

Learning Disabilities & Autism update to Derby City Council Health Overview & Scrutiny Commission

31st January 2023

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April 2021 – the JUCD LD&ASC Road Map ‘North Star Vision’.

“Our ambition is to change how neurodivergent people and people with a learning disability and their families receive any support they might need. We aim to move away from reactive and intensive interventions to preventative and flexible support provided in local communities.”



August 2022 – Working Together co-production workshops.

“To ensure neurodivergent people & people with learning disability are recognised, validated, and empowered to live the lives they want.”

Priority improvements we need to deliver to achieve the vision...

- Addressing our overreliance on inpatient care for autistic people and people with a learning disability.
- Reducing the significant waiting times for neurodivergent diagnostic assessments.
- Ensuring quality & sustainability across Derbyshire’s health, community & social care services.
- Achieving good value for money for Joined Up Care Derbyshire.



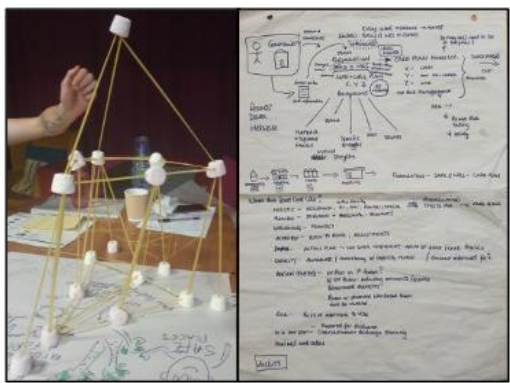
Achievements & future priorities.

Achievements

- Created stronger multi-agency processes & approaches to support admission avoidance & expedite inpatient discharges.
- Continued to excel at key programmes addressing health inequalities (Learning from deaths, Annual Health Checks).
- Had proposals for significant investments in the neurodivergent diagnostic pathway approved.
- Better embedded the voices & aspirations of local people into the ND programme through co-production.

Future priorities

- Delivering a Joined Up Care Derbyshire Recovery Action Plan relating to the availability & quality of local social care provision.
- Implementing an 'all age' neurodivergent diagnostic pathway, including community-services which 'wrap around' the assessment process.
- Addressing the improvements needed to local specialist inpatient services through immediate changes & long term service transformation.



Images from JUCD 'working together' & 'clinical design team' workshops.



Title slide from presentation to clinical design team outlining our aspirations for local inpatient care.



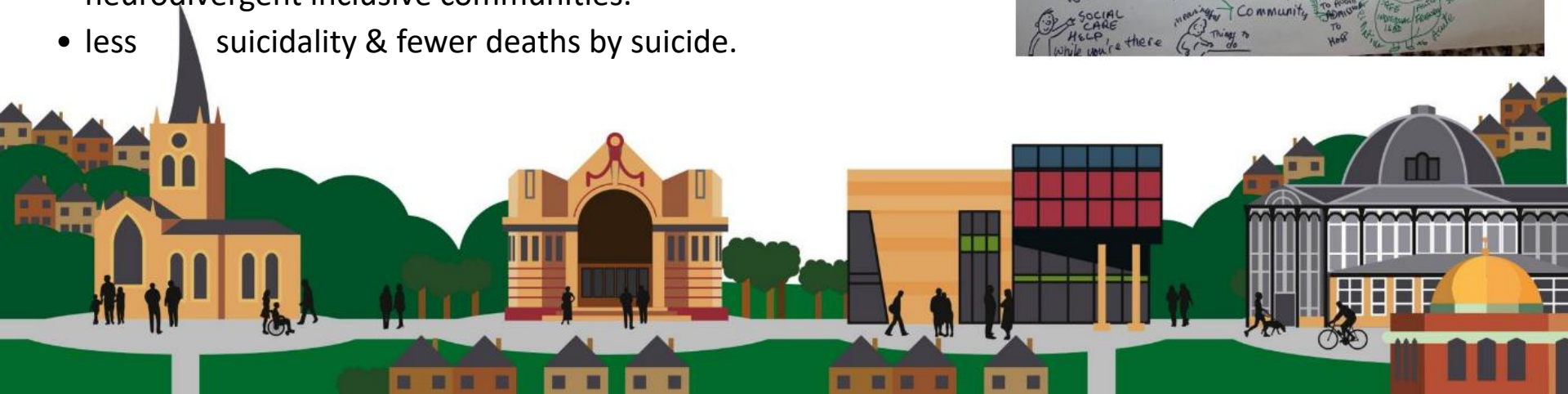
How the future will be different.

Achieving NHS targets for...

- the use of inpatient care for autistic people and people with a learning disability – **target end of 23/24.**
- waiting times for neurodivergent diagnostic assessments – **target 2025 for children.**
- the number of people with a learning disability who have their Annual Health Check & a Health Action Plan – **achieving.**

Achieving local aspirations for...

- more community-based, preventative services – **target 2023/24.**
- Improved local specialist inpatient care – **ongoing.**
- neurodivergent inclusive communities.
- less suicidality & fewer deaths by suicide.



- Joined Up Care Derbyshire Neurodevelopmental Programme vision (slides 6-8).
- Use of inpatient care for autistic people and people with a learning disability (April 2021 – December 2022)
- Autism diagnostic assessment waiting list and times for Derbyshire Healthcare Foundation Trust (April – December 2022)
- Details of achievements since March 2022 attendance at Scrutiny & priorities for next year (slides 11-12).
- NHS transformation investments (slides 13-14).
- Joined Up Care Derbyshire neurodevelopmental services.
- Learning disabilities & autism in Derby, fact sheet.



Joined Up Care Derbyshire's revisited & refreshed shared vision for the Neurodevelopmental Delivery Programme – improving services for people with learning disabilities & autistic people in Derby and Derbyshire. (1/3)

Using a PATH (Planning Alternative Tomorrows with Hope) methodology, 4 stages have been identified to lead us to achieving our shared goals and north star vision:

1. GROUNDING IN THE NOW

At present, Derby and Derbyshire has the following:

- Too many ASC people &/people with LD in inpatient settings
- Too few ASC people &/people with LD registering with their GP and accessing Annual Health Checks (AHCs)
- Too many avoidable deaths of ASC people &/people with LD
- Communities and statutory services that are not LD &/neurodiverse inclusive
- Too many ASC people &/people with LD experiencing health inequalities
- A disparity in services for ASC people &/people with LD
- Too few and appropriate care and accommodation options in the community
- Not enough coproduction and engagement opportunities for people with lived experience to shape services
- Complex operational and finance processes.

2. ENROLLING SUPPORT

Committed partners – Derbyshire County Council, Derby City Council, Derby and Derbyshire ICB, Derbyshire Healthcare NHS Foundation Trust, Derbyshire Community Health Services, Derbyshire's VCSE & provider market, people with lived experience and their families.

4. ACTION PLAN & NEXT STEPS

Our next steps are to continue the realisation of the Delivery Plan through our dedicated workstreams. These are: Crisis & Intensive, Care & Accommodation, Enhanced Community Support, Infrastructure & Enablers, VCSE, CYP, Operational Fidelity, Mental Health Interface, Reducing Health Inequalities, Shortbreaks, Inpatients, and Assessment Pathways.

3. BUILDING STRENGTH

To achieve our vision we have developed the following robust and comprehensive methods of programme delivery:

- A 4-year Roadmap – this captures our ambitions for the next 4 years
 - A trackable and reportable Delivery Plan - this combines and monitors all activities taking place and provides governance
 - 12 committed workstreams dedicated to realising our goals - these act as the 'bridge' to success
 - An up to date risk register – ensuring all risks are identified and mitigated
 - Engagement &/coproduction opportunities to ensure voices of people with lived experience are heard & embedded
 - A 3-year LeDeR strategy.
- All of which are grounded in measurable benefits realisation.

Joined Up Care Derbyshire's revisited & refreshed shared vision for the Neurodevelopmental Delivery Programme – improving services for people with learning disabilities & autistic people in Derby and Derbyshire.

**Joined Up Care
Derbyshire**

NORTH STAR VISION: Our ambition is to change how neurodiverse people and people with a learning disability and their families receive any support they might need. We aim to move away from reactive and intensive interventions to preventative and flexible support provided in local communities.

SHARED GOALS

- No more than 24 adults & no more than 3 children/young people in inpatient care
- A realistic & effective hospital avoidance offer with parity across Derbyshire
- Effective & locally-embedded preventative services in the community
- More people with LD&/ASC registered with their GP & those correctly diagnosed included on their GP LD&/ASC Register, with at least 75% coverage for AHCs
- Less people with LD who have 'constipation' &/ 'epilepsy' as their recorded cause of death
- Compliant with national standards for STOMP/STAMP & LeDeR
- Less people with ASC who die by suicide or experience suicidality
- Less people with LD who have inappropriate DNACPR
- More ASC people & people with LD in permanent employment
Local communities & statutory services being LD&ASC inclusive
- Reduction in ASC/ADHD assessment waiting times to become Standards compliant with one joint all-age ND assessment pathway in place
- LD&/ASC Quality Standards compliant
- C(E)TR/LAEP Policy Standards compliant & a proactive & effective DSR process
- Joined-up operational & finance processes to allow ready access to the right service at the right time without unnecessary barriers or delays
- A marketplace of high quality care & accommodation options fit for purpose
- To ensure ASC people & people with LD are recognised, validated, and empowered to live the lives they want (taken from the 2022 Working Together workshops).

Agreed and ratified by the Delivery Group 16/11/2022

All ways of working are underpinned by a shared commitment to Human Rights – these form the bedrock of our commitment and vision.

Legal protection from abuse. Equal rights and equal opportunities. Right to freedom and security. Respect for privacy and family. Right to life. Freedom of expression, choice and control.

Joined Up Care Derbyshire's revisited & refreshed shared vision for the Neurodevelopmental Delivery Programme – improving services for people with learning disabilities & autistic people in Derby and Derbyshire. (2/3)



Joined Up Care Derbyshire's Neurodevelopmental Programme = This is the joint Health and Social Care programme leading on the transformation of learning disabilities and autism services in Derby & Derbyshire

People with lived experience and who access learning disabilities and autism services in Derby & Derbyshire - autistic people, people with ADHD, neurodiverse people, people with learning disabilities, carers, and family members and friends.

People may access these services at various times throughout their lives as and when needed.



The voices of people with lived experience are central to our local approach to transformation and the shaping of services.

- Services and areas of transformation:**
- The acute treatment unit (Ashgreen)
 - Adult mental health units (Radbourne & Hartington)
 - Community Mental Health Team
 - Community Learning Disabilities Team
 - Intensive Support Team
 - Specialist Autism Team
 - Autism Assessment Teams
 - Community Forensic Team
 - The Dynamic Support Register (DSR) process
 - C(E)TR and LAEP processes
 - VCSE services
 - The provider market place for community-based services
 - Acute hospitals and physical health services
 - GP surgeries, Annual Health Checks, LeDeR
 - Front-door access to Health and Social Care services
 - Inclusivity, awareness raising, and training
 - Operational and clinical pathways

People across Derby and Derbyshire's Health and Social Care system working alongside people with lived experience to bring about transformation: Nurses, Psychologists, Psychiatrists, Clinicians, Social Workers, Case Managers, Approved Mental Health Professionals, Commissioners, Strategic Leads, Operational and Clinical Managers and Team Leaders, Occupational Therapists, Speech and Language Therapists, Physiotherapists, Health Facilitation Team, Non-Medical/Social Prescribers, LeDeR Assessors/Reviewers, Specialist Roles/Teams across services, Support Workers, Community Navigators, Helpline Advisors, Recovery Workers, Link Workers, Community Coordinators and Officers – and many, many more.



Joined Up Care Derbyshire's revisited & refreshed shared vision for the Neurodevelopmental Delivery Programme – improving services for people with learning disabilities & autistic people in Derby and Derbyshire. (3/3)

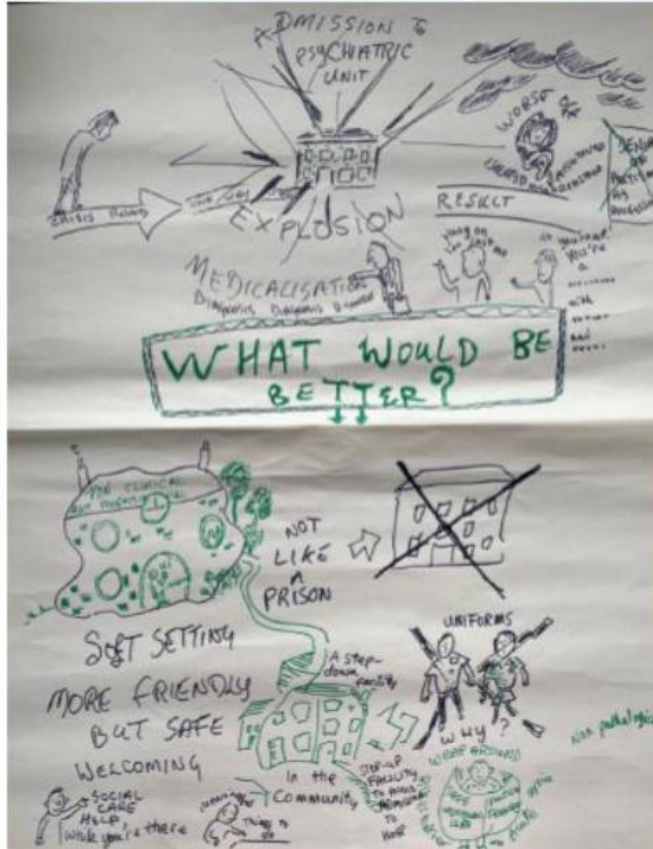
Over the years, voices of people with learning disabilities and autistic people, their families, and carers have informed the development of our shared goals & vision:

Crisis is like a mountain, but you don't always go straight to the top, but that's how it's talked about. There's chasms along the way that without support you can fall into. You need a Sherpa to guide you and help you find ways to cross the chasms and find the way. There are also ledges where you can rest and survive for a while, but sometimes you never come back down, you continue to go up or you can stay there, living in crisis as crisis starts to become the norm. Being in crisis is not understood, not everyone is right at the top, it's individual.



I want to be able to control my sensory environment and my privacy.

We need to cultivate a community – everyone needs their own tribe!



We need to bring people together and share the ownership of the challenge.

We need therapeutic communities where we see the person first as a person, not as a person with a problem.

I want to be my own boss!

You need to know the person to understand! I don't want to hear "you don't look autistic enough!" More emphasis on how to work with a person in the best way + most comfortable way for them.

Things that have gone well for me when in hospital: friendly professional, using personalisation and humour and being made to feel cared for, good explanations of what was happening and why, given time to speak and being meaningfully listened to, and good paramedic care. When reasonable adjustments, basic needs, privacy, and sensory needs aren't met and when people do not communicate or give me mixed messages and I'm not given choice or my trauma or sensory needs are not validated, things do not go well.

When I'm at crisis, I feel like a radiator. I need someone to "bleed" me and release the pressure. There is stress in the pipes!

Joined Up Care Derbyshire

Everyone should have access to an integrated sensory assessment! It helps people to understand themselves and what they need. It helps them develop a personal toolkit and sensory diet.

Why do the services in the community keep changing? You start to use and like a service and then it goes and we never know why.

I have lost a year of my life but I am ready for independent living.

People don't know about personal health budgets or services/support available. We need contact lists, not waiting lists!

I need someone to say "I've got you in this moment." To validate and recognise my need.

We need better use of annual health checks and formulation.

I have been told that I have "behavioural traits not fit for community living."

Crisis is the consequence of unmet need!

There are places in Derby and Derbyshire that are my safe haven – they have people who can help and help me make an action plan.

More provision for step down = between hospital + community but also step-up!

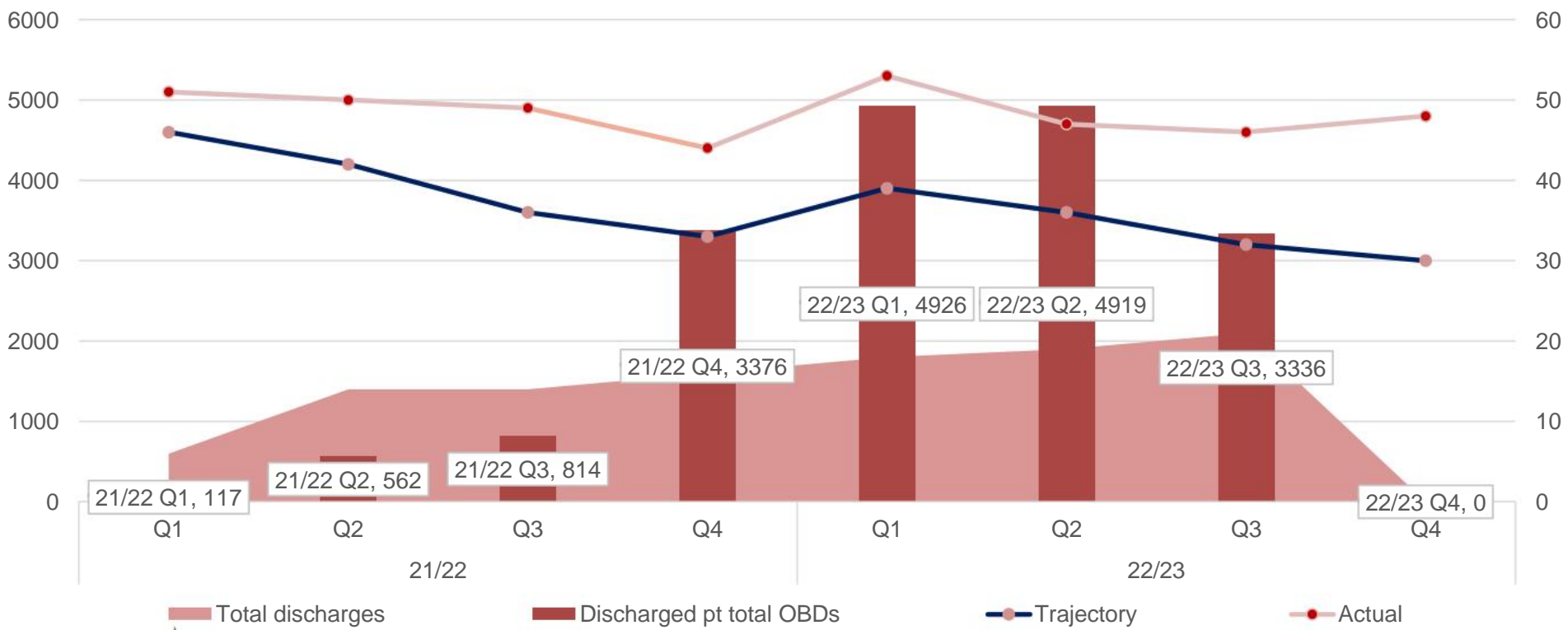
There needs to be a sensory room in every service – especially emergency services. As well as Autism first-aid kits.

*The above quotes have been taken from the Working Together workshops held on 22nd and 27th September 2022, the Autism Strategy codesign work that took place 2021-2022, and various 121 interviews with people with lived experience. Some quotes are verbatim and some are collated from group discussions.



Challenges to achieving our vision (I) – use of inpatient care.

Trajectory Progress / Discharges (incl. Occupied Bed Days)

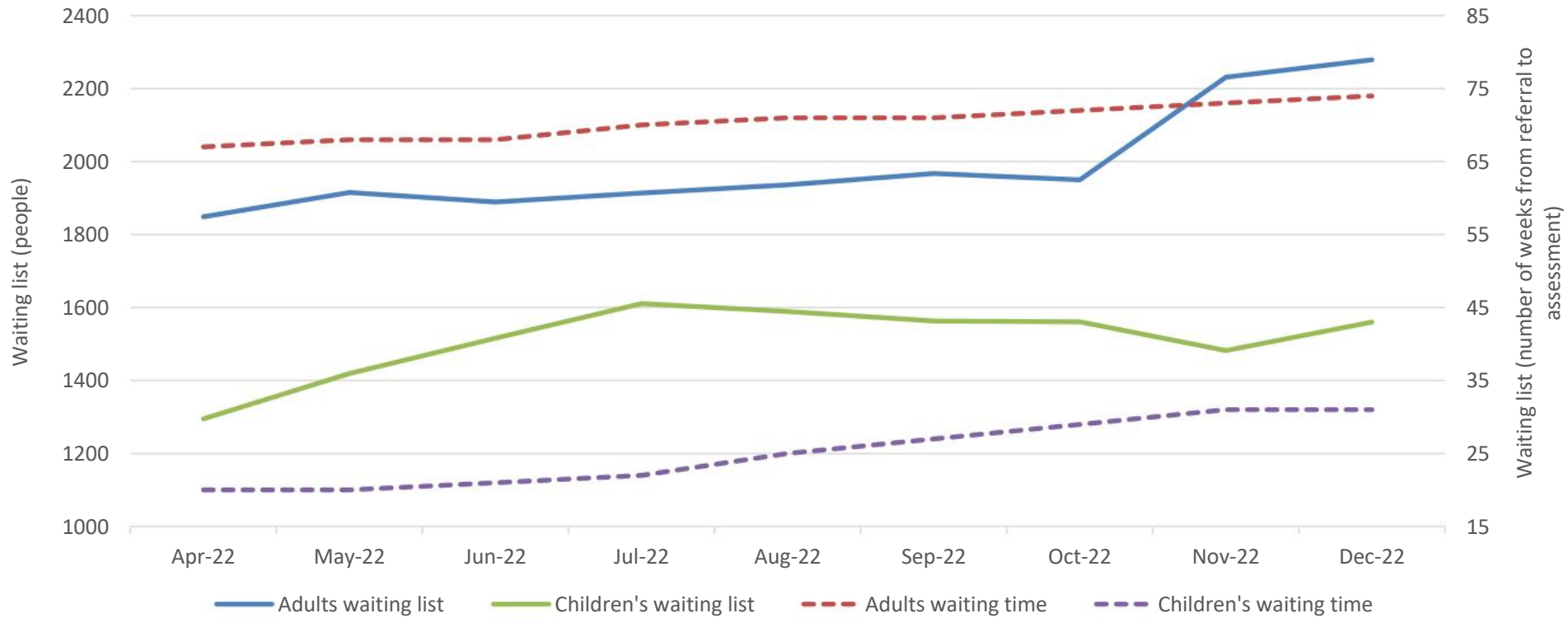


Contributing factors

- The availability of community-based services which can prevent clinically avoidable admissions.
- The quality of inpatient services in providing safe, effective & discharged focused care & treatment.
- Not having enough high quality, sustainable health & social care support for those who may need it.



Challenges to achieving our vision (II) – autism diagnostic assessment waiting list (Derbyshire Healthcare Foundation Trust)



Contributing factors

- The significant rise in demand for neurodivergent diagnostic assessments & the deficit in diagnostic assessment capacity.
- The gap in community-based services which 'wrap around' the diagnostic assessment pathway.



What we have been doing to help achieve the vision (2022)

Welcomed a Local Government Association Peer Review.

Continued to address any inconsistencies across local NHS provision.

New ways of reporting for the system-wide electronic Programme Management Office (ePMO).

New specialist roles to inreach into our local acute mental health wards and bridge the gap between inpatients and community.

New 'crisis inreach' service pilot as part of our hospital admission avoidance work.

Designed new 'book end' Voluntary, Community & Social Enterprise sector services to support the autism assessment pathway.

New multi-disciplinary ways of working to prevent avoidable hospital admissions & **increased** discharges from local acute mental health hospitals.

Fostered closer working relationships across the all partners.

Extended our innovative approach to working in better partnership with the Voluntary, Community & Social Enterprise sector.

Approval for transformation plans in developing a new all-age autism & ADHD diagnostic pathway.

New all-age Dynamic Support Register helping to avoid hospital admissions.

Increased co-production with people with lived experience.

Established dedicated a workstream to focus on health inequalities.



Our priorities for next year.

New services

- Based on learnings of the first prototype, commission a more targeted **crisis inreach** service.
- Commence a children & young people **keyworking** service to support families with complex needs.
- Continue the delivery plan for a specialist Neurodevelopmental **'Step Up' & 'Step Down'** service.
- Implement new **VCSE services** for neurodivergent people to wrap around the diagnostic assessment pathway.

More joined-up working

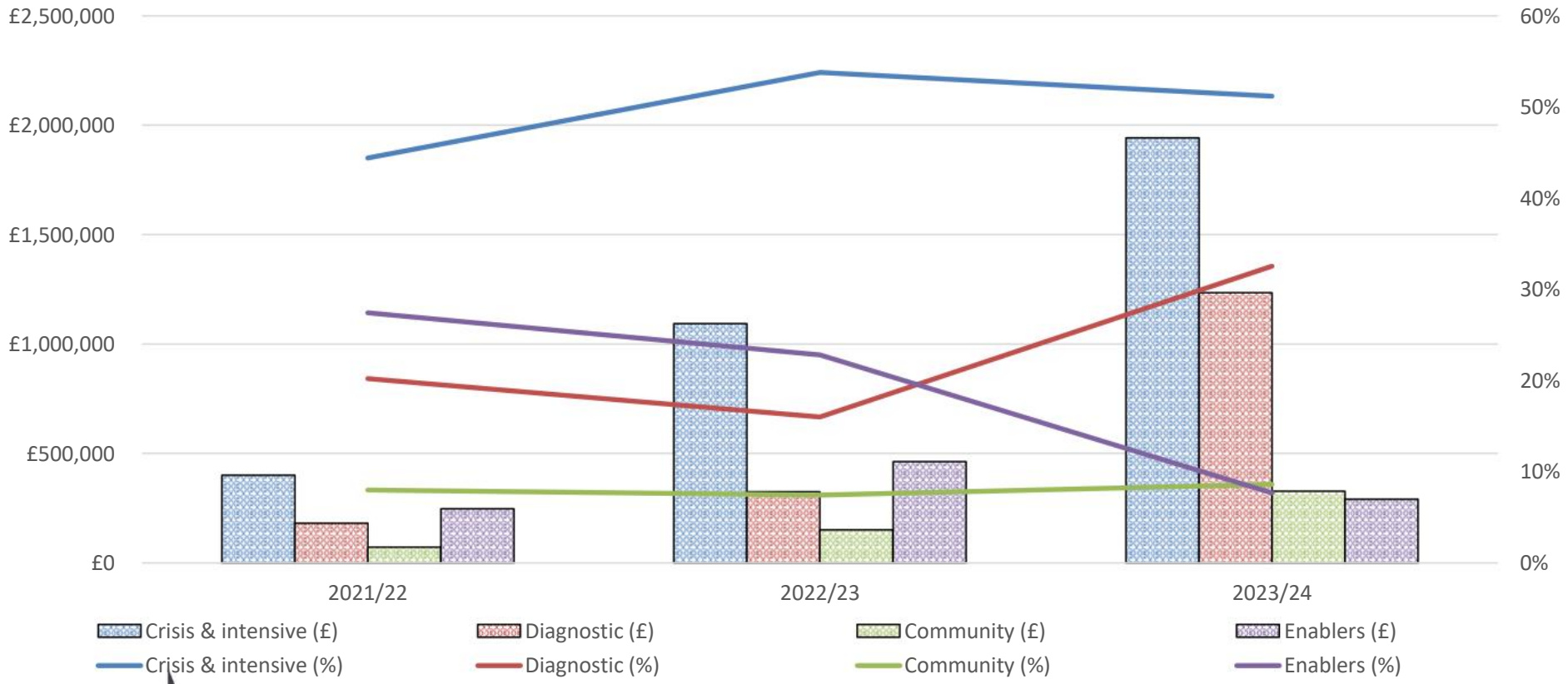
- Deliver on the shared Care & Accommodation Recovery Action Plan to **improve the provider marketplace**.
- Address the **financial & value for money challenges** across all Joined Up Care Derbyshire partners.
- Launch the local coproduced and **Integrated Care All-Age Autism Strategy**.
- Embed the **views & aspirations of local people** captured through coproduction as a 'golden thread' in all we do.

Strengthening our offers

- Implement the **Oliver McGowan Mandatory Training** programme across all partners.
- Deliver an **all-age Neurodevelopmental diagnostic pathway** – inclusive of autism and ADHD.
- Recruit to new NHS & community posts for **better pathways** between hospital and community services.
- Finalise options as to how to **improve local specialist inpatient** services.



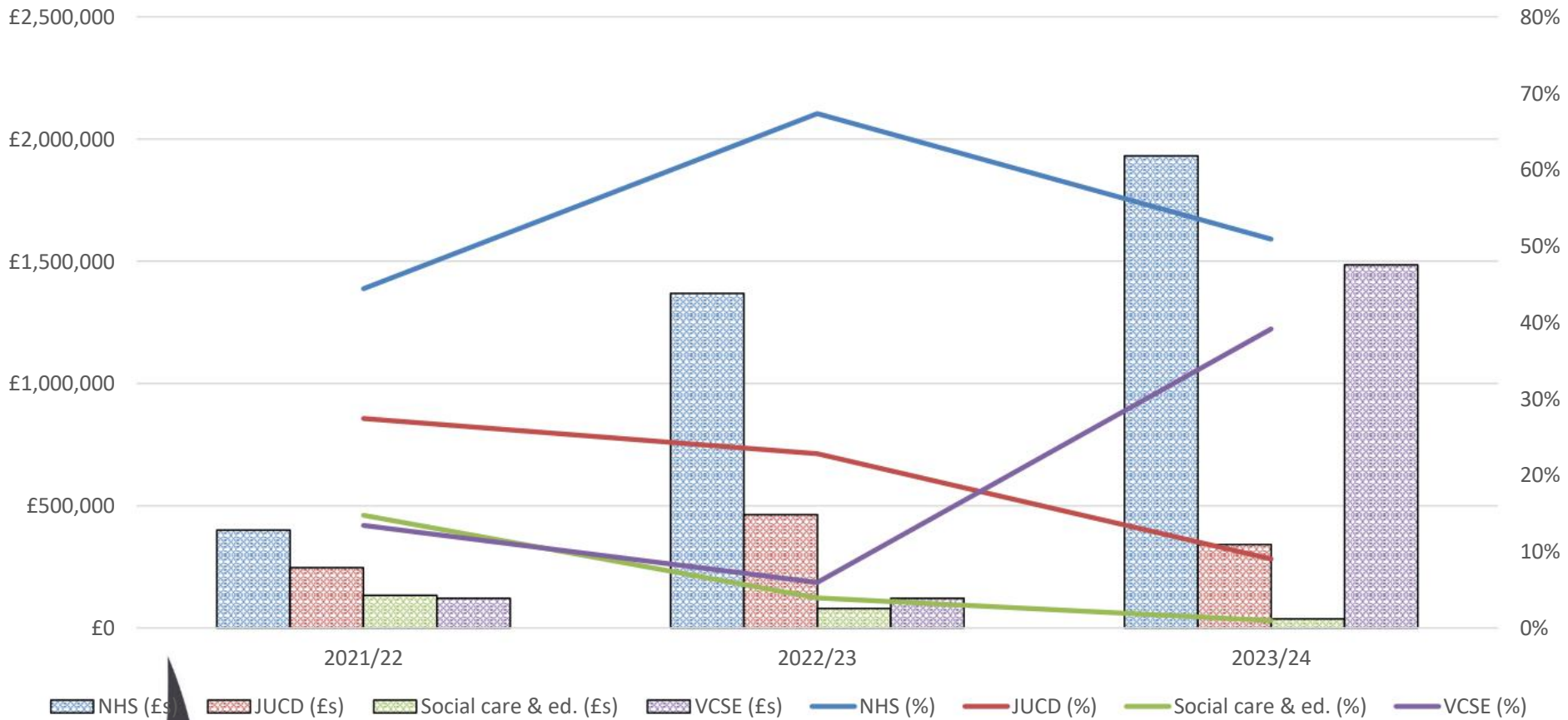
NHS transformation investments (I)



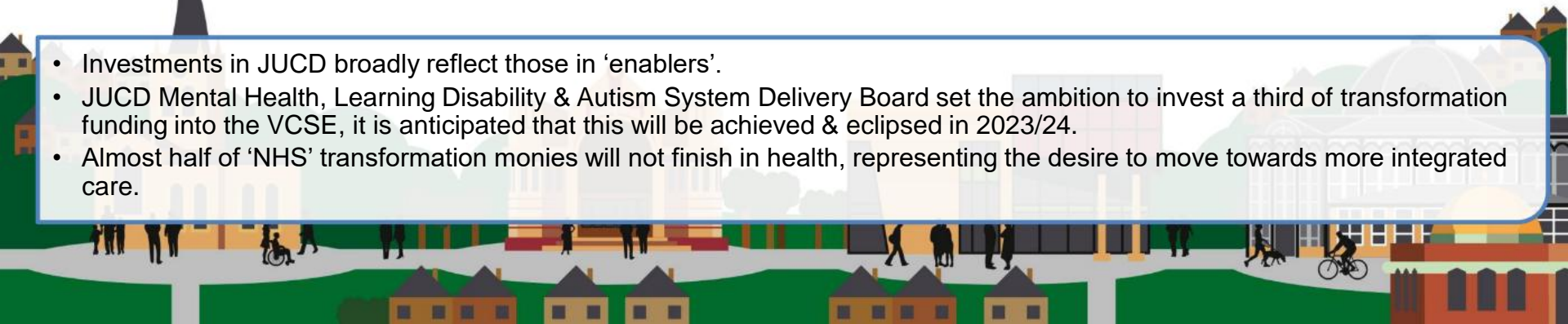
- Greater proportionate investment in 'enablers' earlier in the programme, to embed the infrastructure needed for transformation.
- Recognition of the improvements needed in diagnostic services has resulted in significant investments.
- Ambition is to address the gap between investments in 'crisis & intensive' and 'community' services.



NHS transformation investments (II)



- Investments in JUCD broadly reflect those in 'enablers'.
- JUCD Mental Health, Learning Disability & Autism System Delivery Board set the ambition to invest a third of transformation funding into the VCSE, it is anticipated that this will be achieved & eclipsed in 2023/24.
- Almost half of 'NHS' transformation monies will not finish in health, representing the desire to move towards more integrated care.





Together we are all working towards the same shared and coproduced vision – “To ensure neurodivergent people & people with a learning disability are recognised, validated, and empowered to live the lives they want.” - see appendices for full vision.



Learning disabilities and autism in Derby – *who we support*

(figures as of March 2022)

- Approximately **4,700 adults with a learning disability, 1,500 children.**
- Approximately **1,950 autistic adults, 600 children.**
- 891 'working age adults' with a learning disability in receipt of long-term support from Derby City Council (19% of total estimated population).
- 80% of autistic people experience mental health issues during their lifetime.
- Average age of death for men with LD in Derby & Derbyshire is 60, 62 for women.
- Autism is the most common primary need for children and young people with an EHCP (37%)
- 22% of autistic adults are in any form of paid employment, 2.8% of adults with a learning disability in receipt of long-term support.

