This more organic approach helped some participants feel more at ease and provided us with a different kind of narrative from the structure storyboard approach. Thus, we had a strong mixture of stories which vary in length, style, and subject matter. Once we had recorded the audios via Zoom (due to covid restrictions), they were then digitised by **Baby Grand Productions**.

3.5 Evaluation/Reflections

Overall, the workshops were a success in bringing people together to talk about transition and build individual stories, which represented the individual and their experience of the process. From SBH Scotland's perspective the workshops were insightful, promising and fulfilled the brief for this part of the project. The challenge we experienced, following the structured workshops has been in receiving completed stories from participants, which can then be co-created into digital stories.

Following the workshops, we sent out evaluation forms to participants for feedback. We only received two replies after several nudges. Those who did reply expressed that they enjoyed the workshops, however that perhaps they went a little fast. We found that towards the end of the third workshop some people were still unsure of what story they wanted to tell. Going forward, if SBH Scotland aims to stage more workshops and create more digital stories, alterations will need to be made.

In addition, the stories we have curated do not only tell of transition, but of life with SBH. This was an unexpected outcome; we had previously thought it would be easy for people to focus solely on transition, however, as we have learnt the transition process is wrapped up in so many emotions and other events that it is difficult to tell the story of transition without telling the story of life with SBH. One participant even interpreted transition to mean any transition period in his life and therefore focused on moving into his own flat. Therefore, we have a mixture of rich stories which tell of building independence, self-management of a long-term condition, the relationships that parents/ carers have with a YP who has a complex condition and what it is like to grow up with SBH being a central factor in a person's life. We also found that whilst some of our participants enjoyed the structure that the storytelling workshops gave them to hone their story, others felt constrained and not able to tell the story in a way they felt comfortable with.

It may be that an extra group workshop would have been beneficial to give participants a little longer to interact with each other and use this interaction to create interesting and insightful stories. As will be explored later in the evaluation of the boardgame workshops, an extra workshop at the beginning (which occurred by accident) was a good chance for people to get to know each other. Participants then appeared to be more at ease and more comfortable sharing their stories with others in the group. In addition, we learnt that giving a structure to their story helped some people, but others preferred to weave their story organically.

Continues on the next page

4 Crafting the Transition Boardgame

In addition to digital stories, we have co-created a printable boardgame focusing on transition. This can be played be families, carers, healthcare students and professionals, and in fact, anyone who wants to learn more about, or prepare for, the transfer from paediatric to adult-centred healthcare for YP can play the game. Transition can be difficult and may present some challenges which, with appropriate forward planning, could be minimised. This boardgame aims to prepare YP and their families for transition and suggest ways to enhance a sense of resilience and control. It also offers healthcare professionals a unique opportunity to engage YP and parents in a focused discussion about future planning through a structured and fun mechanism - playing a game!

4.1 What are ‘Serious Games’?

Serious games have been around for a long time, in 1970 Clark Abt gave a first definition of a serious game as games that “have an explicit and carefully thought-out educational purpose and are not intended to be played primarily for amusement”. An updated definition by Michael & Chen in 2005 further defines a serious game as a “game in which education (in its various forms) is the primary goal, rather than entertainment”.

Many approaches towards serious games often include the view towards using them as a “stealth mode” of learning (Michael & Chen, 2006), seeking to slide educational goals in behind an entertainment factor. Kaufman, Flanagan, and Seidman (2016) found that games which seek to impart serious knowledge in an explicit fashion are less successful than those that take an even more “stealthy” approach by embedding persuasive messages within a game’s content or context. They provide an “Embedded Design” model which aims to create a more receptive mindset for players which advises: (1) Intermixing: balancing “on-message” and “off-message” content; (2) Obfuscating: using framing devices or genres that divert expectations or focus away from the game’s persuasive intent; and (3) Distancing: employing fiction and metaphor to increase the psychological gap between players’ identities and beliefs and the game’s characters and persuasive content.

4.2 Community and co-design

In creating a game that accurately reflects the experiences and gained knowledge of young people transitioning from child to adult health services in Scotland, collaborating with those individuals and co-designing a game around their specific abilities, desires, and learning has been core to the entire design process.

Certain specifics were set in place as core requirements for the game:

1. Reflect the experiences and learning of young people transitioning from child to adult health services in Scotland.
2. An easily reproduceable print-and play paper-based game that could be downloaded and printed for play by anyone with an internet connection and a printer.
3. Accessible in design, readability, print quality, and inclusive representation.

In March 2021, four one-hour workshops were run on consecutive weekends with volunteers and their families. Due to covid-19 travel restrictions, the workshops were held online. The first two workshops focused on hearing from participants about their experiences and gathering examples of real-life occurrences and gained wisdom that they wanted to impart to other young people with complex health needs. Discussions also considered what types of games the volunteers felt would be the most engaging and useful to young people in their positions.

Figure 5: We set up a closed Facebook group were everyone could discuss their ideas for the game

Following the first two workshops the volunteers expressed a firm preference for the game to be co-operative, with all players working together towards a common goal. It also became clear that designing the game to focus on discussion and reflection would best achieve the goals of imparting the experiences and knowledge imparted by the volunteers.

Taking these factors into account the draft game was designed taking inspiration from the open licensed game, PlayDecide, a discussion game with a role-playing component, used for players to talk in a simple and effective way about controversial issues. And to combine the discussion elements alongside deck building and storytelling mechanics. Deck building is a common card game mechanic where players aim to collect and add specific cards to a visible ‘deck’ in order to achieve specific goals and outcomes. Five types of cards were created to encompass the types of experiences and helpful wisdoms provided by the volunteers:

1. Character Cards: The fictional character that players are building the deck of experiences around. All three characters must achieve 15 resilience points for players to win the game.

2. Life Events: Big change life events that can bring about positive or negative effects. + or - 5 points

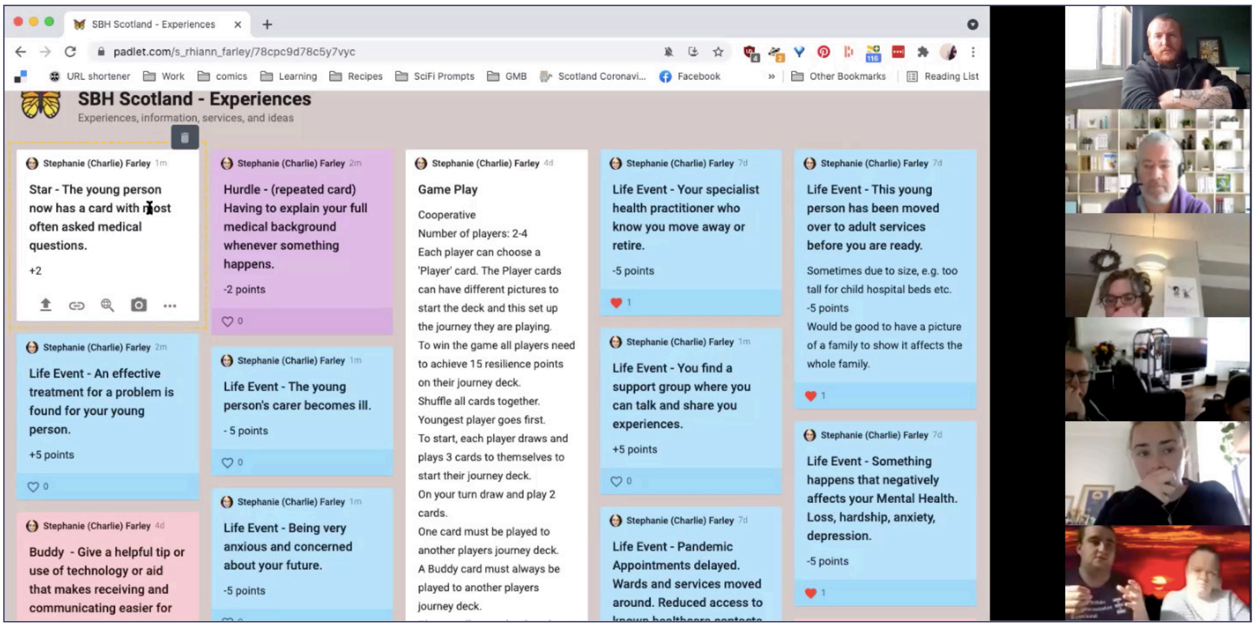
3. Buddy: A card that simulates a friend providing help, advice, or support to the character. +3 points

4. Hurdle: Obstacles and incidents that make the transition harder. -2 points

5. Star: Positive events, tools, or services that make transition easier. +2 points

This draft was created online using Padlet, an online collaborative noticeboard and then demonstrated to the volunteers during the third workshop. They were pleased with the shape and content of the game, providing feedback on additional experiences for each of the card types.

Continues on the next page



SBH Scotland - Experiences

Experiences, information, services, and ideas

Stephanie (Charlie) Farley 1m

Star - The young person now has a card with most often asked medical questions.

+2

Stephanie (Charlie) Farley 2m

Life Event - An effective treatment for a problem is found for your young person.

+5 points

♡ 0

Stephanie (Charlie) Farley 4d

Buddy - Give a helpful tip or use of technology or aid that makes receiving and communicating easier for

Stephanie (Charlie) Farley 2m

Hurdle - (repeated card) Having to explain your full medical background whenever something happens.

-2 points

♡ 0

Stephanie (Charlie) Farley 1m

Life Event - The young person's carer becomes ill.

- 5 points

♡ 0

Stephanie (Charlie) Farley 1m

Life Event - Being very anxious and concerned about your future.

-5 points

Stephanie (Charlie) Farley 4d

Game Play

Cooperative
Number of players: 2-4
Each player can choose a 'Player' card. The Player cards can have different pictures to start the deck and this set up the journey they are playing.
To win the game all players need to achieve 15 resilience points on their journey deck.
Shuffle all cards together.
Youngest player goes first.
To start, each player draws and plays 3 cards to themselves to start their journey deck.
On your turn draw and play 2 cards.
One card must be played to another players journey deck.
A Buddy card must always be played to another players journey deck.

Stephanie (Charlie) Farley 7d

Life Event - Your specialist health practitioner who know you move away or retire.

-5 points

♥ 1

Stephanie (Charlie) Farley 1m

Life Event - You find a support group where you can talk and share you experiences.

+5 points

♡ 0

Stephanie (Charlie) Farley 7d

Life Event - Pandemic Appointments delayed. Wards and services moved around. Reduced access to

Stephanie (Charlie) Farley 7d

Life Event - This young person has been moved over to adult services before you are ready.

Sometimes due to size, e.g. too tall for child hospital beds etc.
-5 points
Would be good to have a picture of a family to show it affects the whole family.

♥ 1

Stephanie (Charlie) Farley 7d

Life Event - Something happens that negatively affects your Mental Health. Loss, hardship, anxiety, depression.

-5 points

♥ 1

Figure 6: Facilitator (Charlie) and participants work to co-produce the game online using **Padlet** *(SBH Scotland, 2021)*

They particularly enjoyed the creation of character cards which were included to provide distancing to increase the psychological gap between players' identities and experiences and the difficult experiences potentially undertaken by the game characters. Implementing all of the co-design elements and feedback from the volunteer workshops, our game designer and graphic designer refined the draft to create a printable PDF document including an overview of the game, how to play the game, and the cards.

4.3 Playtesting and refining the game design

Playtesting is an important element in game design as it is how designers check to ensure that the instructions make sense and are playable, that there are no flaws in the mechanics, and that players interact and experience the game in the intended way. Four playtest sessions were scheduled over April to June 2021. The first playtest was scheduled with Scottish health practitioners, as part of the game design intention included communicating the transition experience from the perspective of a young person going through the process to their health practitioners.

Again, due to covid-19 restrictions the playtests all needed to occur remotely and online. In order to facilitate this, copies of the game document with the cards, already cut out and ready for play, were mailed directly to each playtest volunteer. The playtest was conducted online with each player pulling cards from their own decks, discussing them with other players and then collaboratively deciding which character deck to play the card. Feedback from the health practitioners was particularly positive around the discussion element of the game where players are encouraged to discuss how the events of the cards impact on the characters and which characters were best placed, with resilience points, buddy, or star cards, to handle or benefit from the cards.

Following play testing, the game design was updated and then a new version sent out to the next volunteer young person and their family. Each play tester came to the game with no previous knowledge or view of earlier versions. This was repeated in April, May, and June, each time providing valuable insight and feedback from volunteers and their families on elements of the game for fine tuning and improvement.

Areas of refinement to the design focused on creating clear concise instructions in plain English to communicate the game play, rules, and elements that integrated the "Embedded Design" model. This included further implementation of additional story elements to include a young hero adventuring out into the world framing device to imbue fun and playfulness to the game play while also providing fiction to increase the phycological distance between the players and the game characters. Card content was also edited and updated to provide a mixed balance of "on-message" and "off-message" content. The player characters were further defined as a team of three young heroes setting off on adventures to build their resilience. The 'No hero left behind' element of the game binds the cooperative element requiring that all players work together to help all three characters of the hero team achieve the required number of resilience points for the game to resolve.

4.4 Accessibility, inclusion, and re-use

The original brief for the game was to design a game that is accessible, inclusive, and re-usable by young people and health practitioners preparing for transition in medical services. A number of steps were included in the design and graphic elements of the game to ensure that the game strives to be as accessible and inclusive as possible, including:

1. Designed as an easily downloadable PDF pile for easy print and play by anyone with access to the internet and a printer.
2. An accessible font was purchased for the game text and cards in order to increase accessibility and the design has used a grayscale colour to reduce printing costs. The use of a greyscale was found by our volunteer play testers to not affect their enjoyment of the game as they enjoyed the graphic style and illustration elements.

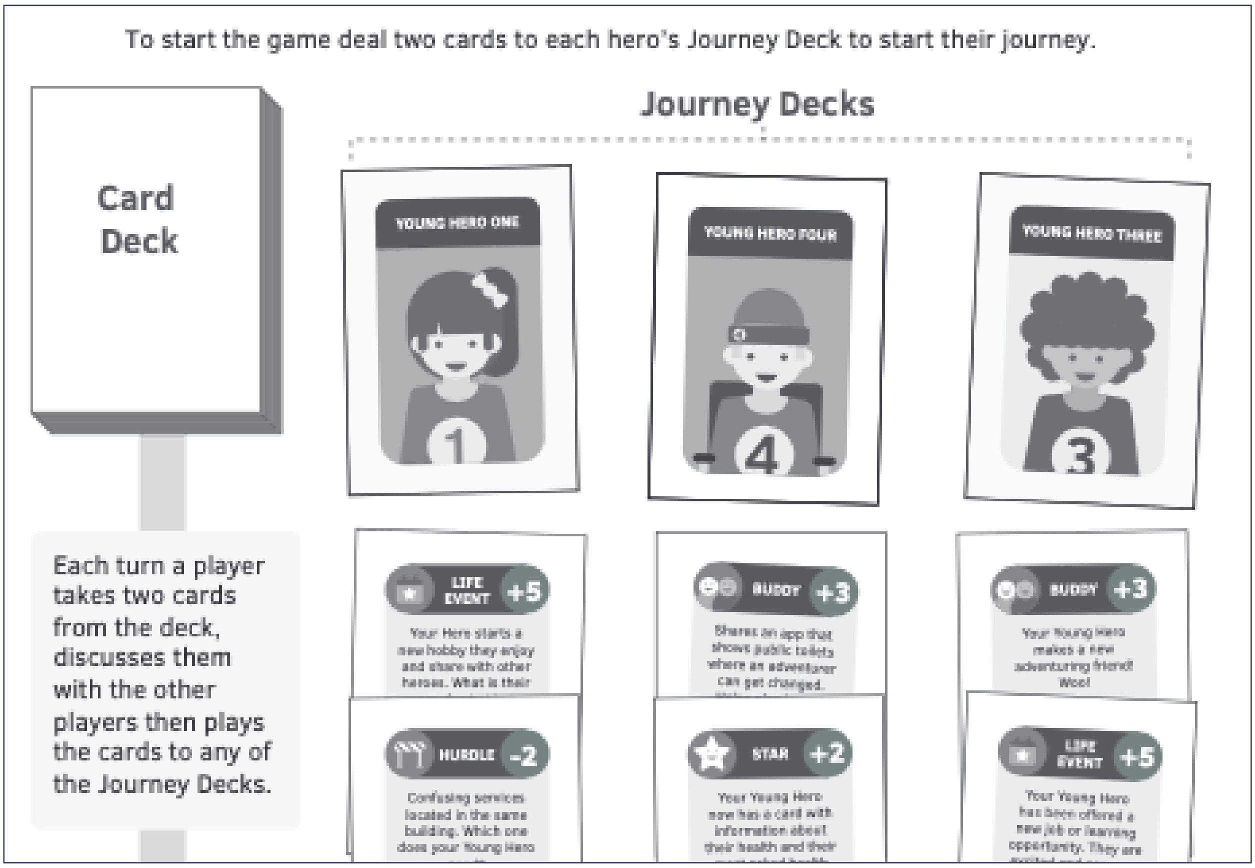
3. The characters and their illustrations were designed with an eye towards gender, race, and ability inclusion and players can choose from multiple hero character options to build their team of three heroes for game play.
4. Blank cards of each type of card, including Hero character cards, have been included on the print and play document with accompanying text encouraging players to create and draw their own hero characters, and their own hurdles, star, buddy, and life event cards to reflect their own experiences.

Re-usability and adaptation by young people and their health practitioners is embedded through the application of a Creative Commons Attribution Share-Alike licence. This licence allows anyone to remix, adapt, edit, and re-use the game according to their needs so long as anything created from the game is clearly attributed to the original creators and also made freely available under a Share-Alike licence for others to continue to benefit from and use.

4.5 Evaluation and Reflections

“it looks great, everyone has done a great job of it and hope it helps a lot of people” - Thoughts from a co-creator who experienced the transition process on the final version of the game

Figure 7: We worked to ensure that the characters chosen were inclusive



To start the game deal two cards to each hero's Journey Deck to start their journey.

Each turn a player takes two cards from the deck, discusses them with the other players then plays the cards to any of the Journey Decks.

Figure 8: We have included a page which demonstrates the mechanics of the game

The boardgame we have produced reflects the intended outcome for this area of the project. We have achieved a printable card game that can be repurposed to serve as an aid to understanding of a transition pathway for a young person with complex health and care needs, residing in a community setting. Although we had expected to create a game about transition, the GameJam approach means that the mechanics of the final product and the game design were unknown from the beginning. This approach allowed for true co-production with all elements of the game decided by people who have experienced the transition process. An unexpected outcome was the collaborative nature of the game which participants really insisted upon, highlighting the desire for the transition process itself to be collaborative.

Participants expressed feedback was that they really enjoyed the workshops as it gave them the opportunity to talk about their experiences with transition in a meaningful and constructive setting as participants felt keen to help others who are going through the pathway.

Continues on the next page

5 Online Learning for Healthcare Professionals about Transition

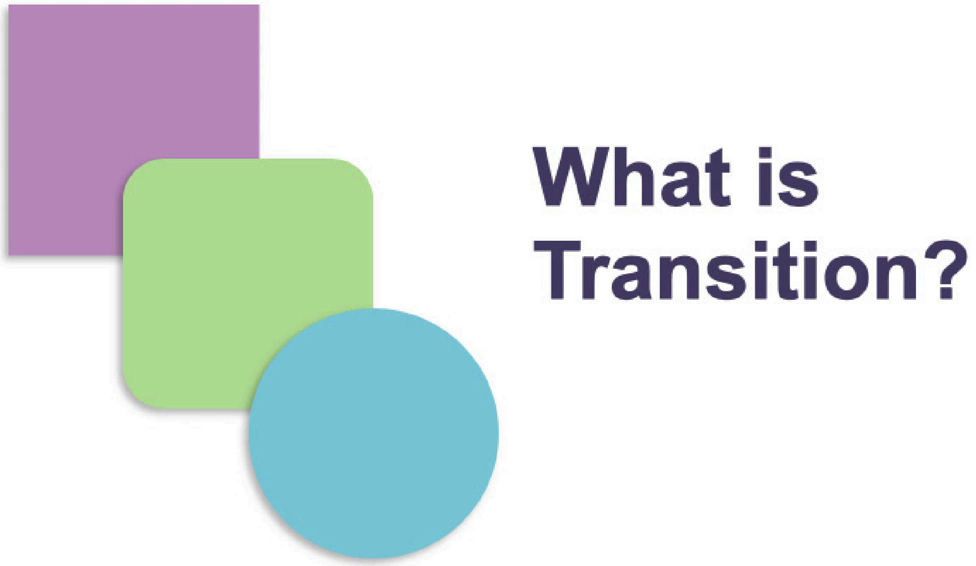


Figure 9: (SBH Scotland, 2021)

As part of this project, we have also developed an online course which is designed to support healthcare professionals learning about the transition from child-centred healthcare to adult health services. Undertaking this learning opportunity, we hope will aid fostering empathy, knowledge and understanding within healthcare systems and ultimately improve the transition process for YP and their support network. The course consists of five modules with set learning outcomes, signposting to necessary and useful resources, opportunities for reflection and a short assessment in the form of a quiz. Upon completion of the course people will receive a certificate which they can use as proof of professional development. This segment of the project benefited from input of a dedicated learning company, **Digital Bricks**.

5.1 Professional and Academic Development for Healthcare Professionals

Our course is targeted at degree educated clinical and other healthcare professionals and practitioners who support YP throughout their healthcare transition. In the original conception of the resource, there were plans to have it as a repository type platform, providing access to a curated library of useful articles, websites, and policy documents. However, it was decided that to enact proper change to practice, learning needed to be steered. In addition, self-driven (free) professional development content is needed for nursing revalidation and a structured course would be ideal for it. Therefore, the resource became a course which includes badges for completing each module and a certificate for completing the course. The resource will remain free and therefore, very accessible to anyone wanting to learn more about transition. This is our attempt to not deter anyone from taking part and continue to encourage avenues for change.

The benefits for healthcare professionals undertaking this course are many and we hope that a critical mass of learners will act to improve practices in healthcare systems. Therefore, the course will encourage healthcare professionals to reflect upon their practice not only with regard to transition, but also reveal a path towards more empathetic and productive practice in other areas of their work.

5.2 Course content

The course contains six detailed modules about the multi-faceted process that we call ‘transition’. Each module links to specific intended learning outcomes which encourage healthcare professionals to reflect on their practice, the practice of their colleagues and the healthcare system as a whole. At the end of the course learners should gain a critical awareness of how transition is experienced by YP and their families and identify key areas where improvements must be made to enhance the process. This learning is rooted in person-centred and rights-based perspectives which firmly support a move towards a healthcare system that empowers YP to have autonomy over their own care. The modules include interactive features for engaged learning, links to videos and useful websites and access to digital stories co-produced with SBH Scotland service users, and their families. These tell of their experience with transition and living with a complex condition such as SBH. The whole course takes six to ten hours to complete.

5.2.1 Module 1:
What is ‘transition’?

This module provides a definition and overview of transition which places learners on a solid foundation to begin their learning pathway. It reveals key multifaceted issues which affect the transition process, outlines the goals and principles of successful transition, and analyses the current healthcare system with regards to the transition process which learners are encouraged to reflect on.

5.2.2 Module 2:
The Role of Healthcare Professionals in Transition

This module uses self-reflection to support experiential learning. It outlines all the areas where healthcare professionals are involved in transition planning and transfer of services. In addition, the module provides opportunities for analysis of disparities that exist in the system and offer learners the chance to reflect on how practice impacts YP’s and families’ experiences of the transition process.

Figure 10: (Ibid)

Continues on the next page

5.2.3 Module 3: Legislation, Rights and Responsibility

The module focuses on the rights, legislation and responsibility surrounding transition. Following this module, learners will be able to exhibit critical awareness of legislation and policy and how it effects practice of healthcare professionals with regards to transition and healthcare for young people. Learners will be asked to reflect on their practice and consider whether they, and those around them, are doing all they can to promote YP's rights as well as the rights of all people with complex needs.

5.2.4 Module 4: Wellbeing and Salutogenesis: What adds up to good health?

Module four delves into the facets of wellbeing and salutogensis and encourages discovery of what adds up to good health and wellbeing. It's provides an overview of guidelines and framework that exist in Scotland to promote positive wellbeing and how this relates to the transition process. This module is all about looking past Young People's healthcare and being open minded to other aspects of life that may affect their transition journey. We ask learners to reflect on their practice and think about ways of implementing a wellbeing-based framework into transition processes.

5.2.5 Module 5: Setting Young People up for Success

This final module provides learning on best approaches to transition planning through fostering more empathy, communication and preparation for transition. Following completion of this module, learners will be able to assess whether YP are ready for transition and exhibit understanding of the transition planning process. We encourage learners to share anything they have learnt throughout this course with their colleagues if they feel it will help improve transition for YP. At the end of the module there is a list of resources which can be shared with YP and their families.

Continues on the next page

5.3 Evaluation and Reflections

Feedback from our project advisory group made up of healthcare professionals, representing NHS 24, the Queen’s Nursing Institute Scotland (QNIS), Edinburgh University and Glasgow Caledonian University, have been generally positive. We have utilised their constructive comments to create a robust learning platform about transition. We have achieved what we set out to do and more; not only does the resource hold digital assets in the form of a repository with learning content for healthcare professionals, but we have also created an online course which steers learning and equips learners with knowledge, understanding and guidance which they can take into their practice.

Continues on the next page

6 Final Reflections

This project, which benefited from a generous grant by The Burdett Trust for Nursing, was set to celebrate the unique contribution of nursing to optimal person-centred care. We wanted to demonstrate the way creativity and playfulness enhance our practice, supporting young people with complex needs and their families, within community settings. We also wanted to highlight the exceptional and innovative care that is offered and delivered by a dedicated team in a third sector organisation – away from the limelight of the NHS. Most of all we wanted to give our users a voice so that their plea is heard and acted upon.

The global pandemic affected our timeline and we had to adjust our original plans, but that gave us a unique and unexpected opportunity. We were able to engage with our users remotely and brought together people who would have not otherwise shared their experiences. We used facilitators who themselves had to adjust their craft and use digital platforms for the first time, whilst working with our users. This experimental approach helped to propel this unique project by removing some barriers and adding a sense of adventure to the way we progressed the work.

Looking back at what we achieved, we can be very proud of the final outcome. We successfully produced educational resources for YP, families, carers and healthcare professionals to support healthcare transition. The different elements that make up this 'product' include; digital stories of our service users, a printable boardgame and an online learning course for healthcare professionals.

What we also achieved is meaningful and productive involvement of our users in shaping and producing the various elements of the project five digital stories co-produced with service users; a printable collaborative boardgame co-created with families who have been through transition and tested by families who are going through transition themselves; and steering the project with others on the advisory group too.

We wish to thank each and every person that helped us along our journey: our families and service users, colleagues and peers at SBH Scotland and those in the NHS, members of our steering group and those facilitators and professionals who waved the magic wand to create the final product(s). Finally, a special thank you is due to our dedicated intern who helped us to pull all the strands together at the end.

References

ARC Scotland, 2017. “Facing the Future Together” [Online] Accessed at: **https://scottishtransitions.org.uk/blank/wp-content/uploads/2017/07/Facing-the-Future-Together-Report.pdf** [Accessed: 8/3/21]

ARC Scotland, 2020. “ARC Scotland’s response to the proposed Disabled Children and Young People (Transitions) (Scotland) Bill” in Scottish Transitions Forum Newsletter (Jan 2020) [Online] Available at: **https://mailchi.mp/20e515628e3a/proposedtransitionsbillresponse?e=02abc6a449** [Accessed: 8/3/21]

Bogossian. A, Gorter. J.W, et al. 2018. “Protocol for a scoping review about ethics in transition programmes for adolescents and young adults with neurodisabilities [Online] Accessed at: **https://bmjopen.bmj.com/content/8/8/e020914** [Accessed: 8/3/21]

Community Catalysts, 2021. “Alexander and AJP Dreams: [Online] Accessed at: **https://www.communitycatalysts.co.uk/story/alexander-and-ajp-dreams/**

Fortune. J, Murphy.P, et al., 2020. “Transition from child-centred to adult-oriented healthcare systems for young people with neurodisability: a scoping review protocol” [Online] Accessed at: **https://hrbopenresearch.org/articles/3-61** [Acccessed: 8/2/21]

Getting it right for every child review of 2017. [Online]. Available at: **https://www.alliance-scotland.org.uk/blog/news/getting-right-every-child-review-2017/** [Accessed 29 July 2021]

Getting to know Getting It Right For Every Child review of 2019. [Online]. Available at: **https://www.alliance-scotland.org.uk/blog/news/getting-to-know-getting-it-right-for-every-child-review-of-2019/** [Accessed 29 July 2021].

Hall. H.A, 2019. “SPICe Briefing: Transitions of young people with service and care needs between child and adult services in Scotland” [Online] Accessed at: **https://sp-bpr-en-prod-cdnep.azureedge.net/published/2019/3/29/Transitions-of-young-people-with-service-and-care-needs-between-child-and-adult-services-in-Scotland/SB%2019-15.pdf** [Accessed: 8/3/21]

Halpin, Z. T. 1989. Scientific Objectivity and The Concept of “The Other” in Women’s Studies Int. Forum, 12 (3), 285-294.

Hardy, P. & Summer, T. 2018. Cultivating Compassion: How Digital Storytelling is Transforming Healthcare, Palgrave Macmillan.

Hesse-Biber, S. N. 2017. The practice of qualitative research : engaging students in the research process, California, SAGE Publications, Inc.

Holmbeck, G. N., Kritikos, T. K., Stern, A., Ridosh, M. and Friedman, C. V. (2021). The Transition to Adult Health Care in Youth With Spina Bifida: Theory, Measurement, and Interventions. Journal of Nursing Scholarship, 53 (2), pp.198–207. [Online]. Available at: **https://pubmed.ncbi.nlm.nih.gov/33482054/** [Accessed 29 July 2021].

Hopson. B, Alford. E, et al. 2019. "Development of an evidence-based individualized transition plan for Spina Bifida" [Online] Accessed at: **https://pubmed.ncbi.nlm.nih.gov/31574471/** [Accessed: 8/3/21]

Kaufman, G., Flanagan, M., and Seidman, M. , (2015) "Creating Stealth Game Interventions for Attitude and Behavior Change: An 'Embedded Design' Model." Proceedings of the Digital Games Research Association (DiGRA)

Law Society of Scotland, 2021. "Written Evidence: Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill" [Online] Accessed at: **https://www.lawscot.org.uk/media/370259/21-01-11-mhd-disabled-children-and-young-people-transitions-to-adulthood-scotland-bill.pdf** [Accessed: 8/3/21]

Levy S, Wynd AH, Carachi R." Transition into adult healthcare services in Scotland: findings from a study concerning service users at the Scottish Spina Bifida Association" in Scottish Medical Journal. 2014;59(4):209-213. **https://journals.sagepub.com/doi/10.1177/0036933014556200**

Lewis, J., Frimberger, D., Haddad, E. and Slobodov, G. (2017). A framework for transitioning patients from pediatric to adult health settings for patients with neurogenic bladder. Neurourology and Urodynamics, 36 (4), pp.973–978. [Online]. Available at: **https://onlinelibrary.wiley.com/doi/abs/10.1002/nau.23053** [Accessed 29 July 2021].

Liamputtong, P. 2020. Qualitative Research Methods, Oxford University Press.

Michael, D. R., and Chen, S. L. (2005). Serious games: Games that educate, train, and inform. Muska & Lipman/Premier-Trade.

Michael, D., and Chen, S., (2006) Serious Games: Games That Educate, Train and Inform, Thomson, Boston, Mass, USA

NHSGGC : Person Centred Health and Care. [Online]. Available at: **https://www.nhsggc.org.uk/about-us/professional-support-sites/nurses-midwives/care-assurance-system-cas-excellence-in-care-eic/nhsggc-cas-standards/acute-cas-standards/standard-9-person-centred-health-and-care/#** [Accessed 29 July 2021].

Patient Voices. 2020. Pip Hardy and Tony Sumner: co-founders of the Patient Voices Programme [Online]. Available: **http://www.patientvoices.org.uk/who-we-are/who-are-we** [Accessed 24/03/21.

PlayDecide, **https://playdecide.eu/about** , coordinated and supported by Ecsite (European network of science centres and museums)

RealTalk, 2020. “Our Story” [Online] Accessed at: **https://www.realtalkproject.org/our-story-1** [Accessed: 31/3/21]

RealTalk, SBH Scotland, 2021. Transitioning Through Care: Storytelling Workshops with SBH Scotland. Unpublished.

Rieger, K. L., West, C. H., Kenny, A., Chooniedass, R., Demczuk, L., Mitchell, K. M., Chateau, J. & Scott, S. D. 2018. Digital storytelling as a method in health research: a systematic review protocol. BMC, Systematic Reviews (41).

SBH Scotland, 2021. Workshop Recordings. Unpublished.

Schumacher K. & Meleis A. (1994) “Transitions: a central concept in nursing” in IMAGE: Journal of Nursing Scholarship 26(2), 119–127

Scottish Government, 2019. “Neurological care and support: framework for action 2020-2025” [Online] Accessed at: **https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/pages/6/** [Accessed: 8/3/21]

Scottish Government, 2021. “Getting It Right For Every Child” [Online] Accessed at: **https://www.gov.scot/policies/girfec/** [Accessed: 8/3/21]

Scottish Parliament, 2020. “Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill” [Online] Accessed at: **https://beta.parliament.scot/-/media/files/legislation/bills/current-bills/disabled-children-and-young-people-transitions-to-adulthood-scotland-bill/introduced/policy-memorandum-disabled-children-and-young-people-transitions-to-adulthood-scotland-bill.pdf** [Accessed: 8/3/21]

Shubik, M. (1971), ‘Reviewed Work: Serious Games by Clark C. Abt’, Policy Sciences, 2(3), 332-334. Retrieved June 21, 2021, from **http://www.jstor.org/stable/4531446**

Storycenter. 2021. What We Do [Online]. Available: **https://www.storycenter.org/** [Accessed 24/03/21.

Spina Bifida
Hydrocephalus
Scotland

Spina Bifida Hydrocephalus Scotland

The Dan Young Building,
6 Craighalbert Way,
Dullatur, Glasgow,
G68 0LS

Tel: 03455 211 811
Email: mail@sbhscotland.org.uk
Web: www.sbhscotland.org.uk
www.hydrocephalusscotland.org.uk

Burdett Trust for Nursing

Real Talk

Digital Bricks

Spina Bifida Hydrocephalus Scotland is a trading name of the Scottish Spina Bifida Association.
Scottish Charity No SC013328. A company limited by guarantee. Registered in Scotland Number 213050.