DEFINING THE OPTIMAL MODEL FOR TRANSITION FROM CHILD TO ADULT PROVISION

FOR YOUNG PEOPLE WITH DISABILITIES AND/OR DEVELOPMENTAL DIFFICULTIES IN GWENT

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Forward

For many parents and carers of children with disabilities and/or developmental difficulties, the term Transition from Child to Adult Provision can conjure up such visions as a vast black hole, a balloon being burst, a frayed, thinning comfort blanket or a broken safety net. For others, it invokes a desire to bury their head in the proverbial sand or to tighten protective arms, both literally and metaphorically, around their children.

Parents/carers fear that when the time comes for their young people to change over from Children Services to Adult Services, they will be abruptly catapulted into this monumental transitional phase. What they really need, as this report highlights, is gentle encouragement and a welcoming gateway to a timescale that will allow them to adapt on both a practical and emotional level. They also need to be given ample time to consider choices and to acknowledge that, whilst it's a time of great change, both to the parent/carer and young person it does not need to be a daunting, overwhelming and debilitating experience. It can be exciting, re-assuring and enabling.

I am one such parent of a child with disabilities and/or developmental difficulties (DDD) who is fast approaching adulthood and like many parents in my position, we have long been empowered to be instrumental in our children's care, development and wellbeing. We now need to be empowered to accept that our children need to be, or want to be, less reliant on us and to entrust others to assist in steering their future, because if we do not we may hinder their self-reliance which is a crucial skill for them to develop in adulthood. However, it must be understood that, due to their complex needs, this may be unrealistic for some young people, or at the very least extremely challenging.

Many of us parents have been in no doubt from very early on in our children's development that the time would eventually come when the network of support they have been receiving will fragment and cease when they become an adult at age eighteen; a figurative age in the case of many young people who have a much younger mental age.

The questions that have rumbled steadily in our subconsciousness for so long now become incessant in the need to be answered, such as what happens now? Who do we go to for advice? How will my child and I adapt?

Such questions as these are challenged and answered in this report which sets out the adoption of a new model of transition across Gwent for young people with DDD aged 14-24 years old, with the fundamental aim that no young person is disadvantaged due to poor transitional care and that transition is very different for each and every young person.

The report identifies the problems that were found to be barriers to the success of transition. It also clarifies the solution, highlighting the key principles to be prioritised; these being unified standards plus preparation and empowerment for the service users and their families by way of a proposed workforce, a single integrated transition plan and an online portal. These are all deemed to be intrinsic in achieving an effective transition for young people.

By placing young people and their families at the heart of the transitional planning processes and highlighting the importance of parents/carers, young people and professionals within health, education and social services working in partnership with a holistic approach, this report could provide the catalyst for the optimal model of transition to adult provision being rolled out across Gwent.

It fills me with optimism and confidence that this proposed model would be instrumental in enabling our young people to strive and continue to develop throughout adulthood, allowing them to reach their full potential in a safe, fulfilling and happy environment.

Sarah Ganderton, Parent

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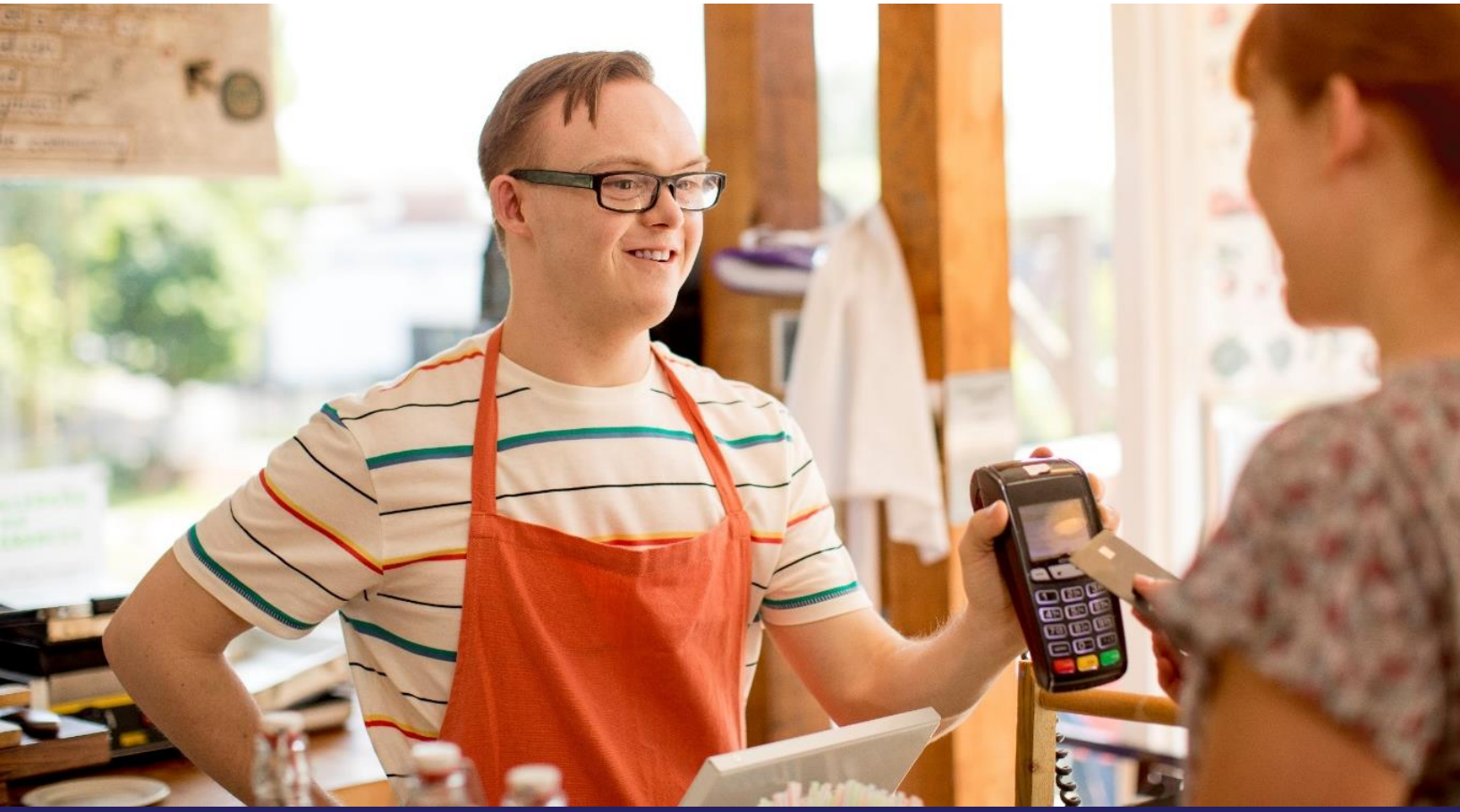


1 INTRODUCTION

This report proposes a new model of transition across Gwent for young people aged 14-24 years moving from child to adult services, based on the findings of a large-scale research project carried out by Sparkle. Young people, parents and professionals in the Gwent area were consulted by means of interviews and focus groups in the development of this model. The proposed improvements within this report are, therefore, driven by the combined ideas of service users and service providers, many of whom have direct experiences of transition from child to adult services.

The Social Services and Wellbeing (Wales) act 2014 explicitly states that people should have control over what support they need, and making decisions about their care and support as an equal partner. Furthermore, they should have easy access to information and advice, underpinned by a preventative approach to meeting care and support needs. However, there is currently no explicit resource for young people or their parents regarding the options available to them following transition, and the majority of young people appear to have little meaningful involvement in the planning or delivery of their care package following transition to adult services. The underlying principles of this act are that people are at the heart of the system, and timely support will prevent escalating needs. Providing timely and comprehensive support at transition is central to this. This ethos has been spelt out in more detail in the Care Quality Commission report 'from the Pond into the Sea' regarding children's transition to adult health services for England highlighted very similar findings to those found by our research. Thus future CQC inspections within England will now explicitly look for evidence that Commissioners have listened to, and learnt, from young people, and that a transition plan, and a lead professional to support young people through transition should be in place. All of these aspects are addressed within the proposed 'optimal model for transition from child to adult provision' report.

1.1. WHAT IS TRANSITION?

"Many families feel like they fall off of a precipice when it comes to transition, or liken it to going into a black hole into adult services." (Professional: Child Services)

Transition is a simple word for a complex process. The term 'transition' for the purposes of this report, refers to the journey a young person makes into adulthood which, for young people with complex needs, includes the gradual change or transfer from one service to the next. Transition for young people with complex needs should be a purposeful and planned process (NICE, 2016). As early as the age of 14, a young person and their family ought to begin working with professionals to make preparations for the young person's post-18 future. During this time, the young person's perspectives should be understood, and their health, educational and psychosocial needs should be regularly reviewed and assessed by professionals (Care Quality Commission, 2014). Transition support and services are, therefore, provided in order to facilitate the gradual transfer from services designed for a child to adult orientated systems (Blum et al., 1993; Beresford, 2004).

Transition is, of course, broader than a simple transfer between services; indeed, transition to adulthood is an essential and natural part of any young person's life which might involve leaving school, going to college or university, moving out of the family home, starting work, making new friends, and learning to lead an independent life. Transition involves physical, social, emotional and psychological changes as a young person starts their journey into adult life, makes important decisions about the future and faces new challenges, opportunities and risks. Transition into adulthood is, therefore, an inherently daunting time for any young person and their family.

It has long been recognised that young people with disabilities and/or developmental difficulties or complex health needs face far greater challenges in their transition to adulthood, requiring extra consideration, planning and support. In many cases, these young people have been receiving support outside the family support system for many years that address health, social, educational and psychological needs. The complexity of needs often means that services received as a child will need to be continued into adulthood, therefore, the young person will

need to transition from child services into adult-orientated services. It should then become the responsibility of the service to ensure that each young person is not disadvantaged by the move from child to adult services, that every individual has the opportunity to thrive and fulfil their full potential (Beresford, 2004).

1.2. LEGISLATIVE FRAMEWORKS AND GUIDANCE

Prior to 2018, two key policy frameworks have underpinned the transition process: The National Service Framework (NSF) for Children, Young People and Maternity Services in Wales (2006) and the Special Educational Needs (SEN) Code of Practice in Wales (2004). The NSF sets out the *minimum* quality of services that young people have a *right* to expect and receive regarding transition. Fundamental ideas such as an inter-agency system to identify young people, key worker responsibilities until the young person reaches 25 years old, support for the family and joint-organisation transition planning, amongst others, are recognised as minimum requirements in transition, that should be actioned (WAG, 2006). However, of the actions relating to transition, *none* were prioritised as requiring immediate attention and instead, were set to be delivered over the 10 years of the NSF programme. Therefore, while there are excellent recommendations for improvement, little has been done to implement these ideas thus far.

The SEN Code of Practice in Wales also provides a set of guidelines and practical advice to Local Education Authorities (LEA), setting out a step-by-step process for transition from year 9 onwards (NAfW, 2004). However, the SEN code of practice for Wales offers limited advice for those *without* a statement of SEN and lacks comprehensive guidance relating to the input of agencies such as social care or health services. This means that transition lacks a clearly defined pathway for multi-agency working, which may contribute to confusion over which agency takes the lead in transitional care. Furthermore, the Education, Lifelong Learning and Skills Committee (2007) in Wales expressed concern over the effectiveness of the transition process, highlighting that it is an overly complicated and bureaucratic system which needs simplifying and clarifying (NAfW, 2007).

In response to these concerns Gwent, funded by the European Social Fund, produced the "Pan-Gwent Multi-Agency Transition Protocol for Young People with Disabilities and/or Additional Learning Needs" in 2012, with transition guidelines for those who were likely to experience complex transitions (Multi-Agency Transition Group, 2012). Yet despite this document, the findings of this report suggest that many professionals lacked awareness of its existence or expressed dissatisfaction with its guidance. While areas of Gwent certainly aim to operationalise this document, the consensus of our findings suggests that it lacked clarity, had poor implementation and, as we enter 2019, may be due an update. Please refer to Appendix A for a detailed account of these legislative frameworks and guidelines.

1.3. ACADEMIC LITERATURE

Current research in this field consistently reports on the negative experiences of transition for young people with DDD and their families. The consensus in the literature suggests that young people experience transition as a time of extreme pressure, fear, confusion, uncertainty and panic, with many parents feeling overwhelmed and unsupported. The literature around the topic highlights that young people and families alike, are dissatisfied with the current structures and processes surrounding transition and that both a structural and attitudinal change is needed to make meaningful changes in the future. Yet, notably, there is very *little evidence* of what an *optimal* model of transition may look like, nor is there any active evaluation of services.

Indeed, while the literature around transition is certainly growing and multiple perspectives such as young people and caregivers are being sought, there remains a gap in knowledge. To date, there are few studies that have 1) united the thoughts of young people, caregivers and professionals on transition 2) addressed shared concerns across a range of disabilities and/or developmental difficulties and 3) proposed a functioning model for transition. The focus around transition and services for young people has mostly been disease or condition specific, and while this is extremely valuable to determine specific experiences, it does not address the holistic, multidisciplinary, yet individualistic reality of transition. Transition needs to be addressed on a universal scale; inclusive of all conditions, relating to disabilities and/or developmental difficulties, and services, in order to give real-world, functional solutions that

can be operationalised across the UK. Please refer to Appendix B for a detailed account of the academic literature.

1.4. TRANSITION IN GWENT

Despite a plethora of national and regional guidance, academic publications and charity resources across the UK, young people with disability and/or developmental delay (DDD) and their families are consistently reported in publications to have poor experiences of transition with many feeling worried, confused and unsupported in the journey to adulthood. The Children's Commissioner in Wales has listed "transitions to adulthood for all young people requiring continuing support and care" as a key priority in their 2016-2019 plan and produced recommendations within the 'Don't Hold Back' report on transition (2018). However, our research indicates that these recommendations are yet to reach families living in the Gwent area. This is not to suggest that agencies in the Gwent area have been inactive in developing transition, however, these efforts appear to be ineffective at achieving their aims at present. There are projected to be a total number of 32,635 young people aged 14-18 years living in Gwent in 2019 (WAG, 2016), and with a national average disability figure of 8% for children (DfWP, 2018), there are approximately 2,611 young people with disabilities or developmental difficulties who fall within the typically defined transition age group (14-18 years old).

While the transition process has indeed seen improvements over the past decade, further developments are essential in order to fulfil Gwent's vision that "young people with disabilities and additional learning needs will have well-planned and well-coordinated transition support throughout their transition into adulthood" (Multi-Agency Transition Group, 2012).

1.5. WHO ARE SPARKLE?

Sparkle is the official charity partner of the Serennu Children's Centre and each year must raise more than £600,000 to fund the suite of vital, enhanced services that they currently offer. The guiding principle for Sparkle is to ensure children with disabilities and/or developmental difficulties and their families are fully supported to participate in valued childhood experiences,

and have access to the same range of opportunities, life experiences, activities and family support, as any other child and their family.

Families are at the centre of the decision making by Sparkle, achieved by proactively obtaining the views and opinions of the children, young people and families who access the Centre by undertaking evaluations throughout the year, gathering feedback and looking at ways to improve and develop service provision at the Centre. In March 2018, an event was held at Serennu Children's Centre to gain insight into the extent and importance of transition improvement in Gwent. It brought together young people, parents and professionals, including chief officers, social service managers, transition support officers, head teachers, education specialists and family liaison officers (although invited, no health representatives attended). Transition was identified as an area of concern by all who attended, which formulated a strong rationale for evaluating the current transition model in Gwent (see Appendix C for more information). Subsequently, Sparkle made a commitment to fully understand these experiences and dedicated a full-time role to research the optimal model for transition from child to adult services.

1.6. BACKGROUND TO THE SERENNU CHILDREN'S CENTRE

The Serennu Children's Centre, a purpose-built award-winning building set within its own grounds, opened in 2011 to provide integrated care, treatment and leisure activities to children and young people aged 0-18 years old with disabilities and/or developmental difficulties from Newport, South Monmouthshire and South Torfaen. It was identified that children who have a disability and/or a developmental difficulty and their families have needs that require interventions from multiple service providers, such as social services, health, education and the third sector and, therefore, one of the primary benefits of the Centre is that families can access the treatment, care, information and support they need under one roof.

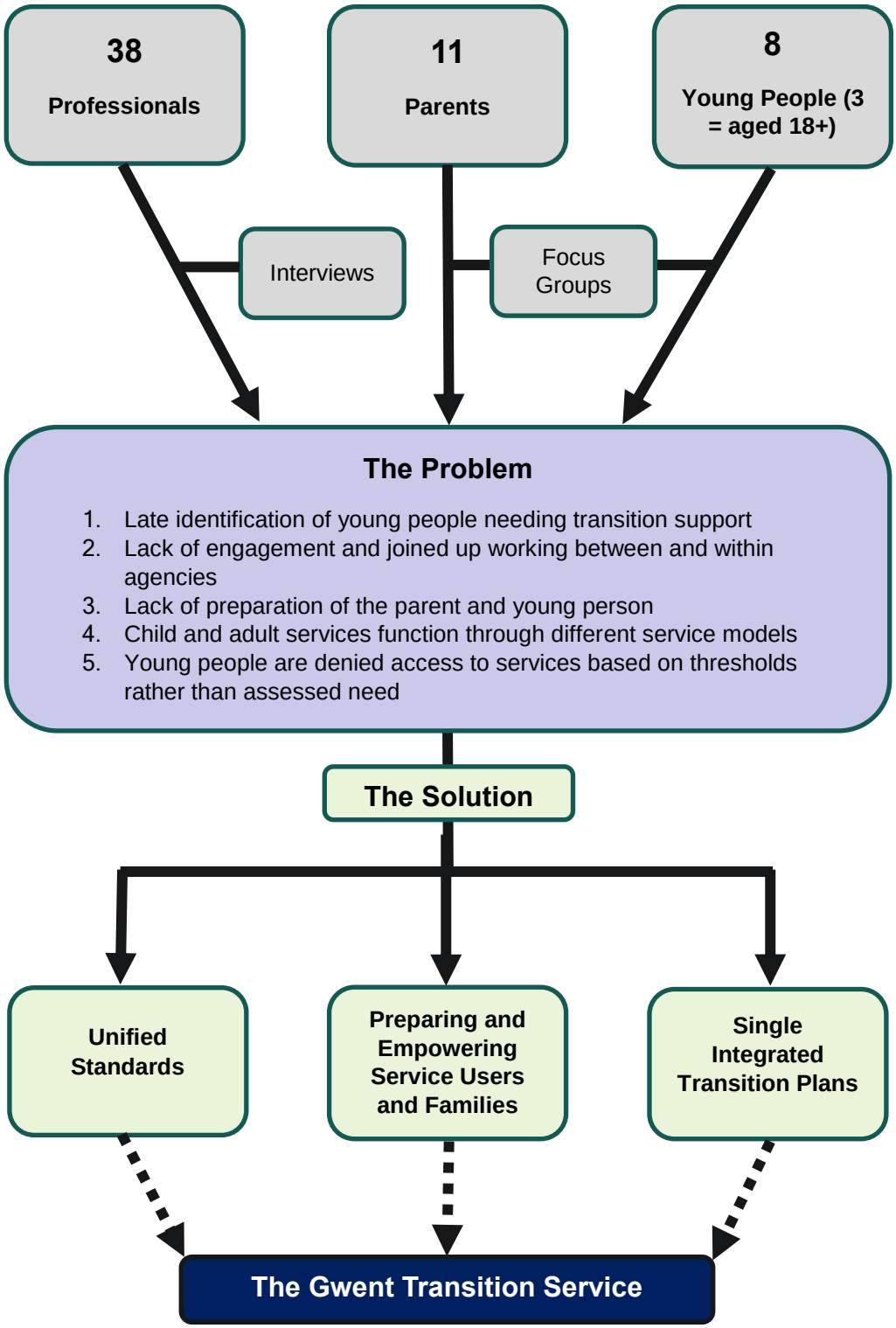
1.7. RESEARCH AIMS

The present report aims to understand the process of transition from child to adult services currently delivered within Gwent. To fully capture the complexity of transition across a range of

individuals (including professionals, parents/caregivers, and young people), a qualitative design was considered the most appropriate. It aims to understand service user and service provider experiences, achieving rich, detailed accounts of transition with the vision of establishing an optimal model for transition for young people with disabilities and/or developmental difficulties (DDD).

During the period, May 2018 – February 2019, the Psychology Research and Development Officer at Sparkle (Chloe Hurrell) undertook the Gwent-wide research project, which involved a literature search, research at a local and national level, evidence-based academic research, and research into legislative and policy frameworks. Through interviews and focus groups, participants were encouraged to engage in an open discussion to reflect on the process of transition, what is going well, what is not going well, what service user and provider priorities are in transition, and how services might be improved for the future. For a detailed breakdown of the methodology, please refer to Appendix D.

Figure 1: A breakdown of the research including participants, the problem and the solution.



2 THE PROBLEM

2.1. METHODS

Data from interviews and focus groups were coded, rigorously analysed and separated into themes to understand the collective experiences of transition from young people, parents and professionals in Gwent. Professionals included those in child and adult services, across agencies including health, social care, education and Careers Wales, with professions ranging from teachers, therapists and social workers to service managers and divisional directors. Young people ranged from 14-24 years old and included both those who are in the planning stages of transition (e.g. 14-17 years old) and those who have recently transitioned (18-24 years old). Likewise, parents and caregivers also represented those on either side of the transition process.

2.2. FINDINGS: PROBLEMS IN TRANSITION

Five key themes emerged from the research that were deemed fundamental barriers to the success of transition.

1) Late identification of young people needing transition support

Gwent guidelines state that professionals should be aware of individuals from 14 years old who are likely to transition to adult services with additional needs. However, some services do not identify transition plans until the young person is at least 17 years old. Indeed, many professionals detailed experiences where referrals were received too late to provide the level of transition support they felt was required. They recognise that certain young people are more likely to 'slip through the net', in particular, those who are not in special schools, not 'looked after', attending out-of-county schools or not known to services.

"Often they would come to us at a crisis point, at 17 or 18 and ¾ or 18 and ½ and we'd be like "how did we not know about this young person?" They'd been in the system and everybody knows about them but they haven't been to talk to us about them." (Professional)

2) Lack of engagement and joined up working between and within agencies

Relevant agencies often take a silo approach to transition planning; each agency will create their own plan without conferring with each other. Services are unable to prioritise multi- and within-agency transition planning meetings, which can lead to duplication of assessments and ultimately, a lack of an effective handover. This is both time and cost inefficient for all services and impinges on service user experiences of transition.

"It can be quite disjointed between health, education and social services…we end up planning transition in isolation." *(Professional)*

3) Lack of preparation of the parent and young person

Services do not prioritise supporting and preparing the family for transition, therefore, families feel that there is no one they can turn to for advice. There is a distinct lack of access to accurate information about the process, and what is happening at any given stage of transition. Families are distraught and unconvinced that effective transition planning is taking place due to lack of communication between professionals and families. As a result, parents often become their own advocate to help them navigate their way through the system. This is hugely anxiety-provoking, confusing and stressful for parents and young people, particularly when services provide incorrect information. As recognised by professionals, this "sets families up to fail" as they are not equipped with the skills to thrive. The parental fear of 'letting go' is consequently exacerbated, which inhibits the young person's ability to develop self-reliance, an essential skill for adulthood.

"It frightens me, the idea of change and having uncertainty… for people with an additional need perhaps, or learning difficulties, perhaps… [transition] can tend to be a more daunting time" *(Young Person)*

4) Child and adult services function through different service models

Child services focus on providing support to the *family* so that they are best equipped to support their young person as they develop.

"…there is nobody at the moment, nobody that can advise me what he should do… I'm just ringing up people randomly" *(Parent)*

Yet *adult services* focus on identifying the individual *young person's* specific needs and providing support to overcome these deficits. While neither service model is considered superior, the abrupt cultural change and approach to service delivery has an adverse impact on the experience of transition for the entire family. It was evident during this research that certain services are disengaged from the transition process, and when clinical responsibility is handed over to a different service model, further issues can manifest which may not be optimal for young people with complex medical or mental health needs.

"Our focus is on adult whereas children's services are more focused on the children and the family so there's a different dynamic that's going on and I think that's something that needs to be a bit more blended" (Professional)

5) Young people are denied access to services based upon thresholds rather than need

Often when young people move from child to adult services, adult services will carry different eligibility criteria and thresholds which results in some young people unable to access previous levels of support (see Appendix E for example). Therefore, child and adult services do not directly align and despite a young person's needs not changing on their 18th birthday or having received support from children's services, there is an increased risk of having reduced or being completely denied post-18 support. Social needs, in particular, are often the first need left un-met and parents are relied on to set up and run support groups to meet this need. Young people are described as needing to reach crisis, or their condition worsen, before adult services will react and reinstate previous levels of support provided in child services.

"The worst case scenario is that the young person needs to get really poorly again and then adult services must get involved and react. Sometimes the young person needs to get to crisis again." (Professional)

2.3. FINDINGS: POSITIVE CONTRIBUTIONS IN TRANSITION

The following section reflects the positive experiences and examples of good practice, as well as the perceived positive contributions to transition, which would be required for future improvements. In some instances, a positive contribution was recognised but not used frequently enough. Overall, four key themes emerged.

1) Person-centred approaches are invaluable

Families and professionals alike agree person-centred practices are of highest priority; the young person should be listened to, have choices, be happy and safe in their adult life. They stress that understanding the hopes, dreams and needs of the young person from an early stage is integral to the success of the transition since the process is entirely unique to each individual young person. However, many question whether services are fully achieving person-centeredness and believe we could be doing more. Many believe that young people should have the opportunity to attend annual reviews, regardless of their abilities, and be fully involved in decision making. To enable this, young people must be prepared and supported in anticipation for transition so that they are able to cope emotionally, have enough time to consider choices and learn the skills needed for adulthood. Indeed, embedding person-centred approaches and providing anticipatory support engages young people in transition, encouraging the development of autonomy and self-agency. Furthermore, professionals felt that parents could be better supported to recognise and respect the emerging autonomy of their young person.

"I always had a choice. I could either come to my review or go to the lesson. But they were always very good because they always gave me that choice… everybody's needs are different. No one child is the same... So something that might be important and a lot for one child might not be important for the other child."

(Young Person)

2) Shared responsibility for transition across child and adult services

Professionals feel that a whole-system, collaborative approach to transition is essential to sustained positive outcomes in transition. To achieve this, all stakeholders need to share responsibility for

transition, clearly define their roles, and actively establish shared goals and action plans. Child and adult services should work together, for example through multi-agency meetings and joint clinics, so that families can expect a genuine partnership and trust that both services are taking ownership for transition planning. Agencies need to continue sharing best practice ideas, engage in problem-solving, and learn from each other's successes in transitional care. Whilst child services may take a lead in ensuring young people and their families understand the transition process, adult services need to be visible *from the beginning* and build trust with the service user and family.

We've stopped it being called a children's issue…People realise that it's probably an adult services model issue as much as the children's services model. People are taking responsibility. (Professional)

3) Formal and informal support networks

Receiving support through established services, such as schools, and informal support networks, such as family, is important for young people and their families. Young people are reassured most by those they trust and who know them best. They value the support of their families, yet they also prioritise support from friends who can share their experiences and offer alternative insights; particularly when parents cannot see their perspective. Transition officers are seen as the most important source of formal support, acting as someone who can oversee the process and alleviate anxiety through information sharing and problem-solving. They are perceived by professionals as best positioned to understand the young person, the family and are able to capture the entire vision when elements get lost. Transition officers take the lead, guide the entire process and can offer support to the young person, the family and the professionals.

"…having the transitional officer, that was great because you had somebody and you had somebody that actually knew your child, isn't it, which makes a huge difference." (Parent)

4) Enhanced relationships between agencies

Professionals agreed that transition relies heavily on multi-agency working, therefore, building positive working relationships between

agencies is essential. This improves communication, allowing for better handovers, increased awareness of services, and opportunities for consultation and advice. Professionals are better informed when communicating with young people and families, thus allowing for accurate signposting and improving overall experiences of transition. However, meaningful connections are not always taking place on the ground or universally. Without enhanced relationships between agencies, transitional care can be jeopardised, such as when professionals leave or move into different roles. Indeed, transition should not rely on the willingness and personality of individual workers to uphold connections between agencies and calls for a whole team effort in this matter. Potential facilitators of effective multi-agency working were identified by professionals as joint training and the co-location of teams.

"Transition also works well when professionals actively make and sustain relationships – building relationships is one of the foundation pillars for getting a positive transition outcome" (Professional)

2.4. ADDITIONAL CONSIDERATIONS

As we progress to identify solutions or improvements within this report, it should be noted that ongoing influences such as legislation, funding cuts and funding disputes have significant impacts on the experiences of transition. While no model we propose can directly influence these factors, those delivering transition services need to remain vigilant as to the additional pressures this creates for young people and their families.

"Transition is about a sustainable stepping stone and getting where you want to be because you have done the planning beforehand." (Professional)

2.5. BENCHMARKING

To identify the gold standard model, it is important to report that Sparkle reached out to 46 organisations including relevant charities and groups who work with young people with DDD. They were asked to comment on their observed experiences of transition, share publications and resources, contribute their recommendations for future transitional care, and finally, to identify any areas in the UK or

organisations considered to have an excellent transition to adulthood process. None were able to provide suggestion or evidence of a highly commendable or gold standard model for transitional care (refer to Appendix F for a full list of organisations). However, during searches, three initiatives were found to have interesting contributions to transition and were considered within this report's proposed service delivery model:

- Real Opportunities Project (funded by the European Social Fund) that operated across 9 local authorities in Wales from 2011 until 2014, and engaged with 1,766 young people over its lifetime (Beyer, Kaehne, Meek, Pimm and Davies, 2014).
- "Preparing for Adulthood" programme, funded by the Department for Education, which offers a website, resources (e.g. audit tools), workshops for parents and training for professionals to develop and share best practice. They currently only operate in England.
- The 'Ready, Steady, Go' transition programme introduced at the University Hospital Southampton NHS Trust, which offers a pack of resources designed to support high-quality transition for young people moving to adult healthcare. Recognised by NICE guidance, the programme provides structure and aims to reduce the risks associated with moving to adult services. This example does not relate to general implementation of all NICE guidance, but specific implementation of a specific piece of guidance (NICE, 2017).

"There is a lot to be taken into account around transition… but I would say that it is a very very poor process… You're calm on top but you're like a duck underneath, you're chasing your tail trying to get everything right quickly… It can be a challenge to make sure that it goes smoothly." (Professional)

3 THE PROPOSED OPTIMAL MODEL FOR TRANSITION

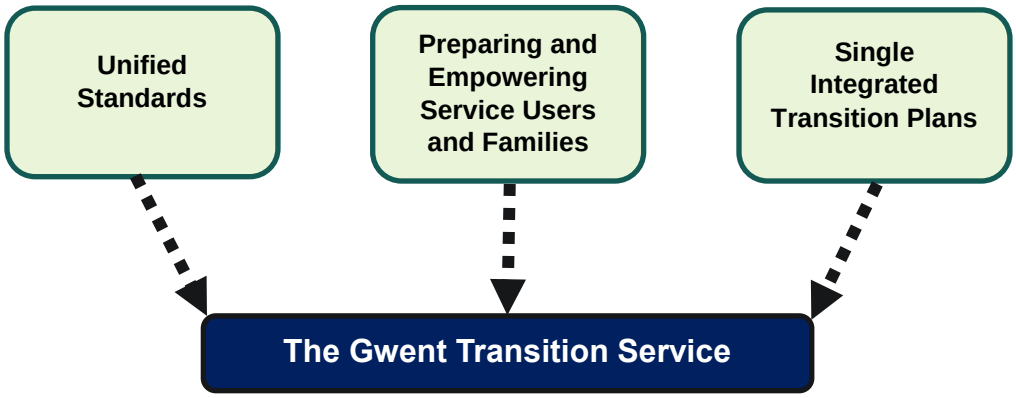
3.1. THE GWENT TRANSITION SERVICE

We propose the adoption of the ‘Gwent Transition Service’ for young people with DDD aged 14-24 years old. Enabled by a team of specialised transition workers, the new service will transform transitional care and create a ‘gold standard’ service model to meet the needs of service users and maximise efficiency for professionals. Our priority is to ensure that young people with DDD are seen by a dedicated team in a timely way and that no young person is disadvantaged due to poor transitional care.

The service will consist of a team of professionals, including a dedicated manager, transition officers, support workers and administrator support. Together, they will provide a dedicated service for transition, underpinned by three key principles.

3.2. KEY PRINCIPLES

Within the proposed service delivery, the following key principles should be prioritised in order to have a substantial impact on the experience of transition.



1) Unified Standards: Agencies need to work together to provide a whole-system response to transition, which is transparent and consistent. Child and adult services need to work together to create *unified policies, guidelines, eligibility criteria and thresholds* and maximise inter-agency collaborative working. This process will require regular audit and be supported with staff training to ensure changes are implemented.

2) Preparing and Empowering Service Users and Families: Young people and families need to be encouraged to begin early preparation for transition; thinking about future hopes, ambitions and plans from the age of 14 years old. Utilising modern approaches, including a fully accessible online planning facility (web-based), young people and families will be prepared for transition with both practical and emotional support. Early preparation and empowerment provides vital opportunities for person-centeredness and ensures proactive transitional care, rather than reactive care.

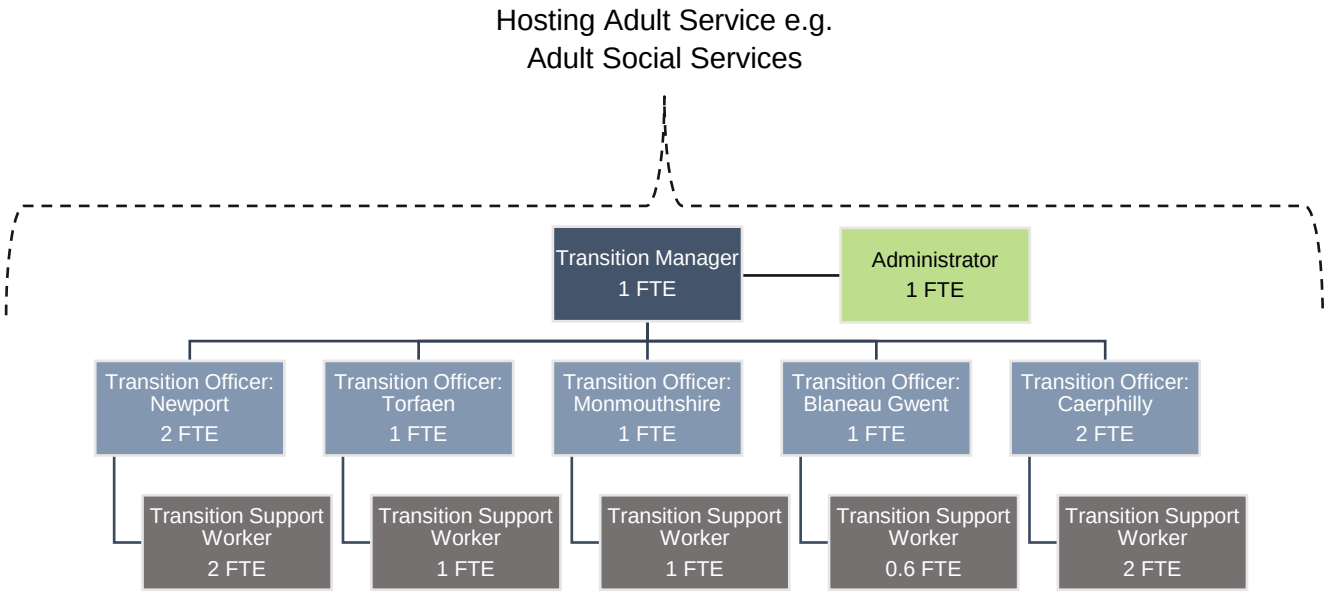
3) Single Integrated Transition Plans: Young people will receive *one* highly individualised plan which meets their needs, strengths, interests and addresses any potential risks to achieving goals. It will unify transition plans from multiple agencies involved with a young person, reducing the risk of duplicated work and creating an easy-to-follow plan for the young person and family. Plans will be drawn up prior to transition (14-17 years old), communicated effectively, and then built upon throughout adult services according to the needs of the young person.

3.3. WORKFORCE STRUCTURE

The Gwent Transition Service would optimally be placed *within an adult team*, such as adult social care, and would foster strong links between social care, health, education and the voluntary sector. This would allow adult services to build early relationships with the young person and the family, fully understand each young person's potential future needs and, therefore, foresee future caseloads and expenditure. It allows for early planning, since adult services will begin working with a young person from 14 years old, and also give services the opportunity for proactive transitional care, rather than reactive care. Ultimately, the young person will remain within the adult services for the rest of their lives, thus it is important that

they are the key link, starting with close work with children's services to understand their needs and family situation.

The figure below reveals a proposed workforce/staffing structure for the Gwent Transition Service, recognising three levels of staffing and subsequent expertise:



Transition Manager: £37,570.00 - £43,772.00 per annum

The Transition Manager is responsible for planning, maintaining, developing and overall management of the Gwent Transition Service in accordance with relevant legislation, policies, guidance and procedures. They will provide leadership, have in-depth specialist knowledge of transition and be accountable for the smooth operation of the service, both in a business and service user experience capacity. They will offer a point of escalation for conflict resolution and offer guidance across multiple agencies. They will be responsible for overseeing the development and maintenance of single unified standards agreed between all agencies. The Transition Manager role engages with stakeholders and policymakers at organisation level to support the development of inter- and within-agency transition policies, guidelines and processes across Gwent. Key responsibilities include:

- Collaborating with relevant agencies to fully review policies, guidance and procedures develop unified standards of transition to be applied across child and adult services in all areas of Gwent.

- Developing auditing tools and encouraging agencies to measure the process and success of their transitional care, compiling an annual report which states these results and compares agencies across Gwent.
- Providing professional leadership for staff within the transition team, supporting them to have the appropriate tools to carry out their role.
- Monitoring and evaluating the Gwent Transition Service, implementing strategies to improve the service based on service user and provider feedback.
- Disseminating the learning from the Gwent Transition Service model regionally and nationally, as required.

(Please see Appendix G for full job description).

Transition Officer: £24,214.00 - £30,112.00 per annum

The Transition Officer will provide exemplary transition support, taking ultimate responsibility for the experience of young people in transition from child to adult services aged 14-24 years old. They will have responsibility for identifying and working extensively with young people who are likely to have more complex or problematic transitions and will require support e.g. young people receiving support from two or more agencies, or who are unlikely to successfully transition without support to adult services. They will manage a caseload, working in close collaboration with young people and their families, to develop Single Integrated Transition Plans that are sensitive to the holistic needs of the individual young person. The Transition Officer will work in partnership with services to ensure multi-agency involvement and facilitate transition meetings in their locality (see Appendix G for full job description). Key responsibilities include:

- Managing their own caseload, undertaking key worker responsibilities, for children and young people with disabilities and/or developmental difficulties in the age range of 14-24 who need transition support.
- Working in partnership with services to identify young people aged 14-24 years old within an identified geographical area who are likely to have complex or problematic transitions
- Planning and delivering a Single Integrated Transition Plan, which clearly communicates the wants and needs of the young person, and compiles the recommendations of all agencies involved, where necessary.
- Working in collaboration with the wider transition team to produce a multi-agency joint training package.

- Delivery of mandatory staff training on transition within a defined geographical area.
- Providing information, advice and assistance services (IAA) to young people and families on request, giving options of phone and face-to-face information sharing.

(Please see Appendix G for full job description).

Transition Support Worker: £18,813.00 - £20,795.00 per annum

The Transition Support Worker will work directly with young people themselves, providing low-level programme specific support, working towards pre-determined Individual Skill Development Programmes for relevant young people. They will support these young people to develop key skills for adult life according to their assessed needs, e.g. using public transport, cooking, interview skills, social skills, personal hygiene, and work towards inclusion within the wider community. To do so, they will support in the running of a programme of workshops throughout the year across the county (in partnership with local charities, guest speakers and schools, for example) aimed at preparing and equipping young people for transition. In addition to providing low-level support, Transition Support Workers will support in delivering an agreed package of training and workshops for both professionals and parents/carers, supporting the Transition Officer. Key responsibilities include:

- Providing low-level support within a group setting (e.g. Independent Living Skills Group), with some 1-1 work where necessary, to develop and work towards Individual Skill Development Programmes.
- Where necessary, assessing and observing young people in their home and school settings to understand current skill levels and identify areas of improvement for adulthood.
- Supporting and facilitating agreed workshops, where appropriate, aimed at preparing the young person and family for transition to adult services.
- Supporting in the delivery of an agreed joint training package to professionals with the aim of raising awareness of each other's roles, responsibilities and processes.

(Please see Appendix G for full job description).

Administrator: £17,652.00 - £19,020.00 per annum

The administrator will act as an assistant to the Transition Manager and provide comprehensive administrative support ensuring a smooth and efficient service. They will manage and coordinate diaries as required, arrange appointments and meetings, book rooms and refreshments, deal with

incoming and outgoing mail, and undertake administrative work for meetings. They will be required to keep databases up-to-date and maintain/update a website. They will act as the main point of contact for the Transition Manager and have excellent knowledge of the Gwent Transition Service. Key responsibilities include:

- Undertaking administrative work for relevant meetings, ensuring that agendas and paperwork are prepared, quality assured and distributed by a predetermined deadline; attend meetings to take minutes, and subsequently, produce accurate final drafts of minutes for approval.
- Maintaining and updating an online, web-based service which supports the Gwent Transition Service as required and appropriate.
- Acting as the first point of contact for visitors and callers, dealing with incoming queries answering enquiries where appropriate.

(Please see Appendix G for full job description).

3.4. SERVICE COMPONENTS

Further breakdown below shows the specific functions/components of the Gwent Transition Service, and how each component fits within the three key principles of the delivery of the service.

Principle	**How will this be achieved?**
Unified Standards	***Creating Unified Standards:*** a full review of processes will be undertaken by the Transition Manager, including the evaluation of guidelines, eligibility criteria, and policies across the Gwent area. A new set of standards will be created to ensure all agencies are working to the same standards. Auditing tools will be developed across all 5 local authorities in the Gwent area in both children and adult services to measure the progress and success of their transition work, in addition, this will highlight areas of best practice and areas for improvement (see Appendix H for example). ***Training Package:*** identified agencies will be required to attend a minimum of two joint training workshops and events per year (offered up to 6) which aim to

	raise awareness of each other's roles, responsibilities and processes. Discussion in relation to transition between agencies will be facilitated, allowing for networking and building of more positive and meaningful relationships. In addition, audit data will be presented annually, with a requirement for services to attend and contribute to discussions. 'Transition champions' will be adopted across Gwent within all relevant health, education and social care teams through face-to-face training and online modules developed. Finally, toolkits for parents/carers and professionals (that are quick to read, easily circulated and highly impactful) will be utilised to support general awareness, understanding, knowledge and engagement in transition services.
Preparing and Empowering Service Users and Families	***IAA (Information, Advice and Assistance) Services****:* Information about transition will be shared with young people and their families in the year of their 14th birthday using an 'Introduction to transition' workshop. Numerous workshops (e.g. anxiety and transition) will be held throughout the year and the topics determined by young people/caregivers. IAA will be available through the Gwent Transition Service and drop-in transition sessions will be available for those requiring face-to-face support. Toolkits, guides and other resources important in transition will be fully accessible through the Transition-Online website (e.g. FAQs, guides to transition, friendships). Webinars will also be available online to complement workshops and will be produced in close collaboration with young people. Messages about important meetings and events will be communicated to young people and parents through emails, with future potential for development of a Gwent Transition Service mobile phone 'app'. ***Skills Development/Practical Support:*** Young people will be encouraged to create and work towards individualised skill development programmes upon accessing the Gwent Transition Service or Transition-Online. Skill development will be supported through independent living skills groups, and 1:1 support for those who find it more challenging to participate in group interventions. Young people will be supported to develop their strengths, emotional resilience and independence needed for the movement into adulthood (please refer to Appendix I for a list of potential targeted skills for independence).

	Emotional Support: drawing on current provision where possible, families and young people seeking peer support will be signposted to relevant support groups. Signposting and referrals (e.g. counselling) can be made for those who require additional emotional and behavioural support. The establishment of buddy support systems will also offer an opportunity to develop friendships, and for young people to support each other into adulthood.
Single Integrated Transition Plans	***Person-Centred Planning:*** Placing young people at the heart of the planning process, and producing a range of resources in close collaboration with the young person, families and relevant professionals. Resources may include: 'one-page profiles', 'hospital passports' and utilisation of NICE endorsed resources such as the "Ready Steady Go" programme (Appendix H). ***Integrated and Coordinated Planning:*** A single, holistic, unified plan will pull together documentation from all relevant agencies concerning the young person's transition and updated as necessary. It is proposed that an online, web-based planning 'portal' (see section 3.5. for details) will host the entire Single Integrated Transition Plan. Following a secure log-in, this will allow for quick and easy updating of progress within the plan whilst also enabling communication across all stakeholders and systems (health, education, local authority etc.). Transition Support Officers will be available to host, attend and facilitate multi-agency transition meetings to ensure joined up working and engagement, eliminating the silo approach to planning, and time-wasting through duplicated work. Where agencies are unavailable to attend, Transition Officers can request information, documentation and compile any suggestions or concerns to support communication and progress within the plan. A standardised form, or checklist, with essential information required for planning meetings, will be developed to maximise efficiency.

3.5. "TRANSITION-ONLINE"

The Gwent Transition Service will be supported by a secure, online 'portal' that young people, families and professionals can log into to view, update and comment on the Single Integrated Transition Plan. This online facility would ensure young people have full access to, and potential for participation in, transition, and families can receive 'live' updates on the plan's

progress. The portal would provide information, advice and assistance (IAA) to those needing low-level support and detail the referral processes/criteria for all post-18 provision, including how to access specialised transition support. All transition information can be held in *one* online system, supporting paperless planning, and mitigating the need for constant travel for meetings, emailing and phoning for updates. Transition-Online will be a transparent service, explicitly detailing a range of services including how they can help young people and families, contact details and/or their referral processes, for example. It will also host details of upcoming training and support events, and signpost to relevant services within the region. This service will be vital for families with busy and hectic lives, and also for those who live in rural areas, and professionals who have difficulty attending multi-agency planning meetings due to high work pressures and clinical duties. Please see Appendix J for further details on the "Transition-Online" proposal.

3.6. ELIGIBILITY CRITERIA

In alignment with the typical trajectory for transition, the service would be available for referral from the young person's 14th birthday and will accept referrals for young people up to the age of 19 years old (the year young people typically leave special schools). Referrals can be obtained through two avenues, 1) young people are identified and referred by professionals such as within social care, the health board, ISCAN, schools, or 2) young people or their caregivers self-refer into the service, for determination of eligibility. The use of the Gillick competency test will be considered where appropriate for young people, when obtaining consent, or where a young person does not have the capacity then parental consent will be sought. Point of referral to establishing a date for initial appointment would ideally be 2 weeks, with an outcome communicated to the young person, family and referring professional. The service may allocate a Transition Officer for planning, a Transition Support Worker for independence skills development, or signposted onto the correct service for their needs, or a combination of the above dependent on needs.

The service would cease by the 25th birthday at the latest; a point at which most young people should be settled into adult life. However, emphasis should be given to the fact that most young people will be discharged from the Gwent Transition Service before this point and only vastly complex, problematic transitions will continue until the 25th birthday. In typical transitions, a

gradual step-down process will be utilised as the young person demonstrates readiness, with consideration for busy times such as at 16 years old (when transition planning intensifies) and 18/19 years old (when young people finish special schools/college). Cessation of the service will continue until 1) completion of a transition plan which meets the assessed needs of the young person, and 2) evidence of a sustained outcome upon a 6-12 month review. As the service would offer fully tailored transition support, cessation of the transition service will entirely depend on the needs of the individual, to ensure that all intervention is relevant and timely.

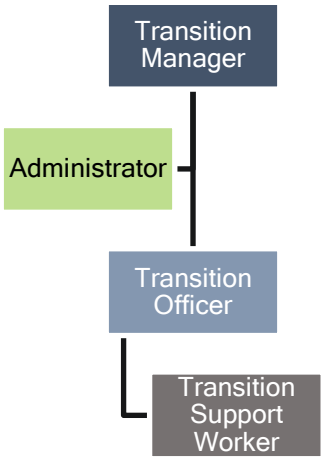
3.7. RECOMMENDATIONS

There are many ways in which this service could function. This report proposes three options for consideration, detailed below, recommending that **Option 1: The Gwent Transition Service (Gold Standard)** be adopted Gwent-wide following a successful feasibility and pilot study.

3.8. OPTION 1: GOLD STANDARD (RECOMMENDED)

Cost: £495,150.11 (capacity 1,509 young people in Gwent per year)

Adoption of the entire Gwent Transition Service, including a dedicated Transition Manager, Transition Officers, Transition Support Workers, all supported by an administrator, which would allow fulfilment of all service components outlined above. Attention to transition policy, guidelines, thresholds and processes (standards), alongside fully supported young people, families and professionals will contribute to Gwent emerging as a potential Centre of Excellence in transition care. In addition to serving the needs of users, the program will achieve considerable efficiencies over 'routine care'. Gwent will demonstrate an ongoing commitment and have the capacity to develop excellent transitional care, in line with current Welsh Government and NHS priorities.



3.9. OPTION 2: BRONZE STANDARD

Cost: £269,872.19 (capacity 768 young people in Gwent per year)

Limited adoption of the Gwent Transition Service, omitting the roles of the Transition Support Workers and dedicated Transition Manager. Within this option, it is suggested that management support will be sourced from an existing management role within the host service area. A reduced caseload will be expected and will focus solely on delivering the Single Integrated Transition Plans and training professionals to support young people. This option would have limited capacity to work 1:1 with young people, and would mostly rely on families, local organisations and charities to carry out group work to help young people with skill development. While transition planning may become more streamlined, due to the reduced capability for group or 1:1 work, there would be significantly less impact on the preparedness and empowerment of young people and their families in the transition process. This model inevitably means far fewer families will receive an appropriate service, and disjointed and inefficient systems would remain for large numbers of families.

3.10. OPTION 3: STATUS QUO

Rejection of the Gwent Transition Service, and a continuation of the current, inadequate model for transition. Late identification issues continue to risk young people 'slipping through the net' and subsequent stress for professionals who have to rush to complete assessments. Child and adult services remain a cultural shock to young people and families as they move between services. Agencies continue to work in their silos, leading to duplication of assessments and lack of effective handover. Multiple professionals will continue to duplicate work by others with poor or ineffective working between agencies. Consequently, young people and their families continue to feel unsupported and distraught by the process, with an increased likelihood of reaching crisis before services react to the reality, and experience, of poor transitional care.

Please refer to Appendix K for further details on the risks and benefits of each option presented.

Please refer to Appendix L for the breakdown of costs.

4 CONCLUSION

> *"…for me, personally, transitioning from childhood to adulthood is knowing how we're going to manage, how we're going to cope out there… I'm looking forward to getting a job. And more so looking forward to, in time, moving away from my family. Moving out of my house and starting a new adventure there. Either with living with friends or maybe even a girlfriend if I'm lucky… it's things that could make my life even more exciting, enhance it really."*
> *(Young Person)*

The experience of transition from child to adult provision for young people with disabilities and/or developmental delay in Gwent is clearly complex and warrants dedicated attention to the voices of young people, parents and professionals. While it can be hugely challenging to capture the entirety of experiences, as transition is unique to every individual young person, undoubtedly services in Gwent are unable to optimally support transition. This is not through lack of trying, as some localities have taken important steps to address the present issues and have achieved somewhat improved transitional care. Professionals evidently demonstrate insight and awareness of transitional care and are dedicated to improving current structures, while clearly wishing to place young people and their families at the heart of the transition planning processes. Yet, the current model of transition is not optimal; vast problems remain and concerns are shared by all. Young people, families and professionals alike are dissatisfied with the current structures and processes surrounding transition and appeal for meaningful changes in the future. Therefore, transitional care is not an issue we can ignore, however, to tackle this complex problem, we need a multifaceted, whole-system response.

This report has outlined the findings of a large-scale qualitative study, dedicated to listening to the views of both service users and service providers across the Gwent area. It presents a solution, formed through the careful amalgamation of their ideas, and consideration for current best practice recommendations offered within key policy documents. The implementation of the recommended, 'gold standard' model will place Gwent ahead of the rest of the UK for transitional care and will begin to highlight Gwent as a potential Centre of Excellence for an issue that is gaining widespread attention not just in Wales, but in the UK and globally. Indeed,

transition from child to adult provision may never be ‘easy’ as it is within human nature to dislike change, fear the unknown and feel anxious about the future. However, services across Gwent have the utmost responsibility to ensure that each young person is not disadvantaged by transition, to guarantee that all young people are offered the opportunity to thrive and fulfil their potential in life. We believe that the ideas presented in this report will facilitate this opportunity.

5. APPENDICES

Appendix A: Legislative Frameworks and Guidelines

Prior to 2018, two key policy frameworks have underpinned the transition process: the National Service Framework (NSF) for Children, Young People and Maternity Services in Wales (WAG, 2006) and the Special Educational Needs (SEN) Code of Practice in Wales (NAfW, 2004). The NSF sets out the quality of services that young people have a right to expect and receive in regards to transition. The NSF is underpinned by statutory law and its standards in transition are relevant to:

> "*Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers*" (WAG 2006, p.54).

The NSF identified the shortfalls in transition, recognising that "health and social services often fail to meet the needs of vulnerable people at the time of transition into adult services" and that "currently transition planning takes place separately within different agencies" which can lead to disjointed services. Key actions were outlined in relation to transition and are required in order to make effective transitions from childhood to adulthood. These actions include:

- Young people over the age of 14 years are assessed or reviewed to identify potential for continuing needs for CAMHS beyond their 16th birthday.
- There is an inter-agency system to identify young people who will require transition into adult services in the year before their 14th birthday (in year 8).
- A key worker is appointed to all disabled young people at age 14. It is their responsibility to ensure that the young person, their families and all relevant agencies are appropriately involved in transition planning. They will coordinate the planning and delivering of services and continue to monitor and have contact with the young person until the age of 25.
- Information about how to gain access to services and facilities is available to disabled young people in the local community.

- There is one joint organisation transition plan produced for each disabled young person which forms the basis of the Unified Assessment within adult services and specifies arrangements for continuing support and services.
- The joint organisations transition plan is reviewed at least annually. During the year before their 18th birthday the plan is reviewed each term.
- Aggregated information derived from joint organisations transition plans is sent to the area's Young People's Framework Partnerships to inform strategic planning.
- Every lead health professional has adequate arrangements for transfer of young people to adult services, preferably via specific transition clinics involving staff from both paediatric and adult services.

These standards set out guidelines for the minimum requirements in transition and offer recommendations for future improvement. However, of the actions relating to transition, *none* were prioritised as requiring immediate action and instead were set to be delivered over the 10 years of the NSF programme. However, 12 years on, it is undetermined whether these actions were fully achieved by every local authority, or whether all actions were operationalised in similar ways.

The SEN Code of Practice in Wales, effective from April 2002, also provides a set of guidelines and practical advice to Local Education Authorities (LEA), maintained schools, early year's settings and others on carrying out their statutory duties with regards to transition. It sets out a step-by-step process for transition from year 9 onwards, focused around the experience of the annual review. The code of practice relates only to those identified as having SEN and focuses specifically on those who have a statement, as transition planning occurs during the annual review of statements. It outlines the following procedure:

- The LEA must write to all head teachers no less than one term in advance with a list of all pupils on roll at their school who will require an annual review and a date for which the review must be completed by.
- The head teacher (or teacher who has been delegated the task) must initiate the review process and obtain written advice from the child's parents, those specified by the

authority and anyone else considered appropriate. A copy of this advice must be circulated at least two weeks before the date of the meeting.

- Health authorities and social service departments are required by law to respond to the head teacher's request for written advice.
- Where appropriate representations of the health service or social service department or professionals closely involved with the child must be invited to contribute to the review and attend the meeting.
- The review will normally take place in the child's school.
- Following the annual review meeting, the head teacher must prepare a report and submit it to the LEA no later than 10 school days after the annual review meeting or the end of the school term, whichever is the earlier.
- The LEA concludes the review process by considering the report and the recommendations prepared by the head teacher. The LEA must then decide whether to accept the head teacher's recommendations.

In relation to the Transition Plan, the Code of Practice outlines that:

- The year nine annual review should involve the agencies that may play a major role in the young person's life during the post-school years and must involve Careers Wales. The head teacher must also ensure that other providers, such as health authorities and trusts, are aware of the annual review.
- Careers Wales must be invited to the year 9 annual review meeting and must make every effort to attend. Representatives from Careers Wales should be invited to all subsequent annual reviews, and are expected to attend where appropriate.
- The social services department must be invited to attend the review so that any parallel assessments can contribute to and draw information from the review process. Social services should ensure a social worker attends the year 9 annual review meeting and contributes to the formation of the transition plan where a young person is subject to a care order, accommodated by the local authority or is a 'child in need'.
- Health professionals should provide advice towards transition plans in writing and, wherever possible, should attend the annual review meeting in year 9.

- The views of the young person themselves should be sought and recorded wherever possible in any assessment, reassessment or review from year 9 onwards.
- Careers Wales will have the lead role in ensuring the delivery of the elements of the transition plan that relate to the young person's transition into further learning or employment.
- The school remains responsible for convening annual review meetings until such time as the pupil leaves school.
- In the young person's final year of school, the National Assembly has a separate duty under section 140 of the Learning and Skills Act 2000, for ensuring that an assessment of their needs on leaving school is undertaken and the provision identified.

Whilst these guidelines offer practical advice for those with SEN with a statement, they offer little statutory advice or structure relating to those with SEN but *without* a statement. For these young people, the code of practice suggests that:

- Careers Wales should provide schools with information to help the young person make a successful transition
- Schools may wish to draw up Transition Plans to support this process
- There needs to be close collaboration with LEA staff and other professionals involved, so as to provide an appropriate Transition Plan.
- It would be good practice to provide health and social service professionals with a list of pupils at year 9 with SEN who do not have statements but for whom the school considers it appropriate for a transition plan to be prepared.

The SEN code of practice for Wales, therefore, offers limited advice for those without a statement of SEN and lacks comprehensive guidelines relating to the input of social services or health services. In addition, no guidance is offered to outline the responsibilities of each team within social or health services (e.g. child or adult teams) in the annual reviews and Transition Plan. Whilst those the code relates to must consider the code of practice, and must fulfil their statutory duties towards children with SEN, it is ultimately up to them to decide how

to operationalise the Code of Practice. It cannot tell them what to do in each individual case as the practical guidelines offered are not legally binding unless it states a statutory duty.

The Education, Lifelong Learning and Skills Committee (2007) published a review of the current guidance in Wales aimed at encouraging and supporting good practice in transition. Concern was expressed as it found that the transition review process is not as effective as it should be, and may be ineffective. Specifically, it found evidence that young people are often under-prepared for reviews, there can be a lack of coordination between agencies, information and budget sharing could be improved, and young people and their families often feel unsupported in planning for the future. The committee also found that young people and their families have very little impact and are not always involved in transition reviews. Furthermore, concerns were expressed around whether agencies that need to be involved in transition are attending or involved in transition reviews. In particular, adult social services were not often involved in transition planning despite needing to make provision for the young person later in life. Lastly, they highlight that extensive guidance on transition may have led to an overly complicated and bureaucratic system which needs simplifying and clarifying, and further work is required to ensure that transition is consistent across Wales.

In response to these concerns, a number of evaluations have taken place UK-wide which attempt to research, assess and make recommendations for transition. The Kennedy Report (2010) identified transition as a critical problem and ‘long the cause of complaint and unhappiness’ (p.8). It appeals to local partnerships to grasp the arbitrary boundaries around services and to come together to ensure continuity of care, which concentrates on addressing the needs of 16-25-year-olds rather than abruptly ending following a birthday. In addition, the Care Quality Commission (2014) produced an in-depth report, called “From the pond into the sea: Children’s transition to adult health services”, which outlines numerous examples of good practice and recommendations. Despite the reams of guidelines provided within both reports and academic literature, their impact on transition has not been great enough to solve the ongoing issues in transition.

NICE guidelines (2016) have also been produced, which outlines over eighty recommendations for transition. With regard to transition support, the document makes a number of recommendations. These include:

- **Before transfer**: joint appointments, joint clinics, pairing child and adult practitioners, ensuring a contingency plan is produced, creating a personal folder, early information sharing and support from a named worker.
- **After transfer:** young people should be contacted within safeguarding protocols, consider re-referral following non-engagement, determine how to help young people use the service or get their needs met, and ensure consistency of staff for 2 appointments.

The NICE guidelines highlight important principles and are based on person-centred approaches, focusing on the young person's strengths, providing developmentally appropriate service provision and identifying suitable support. They also identify the need for supporting the infrastructure behind transition, including strategies, policies, strategic planning and the development of services. Yet, although overarching values and the ethos behind NICE guidelines are desirable, some have expressed concern as many of these recommendations are viewed as aspirational and underpinned by relatively weak evidence (Colver, 2018). Therefore, guidelines may need further refinement and a better exploration and application of research, and the evidence it provides, is required.

Gwent has also responded to transition and, with funding by the European Social Fund, the "Pan-Gwent Multi-Agency Transition Protocol for Young People with Disabilities and/or Additional Learning Needs" was produced in 2012, which stated transition guidelines for those who were more likely to experience complex transitions. Yet despite the contributions of this document, many professionals lack awareness of its existence or expressed dissatisfaction with its guidelines. While areas of Gwent certainly aim to operationalise this document, the consensus suggests that it lacked clarity, had poor implementation and, as we enter 2019, may be due an update. It was evident that health professionals, in particular, are not meaningfully involved in any aspect of transition, and as far as can be determined, health care reverts to primary care, who then have to initiate secondary care services as required.

Appendix B: Literature Review

Introduction

The transition into adulthood for young people with disabilities and developmental difficulties is internationally recognised as being problematic and continues to lead to poor experiences and outcomes (Mitchell, 2015). Transitions within the UK are no exception and, despite a growing field of research, they continue to be described as sub-optimal (Colver, 2018). Current literature has reached a consensus that transition is a major event in a young person's life, and whilst it can be a time of heightened opportunity, it is equally a time for new risks (Gauthier-Boudreault, Couture and Gallagher, 2018; Blacher, 2001). Indeed, many young people with disabilities and their families tend to describe this time as a 'period of crisis' and a process which is both disjointed and overwhelming (Crowley, Wolfe, Lock and McKee, 2011; Biswas, Tickle, Golijani-Moghaddam and Almack, 2017). Its problematic nature refers, not only to the physical process of transitioning into adulthood through the movement from child to adult services but also to the emotional impacts associated with transition. The experience has been described as a needless struggle for young people and families and presents a reality which is far from seamless (Cheak-Zamora, Teti and First, 2015). The research and literature around the topic seem to suggest that young people and families alike, are dissatisfied with the current structures and processes surrounding transition, and that both a structural and attitudinal change is needed to make meaningful changes in the future. This literature review focuses on qualitative research, to identify young people, parent/caregiver and professional experiences of transition into adult services. It draws from a wide range of experiences within physical, intellectual and/or developmental disabilities, including autism, life-threatening and life-limiting conditions. However, due to the complex experiences of children in care, this literature will not be reviewed in detail and, consequently, the experiences of young people in care and their parents/caregivers will not be included within this research (i.e. focus groups).

Young People's Experiences of Transition

Young people with disabilities and/or developmental difficulties experience transition both positively and negatively. On the one hand, it is an exciting time with new opportunities and increased independence, with young people recognising the importance of making their own decisions during this time, and value directing their own care (Stewart, Law, Rosenbaum and

Willms 2002, p15). Young people feel positive about gaining work which gave them a sense of achievement, self-esteem and made them feel like an adult, despite the challenge of finding work (Cheak-Zamora, Teti and First, 2015). Gaining independence and finding work seems hugely meaningful to young people, yet literature also indicates the importance placed on learning and social development during the transition process (Hughes et al., 2018). Being able to navigate their way through the social world, making friends and continued learning and development in adult life is a significant factor in successful transition experiences. Furthermore, young people reveal positive experiences around school, explaining that teachers are often supportive and understanding of the pressures in transition (Cheak-Zamora, Teti and First, 2015). Parents, teachers and the voluntary sector are identified as valued contributors to transition due to their support, information sharing capabilities, structured activities and advocacy services (Hughes et al., 2018).

Yet, on the other hand, the literature describes how young people, both before and after transition, often feel worried, unheard and confused about the process of transition (i.e. Cheak-Zamora and Teti, 2015). In a study by Stewart et al. (2002), young people with physical disabilities explain that, in addition to the usual pressures of 'fitting in' and adapting to the physical and social changes associated with maturity, they also had to cope with additional pressures due to changes in services. They describe paediatric services as ending "abruptly, leaving them at the edge of a cliff, with a chasm or gulf separating them from adult services" (p.12). Although qualitative research examining young people's perspectives on transition is sparse, the same experiences are consistently reiterated, and tell a powerful story marked by concern and anxiety. Research by Giarelli and Fisher (2013) exemplify this, explaining that transition is a time of extreme pressure, fear, confusion, uncertainty and sometimes panic for young people who find it difficult to "stay afloat in a sea of change" (p.227). As seen in these examples, young people use powerful, emotive words which often capture a story of emotional turmoil and are grounded in a dissatisfaction around the physical process of transition and amplified by additional emotional challenges. For example, young people of this age, particularly those with intellectual difficulties, are more likely to suffer from anxiety and depression due to a lack of insight and maladaptive coping in regard to transition and emerging adulthood (Gauthier-Boudreault, Couture and Gallagher, 2018). Thus, young people risk poor emotional outcomes at a time of increased emotional vulnerability.

Young people, therefore, have mixed experiences and emotions regarding transition. They often lack understanding about the transition process, are unprepared and unready for change; a perceived precursor to a poor transition (Cheak-Zamora, Teti and First, 2015). However, at the same time, they want to make decisions and start living an adult life, viewing transition as an opportunity.

Parent/Carer Experiences of Transition

Parents construct a similar narrative to young people, marked by stress and worry. In particular, considerable concern is attributed to the legal and social process of their young person becoming an adult. Although legally, adulthood in the UK is defined by chronological age, at the 18th birthday, socially, adulthood may be achieved more slowly (for example, by starting work or living independently) (Biswas, Tickle, Golijani-Moghaddam and Almack, 2017). Therefore, research highlights the issue of applying the markers of typical development to young people with developmental disabilities; whilst chronologically a young person is an adult, mentally and socially they could be a lot younger (Ally et al. 2018). Parents express concern with this, feeling that their young person would be unable to handle independence and would become more vulnerable to incidents such as abuse, financial exploitation and unwanted behaviours such as aggression (Rapanaro, Bartu and Lee, 2008; Biswas, Tickle, Golijani-Moghaddam and Almack, 2017). It is unsurprising that caregivers feel anxious about transition and lack trust with adult providers, given potentially limited rapport building alongside provider-led decision making. On the other hand, research suggests that parents might also find it difficult to recognise the signs of adulthood in their young person due to the severity of their intellectual disabilities (Biswas, Tickle, Golijani-Moghaddam and Almack, 2017). The potential implications of these experiences are vast, and interpretation of this might suggest that parents may become less supportive of transition into adult services.

Parents also report transition as poorly co-ordinated, lacking young person involvement, misunderstanding professionals roles in transition and lacking clarity in the division of responsibilities (Gauthier-Boudreault, Couture and Gallagher, 2018; Mitchell, 2015). They felt overwhelmed and unsupported, both for their young person and themselves, during transition (Cheak-Zamora, Teti and First, 2015).

Barriers to Transition

Gauthier-Boudreault, Couture and Gallagher (2018) identified seven barriers to transition; (1) transition plan late and uninformative; (2) lack of knowledge sharing between transition stakeholders; (3) care workers in daily activity centres do not know enough about the young adult; (4) parents act as navigators for their child, which is exhausting for the parent; (5) lack of daily activity centres allowing full-time attendance; (6) intervention approach not suited to the needs of young adults with profound intellectual disability; (7) lack of psychological support services for parents.

In addition to this, 'readiness', both on behalf of the young person and the parent, is reflected as a barrier to successful transition. Young people find it difficult to adjust to the increased responsibility over their own care in adult services and parents are anxious about what will happen to their young person, often worrying about how they will cope and what will happen to them in the future (Crowley, Wolfe, Lock and McKee, 2011; Cheak-Zamora, Teti and First, 2015). Whilst worry and anxiety could be described as a very natural and normal experience in facing the prospect of adulthood when transitioning to adult services, anxiety may increase the risk of the young person and parent resisting, or being less receptive, to the transition process.

Another barrier often presented in the literature is the 'silo-approach' to service delivery, when individual agencies are work separately to one other. This can make a transition from child to adult services feel disjointed, due to lack of coordination and communication (Stewart, 2009). Central to this silo-approach is eligibility criteria. Many young people, when they become an adult at 18, face losing their eligibility for assistance because, where child services judge against one set of criteria, adult services might define different criteria for essentially the same service (Osgood, Foster and Courtney, 2010). Reiss, Gibson and Walker (2005) describe this as "ageing out of treatment" (p.116) since paediatric services end at 18 and then families face problems such as not being able to find, or have access to, a matched service from an adult-orientated provider.

Osgood, Foster and Courtney (2010) question the fundamental approach to child services and attitude assumed by the UK government, explaining that children are seen as dependent,

therefore have less restrictive eligibility criteria placed on services. Yet the need for services does not necessarily diminish the day that a young person turns 18. Whilst the government can provide legislation, policies and guidelines, and has contributed to some successful service improvements, this approach does not guarantee meaningful change or improvement to all services (Beresford, 2004; Colver 2018). For example, in the UK, services for young people with ADHD or ASD are not routinely provided in adult services, despite these young people being at high risk of mental health, behavioural and social issues (Colver, 2018). Similarly, transition services can be lacking in some geographical areas, or have criteria which exclude certain young people, such as those with high functioning ASD (Cheak-Zamora, Teti and First, 2015). Disputes over funding from adult providers can also act as an additional concern (Reiss, Gibson and Walker, 2005). Therefore, material provision and implementation of policies and guidelines seem to be inconsistent, which leaves a gap in services and creates a postcode lottery.

Overall, there are many barriers to transition which may undermine the success of the process. While some aspects are satisfactory, the literature continues to provide evidence of sub-optimal transitions and suggests an overall conflict between child and adult services as they continue to function through different models, leaving service user needs unmet.

Facilitators to Transition

Research has shown that parents and young people have identified a number of facilitators. Early planning of transition in the years leading up to transition with dedicated transition programmes, resources and support mechanisms are all identified as factors which could influence successful transition (Stewart, 2009). Caregivers felt that young people needed to be taught essential skills, such as problem-solving and needed more support with capacity building, to function as an adult (Stewart, 2009; Crowley, Wolfe, Lock and McKee, 2011; Giarelli and Fisher, 2013). Having a keyworker has been recognised as a core component of transition success by professionals and families alike (Noyes et al., 2014; Stewart, 2009). The keyworker acts as someone who shows leadership in transition, who is responsible for coordinating different agencies and can take overall responsibility for a young person's transition. This boosts communication and information sharing between agencies thus aiding a smoother transition.

Whilst young people need to have a large role in decision-making during transition (Johnson, 1995), positive family networks and peer support is similarly important to assist in making informed choices and providing emotional support (Mitchell, 2015). Having these networks can help the young person manage their personal strengths and weaknesses, but can also create stability and security during a time of uncertainty (Giarelli and Fisher, 2013). Along with providing physical and emotional support, support networks can facilitate transition by negotiating and advocating on behalf of the young person where needed. Support networks can also extend to professionals who can facilitate transition by giving educational assistance, behaviour management strategies and emotional support to both the young person and caregiver (Giarelli and Fisher, 2013).

Both caregiver and youth also agree that they need to feel comfortable and trust their new provider, to reduce anxiety during transition and support continuity of care (Cheak-Zamora and Teti, 2015; Gulliford, Naithani and Morgan, 2006). Mitchell (2015) identifies the role experiential knowledge can play in facilitating this aspect of transition; a family can experience a service first-hand which may, consequently, allow rapport and trust to build with the new provider.

Improvements to Transition

The literature around transition suggests that improvements need to be made to UK legislation and its approach in transition and service provision should be reformed to better fit the needs of the service users. In regard to legislation, research identifies the need to review responsibilities and recognise transition as a holistic process, which considers the full life course of an individual and their family, rather than a transfer of services (Beresford, 2004; Stewart 2009). Alongside a holistic approach, Colver (2018) emphasises the need to provide developmentally appropriate healthcare, which suggests that transition should be approached with sensitivity to the developmental stage of the child. For example, young adult clinics are a suggested improvement within healthcare, which may encourage young people to become more involved in transition (Crowley, Wolfe, Lock and McKee 2011). This involvement of young people is reiterated in the literature as integral to successful transition, likewise, parents also wish to be more involved in service planning and emphasise the importance of taking a family centred approach (Beresford, 2004). As an improvement to transition, this may begin the process of repairing relationships between individuals and institutions, building trust in

transition to adult services and addressing young person and caregiver concerns (Osgood, Foster, Flanagan and Ruth 2005). A new approach in transition which reconsiders legislation, is sensitive to developmental stage, and fully involves young people, is a prevalent recommendation in the literature.

Specific provisions have also been indicated for ensuring successful transition, for example, around skills development, capacity building, disease-specific education and training for professionals, emotional and psychological support for young people, and a transition information sharing service (Steward, 2009; King, Baldwin, Currie and Evans, 2005; Crowley, Wolfe, Lock and McKee, 2011; Gauthier-Boudreault, Couture and Gallagher, 2018). Named transition coordinators are also suggested within the literature to support families through transition (Cheak-Zamora, Teti and First 2015; Gauthier-Boudreault, Couture and Gallagher, 2018; Crowley, Wolfe, Lock and McKee 2011). Interestingly, transition services and provision for children with disabilities have existed as condition-specific, and no long-term outcome data has been collected to determine their effectiveness (Doug et al. 2011). This indicates a general lack of evidence-based frameworks upon which to build on and an overall absence of generic transition services which could benefit a large range of service users with different needs.

Much of the literature has focused on understanding the issues of transition but to illuminate the future pathway in transition, models of good practice are needed, yet, few exist. King et al. (2005) proposed a transition model based on three levels of intervention: personal, person-environment and environmental levels of intervention. It emphasised the use of six strategies, linked to short-term outcomes and the long-term goal of multifaceted role engagement, which ensures a comprehensive approach to assist a young person's future planning. Strategies include skill instruction, self-awareness, emotional support, community knowledge, direct experience and community intervention, leading to short-term outcomes such as enhanced knowledge of self and future, enhanced skills, enhanced perceptions of support, enhanced knowledge of the community and more supportive environments. However, this model was largely theoretical and its potential application to practice may be complex to the layman or those from different professional backgrounds. As a result, there is little evidence to suggest

that this approach has been utilised in practice or further validated in research. Improvements to transition and models of good practice therefore still exist as a gap in the literature.

Conclusion

While the literature around transition is certainly growing and multiple perspectives such as young people and caregivers are being sought, there remains a gap in knowledge. To date, there are few studies that have 1) united the thoughts of young people, caregivers and professionals on transition 2) addressed shared concerns across a range of disabilities and/or developmental difficulties and 3) proposed a functioning model for transition. The focus around transition and services for young people has mostly been disease or condition specific, and while this is extremely valuable to determine specific experiences, it does not address the holistic, multidisciplinary, yet individualistic reality of transition. Transition needs to be addressed on a universal scale; inclusive of all conditions, relating to disabilities and/or developmental difficulties, and services, in order to give real-world, functional solutions that can be operationalised across the UK. This research aims to address this gap, determining a solution which is practical and relevant to any young person with disabilities and/or developmental difficulties, and their family, who are about to transition to adult services.

Appendix C: Evidencing the Need for Improvement in Transition

The Serennu Transition Event, March 20th 2018

In order to fully understand the extent and importance of transition issues in Gwent, an event was held at Serennu Children's Centre to bring together both parents and professionals. The aim of this event was to gather information regarding the transition process from child services into adult services and to develop a mutual understanding of each other's situation. It presented an opportunity for parents to reflect on their experiences of transition with their young person, and for professionals from different agencies to listen to and understand these experiences. The event focused predominantly on the process leading into and immediately following transition, with a lesser focus on the availability of post-18 services. Overall, 14 parents, 2 young people and 26 professionals attended the event which opened an interesting narrative on the success of transition in Gwent. Professionals included chief officers, social service managers, transition support officers, head teachers, education specialists and family liaison officers (although invited, no health representatives attended). Parents and young people who attended were either currently experiencing transition or had transitioned already. Important insights into transition across the local authorities in Gwent were identified and discussed, which formulated a strong rationale for evaluating the current transition model in Gwent.

Key Points:

Parent's experiences of transition were varied, depending on the level of specialised transition support received during their young person's transition. However, many discussed a range of failures and recommendations to improve transition for young people and families in the future. The main failures within the system were identified as:

- A lack of communication between professionals and families around the details of the transition process.
- A lack of a specific named person within adult services to contact in order to address concerns and issues.
- A discrepancy in the eligibility criteria for access to services between child and adult services.

- The assessments for adult social services were weighted towards a health focus
- Adult health services are not available until the young person has turned 18, thus potentially leading to a long gap in service provision.
- Difficulties in engaging with adult learning disability services, and poor communication between child and adolescent mental health services and adult learning disability services.
- A lack of clarity as to the eligibility for adult services.
- The experience of anxiety during transition for both the young person and the families, and having to reach a point of crisis before getting support.
- Young people who have multiple complex needs may have a smoother and more effective transition than those without.
- Learning disability services are focused on young people with autism spectrum disorder, rather than learning disabilities as a whole.

Parent's also reflected on aspects on transition and how they might be improved, forming key recommendations which included:

- Having a single point of contact for parents in adult services, which is preferably made available prior to transition from child services to adult services occurring
- Better communication is needed between child services, schools and parents regarding transition, options available and implications for transition when choosing school options.
- Improved communication between child services and adult services, and in particular between the child and adolescent mental health service and the adult learning disability service.
- The transition period should run from 16-25 to enable the young person to mature, to feel ready for transition and for families to adapt at a slower pace than currently.
- There needs to be a continuity of staff to assist in transition and transition planning from child to adult services.

Conclusion:

The outcomes of the transition event were important in understanding the need for improvements to the transition process for young people and their families living in Gwent. The experiences shared at this event were insightful and allowed professionals to reflect on their service, particularly in regards to what they thought they were providing and what families felt that they were actually receiving. The event evidenced a very clear need for improvement in transitional care and demonstrated the importance families placed on supporting meaningful changes to transition for young people and their families in the future.

Appendix D: Methodology

Study design:

The present study aims to understand the process of transition from child to adult services currently delivered within Gwent. To fully capture the complexity of transition across a range of individuals, including professionals, parents/caregivers, and young people, a qualitative design was considered the most appropriate. It aims to understand service user and service provider experiences, achieving rich, detailed accounts of transition and with the vision of establishing key priorities in transition for each stakeholder. Positioned within the interpretivist paradigm, the current study assumes that knowledge is gained through personal experience, and meaning is constructed through interaction and subjective interpretations of social reality. Thus, the methodology reflects an interpretivist approach.

Setting, Sample and Recruitment:

Participants were recruited via an opportunity and snowball sampling strategy. During the period of June – October 2018, requests for interviews were sent out via email to a range of professionals and services across primary and secondary health care, education, social services and Careers Wales. Those professionals who responded and agreed to participate in the research project were invited to attend an interview, held at Serennu Children's Centre or the individual's main place of work. Following this, professionals were asked to suggest other professionals who they judged to be integral to the project. Recruitment for professionals was overall very successful with many showing willingness and interest in participating in the research. However, it proved extremely difficult to achieve engagement from adult health providers. Common reasons for non-participation or withdrawal were lack of response to recruitment invitation, work demands being too high to afford the time to participate and lacking knowledge on transition.

Parents and young people were recruited for focus groups during the period of September – October 2018 where notifications were sent out via social media, emails and posters around the Centre. In addition, flyers were distributed physically and electronically to local support groups and services directed at supporting parents and young people. Professionals who originally participated in interviews were also contacted regarding focus groups, requesting the circulation of flyers within their respective services. Serennu Children's Centre was chosen as

the primary setting for focus group data collection, as many families across Gwent were familiar with the setting and already attended for medical, leisure or psychological services. Young people over 18 years old were contacted through Careers Wales, local organisations and charities, colleges and adult services; professionals were asked to identify young people in their service under 23 years old and extend an invitation to participate in the research, on behalf of Sparkle.

Participants were selected on the basis that they met the research criteria. Families (parents/carers and young people) were required to have a young person aged 16-23 and have the ability to share their view or experiences of the transition process. Thus, participants could contribute effectively to the aims and knowledge sought by the current study.

Data Collection:

Semi-structured interviews were selected as an appropriate method for data collection for professionals, as it allowed for in-depth understandings of service provision expectations, delivery and experiences regarding transition. The interview schedule was designed to encourage participants to reflect on their understandings and role within transition, the successful and unsuccessful processes held within their service, interactions with other services, and possible improvements to the current transition model. The primary researcher conducted the interviews face to face within the interviewee's chosen setting, with whom they had no prior relationship. Data collection ceased following the satisfaction of the following criteria: i) sufficient representatives from key agencies were involved, and ii) saturation of data was achieved. In total, 49 professionals were contacted and 38 participated in interviews, averaged at 50.38 minutes per interview. See below for the interview topic guide.

Interview Topic Guide:

1. How would you define transition?
2. What are your experiences of transition?
3. What can young people and families expect in transition?
4. Please could you explain your role in transition and how you might support young people through transition to adulthood?

5. What things work well in transition?
6. What things do not work well in transition?
7. If you could change anything to help transition work more smoothly, what would you do; what would a perfect transition model or service look like?
8. Do you have any advice for young people and their caregivers going through transition?
9. How familiar are you with the Gwent Multi-Agency Transition Protocol? Do you find it useful?
10. Are there any other issues that you would like to discuss or any concluding comments?

Focus groups were selected to create discussion amongst a diverse range of service users, to elicit common experiences of transition in a non-threatening environment. Similar to interview data collection, focus groups were designed to encourage an open discussion to reflect on the process of transition, what is going well, what is not going well, what are service user priorities in transition, and how could services improve for the future. Separate focus groups for parents and young people were determined appropriate, to ensure the latter could speak openly about their views, even if they clashed with their parents and vice-versa (parents could speak openly about transition without young people listening). In total, 11 parents and 8 young people participated in 5 focus groups, which averaged at 1 hour 44 minutes per focus group. See below for the focus group schedule.

Focus Group Schedule:

1. Please can you tell me a little bit about who you are?
2. What does the word transition mean to you?
3. What are your experiences of transition; are they positive, negative, mixed?
4. What things do not work well in transition?
5. Of the identified answers, what is the most significant barrier or problem in transition?
6. What things work really well transition?
7. Of the identified answers, what is the most significant facilitator for successful transition?
8. What could we do to improve transition?

9. Of the identified answers, what is the most important solution or change that we could make to transition?
10. Are there any other issues that you would like to discuss or any concluding comments?

Additional questions (time permitting): do you feel like you have had enough support during transition? What is your biggest worry about your future plans? What are you most looking forward to in your future plans? Who can help and what can other people do to help you reach your goals?

N.B. Schedule wording was adapted in minor ways to appropriately reflect the audience (young person or parent/caregivers).

Both semi-structured interviews and focus groups were audio-recorded verbatim and transcribed by the primary researcher. Following transcription, copies were sent out to participants to approve or modify appropriately, to ensure the best reflection of experiences and perceptions.

Data Analysis:

The data were thematically analysed using Braun and Clarke's (2006) six stage, nonlinear procedure, used for identifying patterns within data. Thematic analysis is a widely accepted and trusted method for analysis which allows for a rigorous and pragmatic approach (Nowell, Norris, White and Moules, 2017). The first phase starts with '*familiarising yourself with the data*', immersing yourself through repeat reading of the data and actively searching for meanings, patterns and possible codes. Phase two involved '*generating initial codes'* whereby stand-out features were listed as 'codes'. In phase three, '*searching for themes*' codes were revisited and re-focused to consider how the codes might combine together to form an overarching theme. '*Reviewing themes'* occurs in phase four by refining themes and considering whether they fully fit the data and capture the full, overall narrative of the research. Phase five includes '*defining and naming themes'* to identify the core message or 'essence' of each theme, appropriately naming them and identifying any sub-themes. Finally, phase six, '*producing the report',* ends

by providing an interesting story about the data through themes, creating an argument in relation to the research hypothesis and aims.

Throughout the thematic analysis procedure, NVivo 12 was used as an aid and is considered a compatible tool to this form of analysis (Zamawe, 2015). It acts as an efficient, timesaving tool and compliments the rigour of the research since themes can be easily coded, re-coded and cross-checked by an additional researcher.

Rigour:

Quality assurance techniques were applied in order to achieve a thorough, trustworthy piece of research. Prior to data collection, an event was held between professionals and families to discuss key issues around transition and was used to guide the interview and focus group schedules. Thus, questions and schedules were carefully considered. During interviews, attentive listening and respect were shown for participant views and experiences, participants were given the opportunity to comment beyond the questions within the schedule, and the researcher regularly summarised information to the participant to determine accuracy and interpretation (member validation). Following data collection, transcripts were sent to participants to give the opportunity to check for faults and make necessary edits.

During the research process, an ongoing discussion of issues took place among the research team. Findings and themes were cross-checked with an additional researcher and further discussed and scrutinised by a senior researcher at regular intervals. The research process was also mindful of the CASP (Clinical Appraisal Skills Programme) qualitative research checklist, to ensure the satisfaction of a recognised quality framework (CASP, 2018). Finally, a full account of the methodology is detailed so that others can replicate its approach.

Appendix E: Criteria Comparison

Child and Adolescent Learning Disability Service: Referral Criteria

WHO CAN BE REFERRED?

Children and adolescents with a Learning Disability from the age of 4 – 18. Children under the age of 4 will normally be managed by CDT and/or Child Development Advisory Service (Portage). If the young person is 17 and over, please discuss this with the local Community Adult Learning Disability Team.

Referrals will only be accepted for children and adolescents with a moderate to severe Learning Disability in association with complex mental health issues, challenging behaviour with or without a diagnosis of Autism Spectrum Disorder.

Prior to referral to this service, the child or adolescent must have had an assessment by local Secondary Health Services. For those who do not meet the eligibility criteria, further team consultation and signposting may be offered to the referrer.

SUMMARY ELIGIBILITY CRITERIA

- Age range 4-18
- Moderate to severe Learning Disability, with complex, mental health issues, challenging behaviour with or without Autism Spectrum Disorder
- Assessed by local Secondary Services

WHAT INFORMATION WE NEED

We will not be able to process referrals without adequate information. Please see referral form for information required.

- Assessment and information on the nature of the Learning Disability is essential i.e. nature of intellectual impairment and details of social and adaptive functioning
- Details on current and previous interventions and their effectiveness
- Description of current functioning in home and school
- Description of current family/carer composition
- Copies of other available assessments e.g. Speech and Language Therapy, Educational Psychology. Contact details for all relevant professionals should be provided
- Identification of any known risks i.e. home risks
- Contact details for GP

Eligibility for the Community Learning Disability Health Team: Referral Criteria (Torfaen)

- **An individual presents with a significant impairment of intellectual functioning**

In terms of Intelligence Quotient (IQ) a significant impairment of intellectual functioning is taken as an IQ of less than 70.

- **An individual presents with significant impairment of adaptive/social functioning**

An impairment in adaptive/social functioning means that the individual will require significant assistance to provide for his or her own survival and for his or her social/community adaptation. There will be a variation in the degree of assistance required from one individual to another. However, individuals will typically have difficulty in a number of the following areas; communication, self-care, literacy, numeracy, community living skills and socialisation skills.

It is important to view the individuals adaptive and social functioning within the context of their age, opportunities for development and the social-cultural expectations associated within his or her environment.

- **Age of onset of the above impairments is before adulthood (age 18)**

The individual must have obtained significant impairment in both intellectual functioning and adaptive/social functioning during the developmental period. There is a consensus that this is below the age of 18 years.

- **Is the person eligible for our service? (Yes or no and explain why)**

Appendix F: Stakeholders Contacted

- ADHD Foundation
- Afasic
- Autism Independent UK
- BIBIC (British Institute for Brain Injured Children)
- BILD (British Institute of Learning Disabilities)
- Down's Syndrome Association
- The Foundation for People with Learning Disabilities
- Genetic Disorders UK
- Together for Short Lives
- HemiHelp
- MENCAP
- The National Autistic Society
- The Neuro Foundation
- Unique
- Shine
- SWAN UK (Syndromes Without a Name)
- Council for Disabled Children
- Contact
- Action for Children
- Barnardo's
- BPS (British Psychological Society)
- Children in Wales
- British Deaf Association
- Diverse Cymru
- Headway
- Learning Disability Wales
- National Deaf Children's Society
- National Youth Advocacy Services
- Prince's Trust
- RCPsych (The Royal College of Psychiatrists)
- RCPCH (The Royal College of Paediatrics and Child Health
- SNAP Cymru
- Tros Gynnal Plant
- Youth Cymru
- Newlife
- Scope
- KIDS
- Muscular Dystrophy UK
- React
- Aberlour
- ADEW (The Association of Directors of Education in Wales)
- ASDinfoWales
- Children's Commissioner for Wales
- Families First
- RCGP (The Royal College of General Practitioners Wales)
- Preparing for Adulthood Programme

Appendix G: Job Descriptions

Job Title: Transition Manager

Salary: £37,570.00 - £43,772.00 per annum (SCP 41-48)

Responsible To: Host Service Area Management Structure

Job Description:

The Transition Manager is responsible for planning, maintaining, developing and overall management of the Gwent Transition Service in accordance with relevant legislation, policies, guidance and procedures. They will provide leadership, have in-depth specialist knowledge of transition and be accountable for the smooth operation of the service, both in a business and service user experience capacity. They will offer a point of escalation for conflict resolution and offer guidance across multiple agencies. They will be responsible for overseeing the development and maintenance of single unified standards agreed between all agencies. The Transition Manager role engages with stakeholders and policymakers at organisation level to support the development of inter- and within-agency transition policies, guidelines and processes across Gwent.

The successful post holder will:

- Collaborate with relevant agencies to fully review policies, guidance and procedures, helping them to establish gold standard transition practices and develop unified standards of transition to be applied across child and adult services in all areas of Gwent.
- Develop auditing tools and encourage agencies to measure the process and success of their transitional care, compiling an annual report which states these results and compares agencies across Gwent.
- Identify agencies across Gwent that need improvement and assist them in achieving optimal transitions. Also, identifying agencies who are excelling in transition in order to learn from their successes and disseminate practices to other agencies.
- Provide professional leadership for staff within the transition team, supporting them to have the appropriate tools to carry out their role.

- Raise awareness of the Gwent Transition Service, identifying key meetings, for example, in local authorities or health boards where service-wide decision making takes place.
- Be responsible for the overall monitoring and performance of individuals and the team as a whole, and ensure that staff receive supervision thus performance managing staff.
- Maintain knowledge of relevant legislation and research, to ensure that services respond proactively to required changes. The Manager is responsible for the team complying with all the legal requirements in relation to disabled young people.
- Develop and implement the Team's Business Plan, ensuring that it reflects the key values of the service and abides by children and adults' legislation and the personalisation agenda.
- Monitor and evaluate the Gwent Transition Service, implementing strategies to improve the service based on service user and provider feedback.
- Ensure that the Gwent Transition Service team are managed effectively and that they undergo training as necessary to maintain a high standard of service delivery.
- Promote the Gwent Transition Service and drive multi-agency engagement, ensuring that all professionals understand the service and its remit, are aware of its existence and have implemented changes to utilise and accommodate its services.
- Disseminate the learning from the Gwent Transition Service model regionally and nationally, as required.

Please note, pay rewards are based on NHS pay scales 2019/20. An equivalent (SCP) is provided for local government worker salary rates 2018/19.

Job Title: Transition Officer

Salary: £24,214.00 - £30,112.00 per annum (SCP 27-34)

Responsible To: Transition Manager

Job Description:

The Transition Officer will provide exemplary transition support, taking ultimate responsibility for the experience of young people in transition from child to adult services aged 14-24 years old. They will have responsibility for identifying and working extensively with young people who are likely to have more complex or problematic transitions and will require support e.g. young people receiving support from two or more agencies, or who are unlikely to successfully transition without support to adult services. They will manage a caseload, working in close collaboration with young people and their families, to develop Single Integrated Transition Plans that are sensitive to the holistic needs of the individual young person. The Transition Officer will work in partnership with services to ensure multi-agency involvement and facilitate transition meetings in their locality.

The successful post holder will:

- Manage their own caseload, undertaking key worker responsibilities, for children and young people with disabilities and/or developmental difficulties in the age range of 14-24 who need transition support.
- Work in partnership with services to identify young people aged 14-24 years old within an identified geographical area who are likely to have complex or problematic transitions and will need support e.g. young people receiving support from two or more agencies, or who are unlikely to transition into an equivalent adult service beyond 18 years old.
- Plan and deliver a Single Integrated Transition Plan, which clearly communicates the wants and needs of the young person, and compiles the recommendations of all agencies involved, where necessary.
- Manage and facilitate the use of an online, web-based service which hosts the Single Integrated Transition Plans.
- Update the Single Integrated Transition Plans when necessary, ensuring changes are communicated across all stakeholders.

- Be responsible for delivering mandatory staff training/workshops on transition within a defined geographical area.
- Support the development of 'Transition Champions' across Gwent within all relevant health, education and social care teams using face-to-face training and signposting to online modules.
- Work in close partnership with a range of multi-agency partners including child and adult services, across education, health, social care, the voluntary sector and other relevant agencies.
- Facilitate, attend and contribute to relevant transition meetings (e.g. education annual reviews) across multiple agencies, acting as the young person's voice or advocate where either the young person or family cannot attend.
- Provide information, advice and assistance services (IAA) to young people and families on request, giving options of phone and face-to-face information sharing.
- Place young people at the heart of the planning process using a range of person-centred resources to be produced in collaboration, as part of the Single Integrated Transition Plans.
- Work in collaboration with the wider transition team to produce a multi-agency joint training package.
- Facilitate and monitor the buddy support system, connecting young people on the basis of similar experiences.
- Supervise and have oversight of the Transition Support Officer role.
- Support families and develop ways of fostering resilience in young people, helping to reassure families and prepare them for all aspects of adult life.
- Have excellent awareness of safeguarding issues and act on or report these to the appropriate agencies if they arise.
- Have excellent awareness of community activities and provision, as to share this information with young people and families as requested.

Please note, pay rewards are based on NHS pay scales 2019/20. An equivalent (SCP) is provided for local government worker salary rates 2018/19.

Job Title: Transition Support Worker

Salary: £18,813.00 - £20,795.00 per annum (SCP 18-21)

Responsible To: Transition Officer

Job Description:

The Transition Support Worker will work directly with young people themselves, providing low-level programme specific support, working towards pre-determined Individual Skill Development Programmes for relevant young people. They will support these young people to develop key skills for adult life according to their assessed needs, e.g. using public transport, cooking, interview skills, social skills, personal hygiene, and work towards inclusion within the wider community. To do so, they will support in the running of a programme of workshops throughout the year across the county (in partnership with local charities, guest speakers and schools, for example) aimed at preparing and equipping young people for transition. In addition to providing low-level support, Transition Support Workers will support in delivering an agreed package of training and workshops for both professionals and parents/carers, supporting the Transition Officer.

The successful post holder will:

- Provide low-level support within a group setting (e.g. Independent Living Skills Group), with some 1-1 work where necessary, to develop and work towards Individual Skill Development Programmes.
- Where necessary, assess and observe young people in their home and school settings to understand current skill levels and identify areas of improvement for adulthood.
- Support and facilitate agreed workshops, where appropriate, aimed at preparing the young person and family for transition to adult services. Workshops will be held throughout the year and the topics determined by young people/caregivers.
- Support in the delivery of an agreed joint training package to professionals with the aim of raising awareness of each other's roles, responsibilities and processes.
- Support the development of 'Transition Champions' across Gwent within all relevant health, education and social care teams using face-to-face training and signposting to online modules.

- Input information (e.g. Individual Skill Development Programmes) into an online, web-based service which hosts the Single Integrated Transition Plans.
- Attend and contribute to relevant transition meetings (e.g. education annual reviews) when the transition officer cannot attend, acting as a point of contact and communication for the transition service.
- Provide information, advice and assistance services (IAA) to young people and families on request.
- Have excellent awareness of safeguarding issues and act on or report these to the appropriate agencies if they arise.
- Support young people to develop their strengths, emotional resilience and independence needed for adulthood.
- Have excellent awareness of community activities and provision, as to share this information with young people and families as requested.

Please note, pay rewards are based on NHS pay scales 2019/20. An equivalent (SCP) is provided for local government worker salary rates 2018/19.

Job Title: Administrator
Salary: £17,652.00 - £19,020.00 per annum (SCP 14-18)
Responsible To: Transition Manager
Job Description:

The administrator will act as an assistant to the Transition Manager and provide comprehensive administrative support ensuring a smooth and efficient service. They will manage and coordinate diaries as required, arrange appointments and meetings, book rooms and refreshments, deal with incoming and outgoing mail, and undertake administrative work for meetings. They will be required to keep databases up-to-date and maintain/update a website. They will act as the main point of contact for the Transition Manager and have excellent knowledge of the Gwent Transition Service.

The successful post holder will:

- Manage and coordinate diaries as required, arranging appointments and meetings.
- Book rooms and refreshments as required, dealing with all the practical arrangements, layouts, refreshments, audio-visual requirements and setting up equipment etc.
- Undertake administrative work for relevant meetings, ensuring that agendas and paperwork are prepared, quality assured and distributed by a predetermined deadline; attend meetings to take minutes, and subsequently, produce accurate final drafts of minutes for approval.
- Deal with incoming and outgoing mail, sorting and distributing as appropriate.
- Act as the first point of contact for visitors and callers, dealing with incoming queries answering enquiries where appropriate, using own discretion, taking messages and redirecting as appropriate ensuring an efficient and professional approach.
- Maintain and update an online, web-based service which supports the Gwent Transition Service as required and appropriate.
- Monitor the progress of all assigned tasks to ensure they are responded to by the specified deadline.
- Assist with the production and presentation of audio-visual presentations when required, ensuring accuracy and layout.
- As and when required, effectively manage all aspects of the recruitment and selection

process ensuring the correct HR procedures/guidelines are adhered to. Arrange interview dates for candidates, liaising with members of the interview panel, taking up references, coordinating interviews on the day, preparing all documentation for staff induction and participating in the induction part of administrative paperwork for all new employees within the relevant team.

- As and when required, ensuring relevant paperwork is completed for all new employees within the relevant team.
- Maintain a filing system including arranging for files to be appropriately archived on and off-site.
- Maintain an efficient bring forward system for all relevant paperwork.
- Utilise the internet and other sources of information to obtain and compile information.
- Maintain databases on contacts as requested.

Please note, pay rewards are based on NHS pay scales 2019/20. An equivalent (SCP) is provided for local government worker salary rates 2018/19.

Appendix H: Supporting Sample Documents

Sample audit tool for local authorities and health providers:
https://www.preparingforadulthood.org.uk/downloads/preparation-for-and-transition-to-adulthood-audit-tool.htm

Sample one-page profile:
http://helensandersonassociates.co.uk/teams-organisations/leading-organisations/ive-heard-organisations-introducing-one-page-profiles-colleagues-benefits/

Sample hospital passport:
https://www.nhs.uk/Livewell/Childrenwithalearningdisability/Documents/Hospital%20Passport%20Template%20example%20from%20South%20West%20London%20Access%20to%20Acute%20Group.doc

'Ready Steady Go' resources:
http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/ForhealthprofessionalsReadySteadyGoresources.aspx

Appendix I: Skills for Independence

The following list is derived from the Real Opportunities Impact Report (2014), which detailed numerous examples of Independent Living Skills courses which were previously offered within their project (Beyer, Kaehne, Meek, Pimm and Davies 2014, p22).

- Use of Public Transport
- Tackling Bullying
- Introduction to Road Safety
- Safety with Strangers
- Personal Hygiene
- Internet Safety
- Sex & Relationships
- Anger Management
- Confidence Building
- Emotional well-being
- Friends
- Substance Misuse
- Introduction to Community Leisure
- Duke of Edinburgh Award
- Introduction to Countryside Awareness
- Developing Effective Social Skills
- Introduction to Personal Shopping
- Disability Awareness
- Cooking Skills: Following a Recipe
- National Navigation Bronze Award
- Basic Nutrition, Hygiene & Food Skills
- Basic Kitchen Hygiene
- Preparing a Meal
- Everyday Food & Drinks
- Introduction to Countryside Awareness
- Personal Care & Hygiene
- Introduction to Carpentry
- Household Expenses
- Basic Carpentry Hand Tools
- Personal Awareness
- Duke of Edinburgh Award
- Personal Health
- Participating in Leisure Activities
- Law & Order
- Outdoor Safety
- Milestone – Me & Others
- Completing Forms
- Knowing your Local Area
- Pre-interview Skills
- Working as a team
- Person Centred Planning
- Self Advocacy
- Peer Mentoring
- Health & Fitness
- Practical Gardening/Allotment
- Taking Part in Sport
- Beauty Therapy
- Developing a Group Performance

Appendix J: Transition Online Concept

What is Transition-Online?

Transition-Online is an accessible, secure, up-to-date 'portal' that young people, families and professionals can log into to view, update and comment on Single Integrated Transition Plans. The online facility would offer a system designed to support communication and would ensure young people have full access to, and potential for participation in, transition. Young people and their families will be able to receive 'live' updates on transition progress e.g. decisions made regarding funding or placements. The portal would provide IAA (information, advice and assistance) to those needing low-level support and will detail the referral processes/criteria for all post-18 provision, including how to access specialised transition support. Thus, Transition-Online will be a transparent service, explicitly detailing a range of services including how they can help young people and families, contact details and/or their referral processes. All transition information can be held in one online system, supporting paperless planning, and mitigating the need for constant travel for meetings, emailing and phoning for updates. This service will be vital for families with busy and hectic lives and who live in rural areas, and professionals who have difficulty attending multi-agency planning meetings due to high work pressures and clinical duties. There would be three levels of access, including public (detailing transition processes, eligibility criteria, available support etc.), person-specific (accessible to young people, parents and professionals involved with this specific young person, hosting case details including their Single Integrated Transition Plans), and restricted (confidential information accessible only by approved professionals, e.g. safeguarding information and other strictly confidential information).

Transition-Online is by no means designed to completely replace face-to-face support and in-person meetings. It would be best used to supplement communication and assist in coordination in transition. The system encourages and prompts young people and families to begin transition planning, offering a structured format to prepare them for the future.

Core Elements/Ideas:

- **Accessible Platform:** online, as a secure website with appropriate security measures (e.g. password, memorable word, etc.). Young people, parents and professionals can log into the website any computer which, crucially, allows professionals across all

platforms to speak to one another. Transition Officers and the team Administrator will mediate the online system. Any sensitive data (e.g. child protection issues, mental health assessments) will have viewing permissions set, to ensure access to information is only granted where essential and appropriate.

- **Personal Information:** Any assessments completed by professionals should be uploaded onto the online system, so that young people and their families can view these. A profile can be created with personal information, including person-centred documents, which provides professionals with a background to which they can refer to during planning. All young people can create profiles and complete online person-centred documents, regardless of whether they are receiving formal transition support, to empower users to take ownership of transition planning.
- **Single Integrated Transition Plans:** Transition plans are uploaded onto the online system, and each professional can electronically add to the overall transition/care plan. Families can access this at any time to see their progress and will receive email notifications when their plan is updated. Annual reviews will contribute significantly to this plan, and professionals can review it at any time. Again, anyone could make their own transition plan regardless of formal transition support. Young people and families could use a 'goal setting' or 'future planning' section which could include questions involving life aspirations, housing goals, skill development planning, health goals, education objectives, personal goals and employment aspirations. Finally, the transition plans will have a calendar function that users can update with any appointments/assessments and will aim to track transition planning, including offering data for evaluation purposes e.g. time scales.
- **Supported Communication:** Professionals can log any concerns about transition planning through the online system. Young people, parents and professionals can also access dedicated transition forums. Online users can send messages, which prompt automated emails, to young people, parents and professionals. Messages about important meetings and events will be communicated to young people and parents through emails, with future potential for development of a Gwent Transition Service mobile phone 'app' which can send reminders for appointments, upcoming workshops, application deadlines etc.

- **Information, Advice and Assistance (IAA):** An array of resources will be made available online, for example, an explanation of each service available in Gwent including its eligibility criteria, contact details and referral process. A frequently asked questions page will attend to common questions, 'toolkits' around managing challenging behaviour and anxiety during transition and a booking system for family workshops will be available. Information about laws/best practice/rights/responsibilities, local provisions and support groups will be available, including online sign-up/booking systems. Webinars will also be available online which complement the workshops and will be produced in close collaboration with young people, sharing learning from those who have experienced transition to adult services first-hand. Webinars could also be produced featuring professionals such as psychologists, transition officers and head teachers, College course tutors, who could give further advice to aid in the preparation for transition. The website will strive to offer differentiated resources such as videos, games and/or quizzes. Professionals can also access/download resources, and will have access to 'advice/FAQs for professionals' documents and online training modules.
- **Evaluation:** Transition services could be easily evaluated through the online system through the distribution of online questionnaires, a feedback/complaints system and automatically generated statistics/data on website usage e.g. completion and progress of Ready Steady Go resources. Feedback will be reviewed 6-monthly by the transition team, and any suggestions or changes from this put into operation.

Conclusion:

Transition-Online would act as an important catalyst for transition, enhancing communication between all stakeholders involved. Currently, systems across services do not interact with one another which negatively impacts the ability to work seamlessly and accomplish multi-agency working. This online resource offers a viable solution to this problem and acts as an important IAA service to increase the transparency of services in Gwent. In 2019, the accessibility of information is fundamental and, increasingly, technology is being utilised to overcome deficits in efficiency. This modern-day solution is easily understood by young people and will likely significantly increase their participation and experiences of transition planning and care.

Appendix K: Risk/Benefit Matrix

	Risks	Benefits
Option 1	Higher monetary cost for service. A potentially high number of referrals into the service and consequential managing expectations of young people and families. Unknown monetary value, currently, for producing Transition Online. Lack of a pilot study, currently, that could accurately quantify cost savings and evaluate the proposed service.	Highly individualised, Single Integrated Transition Plans, co-ordinated by a dedicated Transition Officer. A specialised support worker to provide low-level support to young people and work towards agreed skill development programmes. Strategic business planning, leadership and commitment to propelling transitional care through a dedicated Transition Manager. Maximised support for young people, with potential for 1:1 support for those with an assessed need.
Option 2	Due to lack of specialised support workers, less young people will have the opportunity to receive support, with very limited capacity to work 1:1, in independent living skill development. Reduced caseload for dedicated Transition Officers, with only those deemed high risk receiving support. Some young people continue to lack transition support, yet have moderate needs for a transition service. Less impact on policies and procedures across Gwent, due to lack of dedicated Transition Manager. Continue to see issues in transitional care across Gwent.	Highly individualised, Single Integrated Transition Plans, co-ordinated by a dedicated Transition Officer. Some opportunity to work with young people towards agreed skill development programmes. Strategic business planning and leadership for the transition team, supported by a manager sourced from within another team different team. Lesser monetary cost for service than Option 1.
Option 3	Continuation of the current, inadequate model for transition, with a significant number of young people not benefitting from single, integrated transition plans. Young people and families continue to feel unsupported and distraught by the process, and the increased likelihood of reaching crisis. Professionals remain dissatisfied with the processes of transition and are left within their silos to attempt to fill the gaps in co-ordinated transitional care.	No monetary costs.

Appendix L: Cost Breakdown

Option 1: Gwent Transition Service (Gold Standard)			
Job Role	**Maximum Wage (per person)**	**On-Costs (per person)**	**Overall Team Cost**
Transition Manager x1	£43,772.00	£6,040.54	£49,812.54
Transition Officer x7	£30,112.00	£4,155.46	£239,872.22
Transition Support Worker x6.6	£20,795.00	£2,869.71	£156,187.09
Administrator x1	£19,020.00	£2,624.76	£21,644.76
		Transition-Online (Development)	**Approx. £73,200***
		Transition-Online (On-going)	**Approx. £1,860 per month**
		Total Service Costs (Gwent)	**£563,036.61 per annum**
		Total Number of Service Users Served	**1,509**
		Average Cost per Service User per Delivery Week	**£7.77**

Option 2 Gwent Transition Service (Bronze Standard)			
Job Role	**Maximum Wage (per person)**	**On-Costs (per person)**	**Overall Team Cost**
Transition Officer x7	£30,112.00	£4,155.46	£239,872.19
		Transition-Online (Development)	**Approx. £73,200***
		Transition-Online (On-going)	**Approx. £1,860 per month**
		Total Service Costs (Gwent)	**£335,392.19 per annum**
		Total Number of Service Users Served	**768**
		Average Cost per Service User per Delivery Week	**£9.10**

***inclusive of the development of a dedicated server-based website and case management tool, and the ongoing maintenance of this facility.

Costings are based on a 2019 population projection for 14-24-year-olds, sourced from Welsh Assembly Government (2016), for each local authority in the Gwent area. A national average statistic for disability for children aged 0-17 was identified at 8% (Department for Work and Pensions, 2018) and applied to population projections, establishing a baseline disability population for each local authority. This baseline figure was used to calculate the level of service need and, subsequently, the level of resource required to support transition in each local authority.

Local Authority	Total Population Projection for Young People Aged 14-24 Years Old	Estimated Population with Disability (8%)	Number of Young People Served: Option 1	Number of Young People Served: Option 2	Cost per Local Authority: Option 1*
Caerphilly	22,147	1,772	484 (27.3%)	256 (14.5%)	£136,765.60
Blaenau Gwent	8,088	647	185 (28.6%)	128 (19.8%)	£57,212.67
Torfaen	10,812	865	242 (28.0%)	128 (14.8%)	£68,386.37
Monmouthshire	10,099	808	242 (30.0%)	128 (15.8%)	£68,386.37
Newport	19,950	1596	484 (30.3%)	256 (16.0%)	£136,765.60

***Cost per LA does not include the development or maintenance of Transition Online. Costings are based on the number of Transition Officers and Transition Support Workers in each locality, further using this ratio to calculate the percentage each LA would pay towards the Gwent Transition Manager and Administrator costs.**

As demonstrated in the table above, Option 1 would serve approximately 29% of the population with disabilities in Gwent and Option 2 would serve approximately 16%. This is based on the estimated caseloads of 128 young people/year for the Transition Officer and 114 young people/year for the Transition Support Worker.

Appendix M: References

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