

100 Stories Project: Transitioning To Real Change



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The 100 Stories Project presents the opportunity to support current improvement initiatives and programmes to develop a detailed understanding of the complex systems young people have to navigate when transitioning from children’s to adult services. This insight, gathered from understanding the experiences of professionals, young people, parents and carers, will enable decision makers to fully understand the challenges within this area and support ongoing action to undertake the changes that are needed through coproduction and the development of systems learning cycles.

Background

Transition is a national priority for improvement, highlighted in a number of change agendas. In February 2022 the Welsh Government released its guidance on ‘The Management, Handover and Accountability of Healthcare Services for Children and Young People During their Transition from Children’s to Adult Services’. Since this time evidence continues to be shared in national reports that there are still issues impacting on the experience and outcomes for young people and families during transition.

Project Objectives

The project will develop a highly informed evidence base, collating 100 stories and narratives from across the system to influence action through generating social proof and using coproduction to work together with all levels of the system over time to progress behaviour change. This project has a focus on the voices we are not hearing, particularly voices of young people and young adults with a neurodevelopmental condition and/or a learning disability.

Project Approach

The 100 Stories Project design was co-created over 2 years, working with multiply partners and organisations to consider a safe and effective methodology that has a strong foundation of evidence and ethical safeguards and considerations. The approach includes:

- Service mapping and data collation
- Training & upskilling participants in ‘Public Narrative’ Technique
- Collating stories through group storytelling
- Completing a ‘Community Enquiry’ for deeper understanding
- Completing a ‘Theory of Change’ with groups and leaders across the system to create a plan for change
- Supporting the development of strategic plans to implement ‘learning cycles’
- Evaluating the impact overtime through the ‘Most Significant Change’ Model

Project Impacts

- Transformation Programmes in North Wales are working with the evidence being generated from the project, with Wrexham University supporting further research.
- The PSB’s & RPB’s are engaging with the project to support leadership engagement & commitment.

Key Conclusions

The greatest successes of the project lie in the detail and content of the stories collated, which has enabled the isolation of recurring themes and the project’s ability to communicate challenges through an alternative medium outside of the traditional forms of reporting, which has enabled the facilitation of meaningful action, building from the natural human response to listening to real human experience through the medium of storytelling.

The stories have gone beyond our original intention in understanding the experience of transition from multiple perspectives and have in fact highlighted the numerous interlinked complexity of the wider system that impacts on the outcomes of young people as they become adults. This is a significant factor, as it creates further opportunities for cross systems learning, which will support the ambitions of the project to create systems of coproduction to support onward learning cycles and strategies with cross system expertise.

Project Outcomes

The early thematic analysis is supporting the findings from our data analysis and mapping exercise, which demonstrate we have gaps in services and growing waiting times are having a negative impact on young people, families and professionals. What has been significant in our learning so far, is the multiple systems wide impacts that can influence a child’s journey into adulthood and their access or need for adult services.



Head, Heart and Hands Methodology

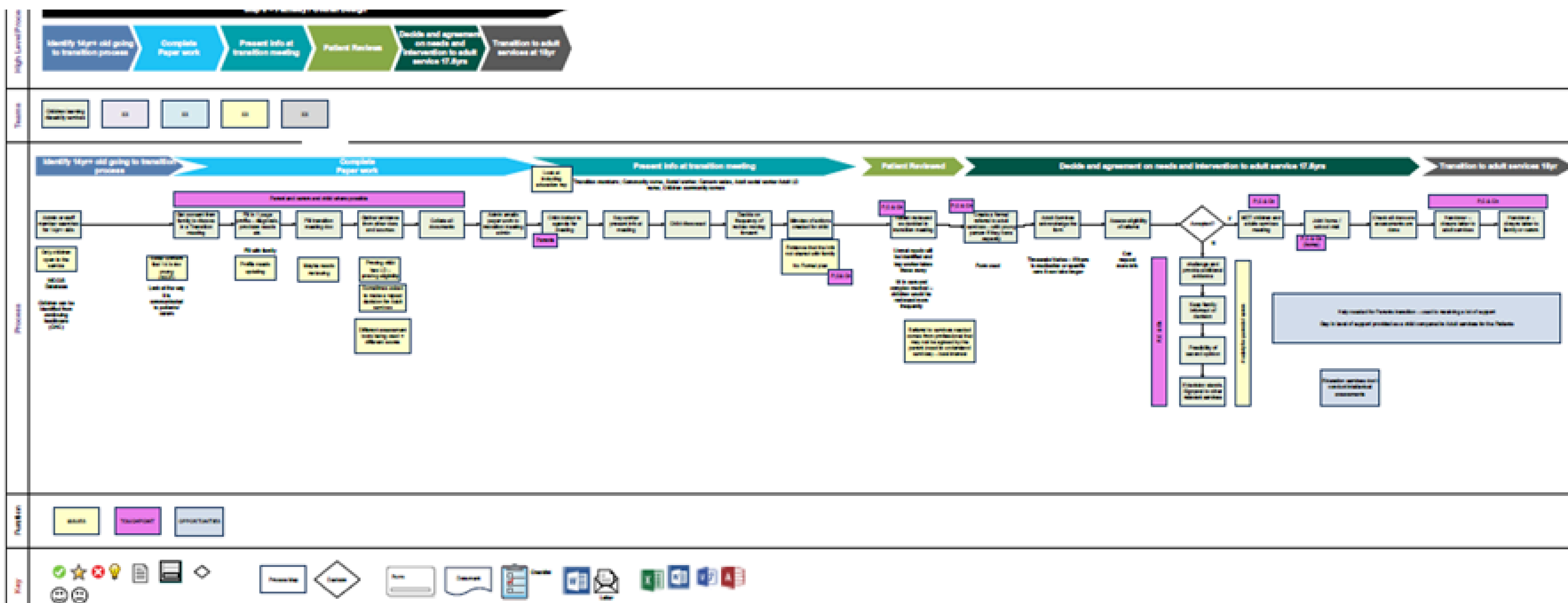


The thematic analysis has highlighted clear challenges in the system



Community Enquiry: What needs to change:

- There is a need to develop a whole family approach during transition
- A consistent offer between adult and children’s services, with an aligned criteria
- More consistency and clear information and communication regarding service access and pathways
- A greater focus on joint working between children’s and adult services and jointly funded services/shared budgets
- Greater opportunities to connect with children, young adults and families, to enable them to have more voice in service delivery
- Greater focus on individual need and less focus on an expectation of diagnosis in education, health and social care
- Work with multiple sectors and society on understanding neurodiversity and learning disability, challenging conceptions/attitudes to open up more opportunities for young people to flourish socially, economically and healthily
- A greater national focus. Leadership and funding is needed to remove barriers for professionals



Service Mapping

Learning Disability Service processes for transition are currently consistent and aligned to areas of national best practice. Areas that may impact the quality and experience of services in the future have been highlighted via the data analysis. These included the risks of rising demand in services and via professional insight during the mapping exercise areas of losing family voice and inconsistency and access to provision in educational and adult services.

Neurodevelopmental Service processes for transition demonstrate a level of regional consistency, however highlight given current pressures of waiting times the challenges in providing transition for children and young people in line with national guidance. Gaps in service processes do highlight a need for further consideration for children and young people not in receipt of medication. There is a need to further explore what pathways are available to these young people that enable access to adult care should this be required.

Data Outcomes Summary

The population of children and young people with a disability is increasing in North Wales, this increases the numbers of children that will require transition in the future.

The overall population of those with moderate or severe learning disabilities is also increasing in North Wales, which increases the likelihood of continued support into adult services.

The waiting times for services are impacting on the age young people are assessed by neurodevelopmental services, leading to later diagnosis, which is impacting on the time to put in place transition processes inline with national guidance.

The increased wait times also have a possible correlation to needs escalation, which can lead to the need for more intensive support or prolonged support into adulthood.

Thematic Analysis Key Learning

Young People are experiencing a gap between children's and adult services, there is a significant difference in eligibility criteria and availability of provision.

Waiting times are impacting on young people's health, social and economic outcomes, which is impacting on them as adults.

Professionals are concerned and often feel helpless to change the system. Parents and carers are often isolated from the transition process and struggle to navigate the complex system, which is impacting on family resilience and ability to cope.

Education, bullying and societal attitudes impact on young people and can drive inequalities that lead to poorer outcomes as they become adults. Young adults are having to manage systems wide barriers and experience inequality.

Young people had limited opportunities to flourish as adults which impacted on Mental health	There are gaps the sector to support these young people as adults	Parents/Carers experience long waits to access support, escalating needs as YP become adults	Young people had experienced bullying affecting their confidence as adults	A lack of information and support for families
	Poor communication during transition and a lack of planning	Complicated systems	Parents felt isolated from transition process	Lack of provision to support neurodevelopmental conditions
Young people do not meet the threshold for Adult MH and LD Services	Young people are unprepared for the changes and what to expect in adult services	A lack of adjustments in school limits the life opportunities of young people as they become adults	Young Women with Neurode... needs are less likely to be assessed...	Age limited is a barrier, young people's support can stop at 18 if n...
			Direct Paym... can be stopp... due t...	CHC fundi... can lead t...
			Children turning 18 before they...	