The Criminal Justice System Learning Disability and Autism Pathway Project

Executive Summary and Report Recommendations
April 2024

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1 Overview

There are limitations with gathering prevalence data for autistic people and people with learning disabilities in the Criminal Justice System (CJS), and there is no reliable systematic method used currently across the CJS to screen for and record either suspected autism or learning disability or diagnosed autistic and/ or learning disability. It is likely that figures gained estimating prevalence are an under-representation of the levels of autism and learning disability in the CJS. The Criminal Justice Joint Inspection (2021) reported, "it seems that perhaps half of those entering prison could reasonably be expected to have some form of neurodivergent condition which impacts their ability to engage".

The CJS is a complex system, where individuals are expected to understand, process and retain significant amounts of information, understand the processes they are subject to, communicate and interact proficiently with a wide range of individuals, to listen, understand and process conversation as well as formulate ideas and experiences into words (Humber & Snow, 2001), all of which can be challenging for autistic people and people with learning disabilities. Within the CJS, autistic people and people with learning disabilities are frequently faced with overwhelmingly complex and stressful situations, and may have faced trauma, which provides further barriers to successful engagement in the CJS. Neurodivergent service users may be "easily manipulated, coerced, groomed, or susceptible to peer pressure" (User Voice, 2023) and are more vulnerable to victimisation within the CJS than their neurotypical counterparts.

Recent research has found that staff in the CJS (both from a justice and health perspective) lack a nuanced understanding of neurodivergence, often do not received sufficient training in working with autistic people and people with learning disabilities, and lack confidence in their own skills in working with autistic people and people with learning disabilities, and therefore do not have the skills to adapt processes or interventions as required (Kargas et al. 2023; The Council for Disabled Children, 2023).

It is clear that autistic people and people with learning disabilities are over-represented in the CJS and have less favourable outcomes. Despite this, there is no current CJS- wide pathway for autistic people or people with learning disabilities. Given that there is not a specific CJS pathway for these individuals, there is not a systemic multi-agency approach to screening and assessment, care planning, making reasonable adjustments, peer- led initiatives, staff training or information sharing, all of which impact on the experiences of autistic service users and service users with learning disabilities in the CJS, as well as their families and carers.

As a response to the NHS-E publication, 'Meeting the healthcare needs of adults with a learning disability and autistic adults in prison', NHSE (Midlands) Health and Justice Team commissioned two evaluations of services; one for autistic adults and adults with learning disabilities (undertaken by the University of Lincoln) and one for Children and Young People with a learning disability and/or

autistic in the Midlands, working with Liaison & Diversion Services and HM Werrington Young Offenders Institute (undertaken by the Council for Disabled Children). Two central recommendations from these reviews were: to develop a consistent, best practice autism and learning disability (LDA) pathway bespoke to the criminal justice system; and to develop bespoke assessment and screening tools for use in criminal justice settings.

There were five stages of the project:

1. Review of the literature
2. Engagement of service users with lived experience in co-production of the pathway
3. Engagement of stakeholders
4. Focus groups to finalise universal pathways
5. Accessible pathway development with a visual designer.

The above stages were completed between September 2023- April 2024 and data from the current literature, co-production with autistic service users and service users with learning disabilities with lived experience of the CJS, and engagement with stakeholders was synthesised to produce the draft pathways. A total of 8 service users completed the service user journey mapping; 4 men, 2 women and 2 young people, and 148 staff attended workshops to discuss the current pathways and how to improve these for autistic people and people with learning disabilities in the CJS.

These pathways were then further reviewed by service users with lived experience and staff with expertise of working with autistic people and people with learning disabilities in the CJS to produce the final pathways.

2 Findings

Key themes that were present in the findings include:

Communication with service users: Information should be presented in a way that the service user understands based on their individual communication needs. Information should be presented at multiple points in the pathway, as needed, and should be given at the right time.

Having the Right Support: Every service user should receive the right support for them, depending on their needs. Often this may include multiagency planning and support, which may require partnership working, peer support and well-planned transitions, with the service user at the centre. Reasonable adjustments should be made, depending on their needs, and any adjustments should be reviewed as the person moves through their journey. Ensuring that service users are safe and feel cared for and supported is key.

Processes: The findings highlight the importance of creating clear guidelines for screening and assessment given the wide variety of screening tools that are currently used within the CJS. Assessments should be based on NICE (National Institute for Health and Care Excellence) guidelines and should include recommendations about reasonable adjustments and care planning. Service users' physical health needs should be met and seen as linked to their sensory needs as well as mental and physical wellbeing. It is key that services develop appropriate information sharing guidelines and systems that allow the safe and secure transfer of necessary information to ensure that service users do not need to unnecessarily repeat assessments, and to ensure that accurate and up to date information is handed over. All services should comply with guidelines and relevant policies and ensure that quality assurance is truly embedded.

Resources: It is key that staff are well trained in working with autistic people and people with learning disabilities within the CJS, and that they are given ongoing mentoring and support. Employing specialist staff, such as learning disability nurses, SALTS, OTs and psychologists would allow knowledge and expertise to be generalised within systems. Additionally, developing a specialist team would support services to meet the needs of service users with complex needs within the CJS to improve service- user outcomes.

Environment: Service users and staff reported that often CJS environments are chaotic and stressful. Reducing sensory stimulus, making environmental changes such as providing quiet spaces and low stimulus areas, and reducing unnecessary transitions (such as between wings in prison) may support service users to feel safe and to manage their sensory needs.

3 The Development of CJS Pathways for Autistic People and People with Learning Disabilities

Given that there is not necessarily a linear pathway for all individuals within the CJS (individuals can move from child to adult pathways and may 'loop' around parts of the pathway on multiple occasions), it was necessary for multiple pathways to be developed that are applicable either in isolation (for example in the case of service users who are arrested by the police, but where no further action is taken), and also for all pathways to interconnect to form a complete pathway, spanning initial entry to the CJS, all the way through to transition to the community. Separate pathways were developed to cover the journey through the CJS for children, taking into account that when they turn 18 years of age (or 19 in some cases), they transition to the adult pathway.

Both sets of pathways are split into the following sections, in line with the workshops undertaken with staff and with service users' descriptions of their journeys, as follows:

- Police and The Courts
- Prison Custody
- Secure Hospital
- Community Release.

Two versions of each pathway were produced; one that includes key touch points during the journeys and necessary steps that should be taken by professionals along the pathway, and one visually accessible version created with a visual practitioner and further developed with service users. The visually accessible pathways are available as stand alone documents.

On the standard pathways, 'touchpoints' (points of contact/ interaction and processes) are noted along the central line in blue boxes and 'actions' are in green boxes. As it was not possible to portray all aspects of the pathway within the diagrams, the pathways should be used in conjunction with the themes, change points and recommendations made in this report.

The accessible pathways are designed to be read from left to right, with the left-hand side representing initial police contact, moving through contact with the courts, custody and/ or secure hospital settings and transitioning out into the community.

In addition to the pathways produced, due to the complexity of the pathways, clear themes and subthemes that emerged from the data and relevant change points have also been described and included in the main report. Given the importance of screening and assessment, screening and assessment guidance was also produced.

4 Project Recommendations

There are clear opportunities to develop this multi-agency pathway across systems to achieve increased consistency and better outcomes for service users, greater collaboration between agencies, and to develop skills and knowledge in staff.

Whilst this project is commissioned by health, it is clear that for the recommendations of the project to be achieved, a whole- systems approach will be required, involving collaboration between health, HMPPS, HMCTS, the police and social care. Given that there is a cross-government working group focusing on this topic, established by the Ministry of Justice, it would be of benefit for this to also be linked with their work moving forwards.

Whilst some of the care principles can be undertaken within existing services, it is noteworthy that the current project found, in line with Kargas et al.'s (2023) findings, that resources are necessary to provide many of the care principles and that systemic and multi-systems changes would be required to develop the pathways outlined.

An overarching point of note is that it is key for autistic service users and service users with learning disabilities with lived experience of the CJS to be involved in developing and evaluating services, including but not exclusive to developing peer support networks within the CJS, in addition to being employed within services in order to capture the reality of their lived experience and to ensure that systems and professionals learn from this. Partnering with pre-existing services that champion and represent the voices of neurodivergent individuals in the CJS may be a way of ensuring that service users are included in all aspects of service design and delivery.

Broad recommendations from the project are as follows:

1 For the results of the current project to be shared with all collaborators and for ongoing feedback to be given to those involved about any progress with developing these pathways after this project is complete.

2 For all service areas to review the themes and change points produced from this project, and to produce individual guidance on how these change points could be implemented within existing services.

Within this, clear guidance would need to be developed for relevant professionals, including:

(a) Clear guidance and training in the process of screening, interpreting and evaluating screening measures

(b) Giving feedback to service users and relevant professionals

(c) Making referrals for formal diagnostic assessments for neurodivergent conditions (including clarifying which services are responsible for carrying out these assessments under current commissioned agreements)

(d) Providing answers to frequently asked questions.

These would need to be produced by people working in these areas with relevant expertise in the systems and would require co-production to be at the centre.

3 A diagnosis of autism and/ or learning disability should not be necessary to be on a learning disability and autism pathway. Given the long waiting times, complexities in diagnostic overshadowing and significant challenges in conducting some assessments for autistic and learning disability where there is a lack of a developmental history (which is not uncommon for people within the CJS), access

to autism and learning disability pathways should be needs- led and underpinned by a high quality, evidence- based psychological formulation of need rather than relying solely on diagnosis.

4 To work with commissioners to develop a specialist forensic learning disability and autism team to provide support to CJS services across the pathway in:

(a) Developing psychologically underpinned formulations

(b) Diagnostic support in complex cases

(c) Case consultation

(d) Advice on reasonable adjustments

(e) Advice on managing risk taking into account neurodivergence.

Such a team could also be commissioned to support staff training and to provide individual interventions with service users with complex needs on the pathway. Specialist staff with a high level of clinical expertise and experience would need to be recruited and would include a clinical lead, peer support workers, learning disability nurses, psychologists (forensic and/ or clinical), SALTs, and OTs.

Ideally, such a team would be jointly commissioned to work across the CJS pathway, including working collaboratively with health and justice teams, youth justice teams (where appropriate) and police in police custody and in the community; with health and justice, court teams and YJS and NPS in the courts, with HMPPS, health and education within prisons; and with health and NPS in the community. In order for the team to work collaboratively with all system partners, links with education and social care would also be required.

It would be possible for these distinct parts of support for the system to be commissioned separately, although given the sometimes-cyclical nature of individuals' involvement in the CJS, a whole system approach may provide greater continuity of care and consistency.

In workshops and focus groups, there was a clear appetite from services to develop this idea and for such a team to feed into multiple points of the pathway. It may be possible for the team(s) to work with the following stages of the pathway:

1) Police and police custody (including health and justice and court teams).

2) Working into prison and youth custody.

3) Transitioning out of a custodial environment and into the community (including developing close links with probation and YJS teams). Within this area specifically, it may be possible to develop a pathway similar to the consultation- model used as part of the Offender Personality Disorder pathway (OPD Pathway), which is an established model relying on effective partnership working.

4) There are definite pockets of expertise within forensic mental health services, both within hospitals and in community forensic settings; however, it may be that the specialist team could also provide consultation and support to forensic hospitals and forensic community services where this expertise does not already exist.

5 For services within the CJS, across the pathway, to agree on which screening and assessment tools are most appropriate to use within the CJS for autism and learning disability. Specific consideration needs to be given to the appropriateness of tools considering age, sex, race, culture, language spoken and level of language comprehension. Guidance on available measures, based on current knowledge, for use with children and adults are available within the final project.

Short- Term Development Projects

Specific pieces of work that should be designed and implemented, which will require upfront investment, but could be maintained in the longer term, include:

6 Develop a professional network for staff support and staff development for those working with neurodivergent individuals within the CJS. Ideally this network would have a clear facilitator, lead agency and lead professional/ facilitator, and named, accountable professionals represented from each agency.

The network would include professionals involved across the CJS and could build on the positive engagement within this project, where there has been involvement from all stakeholders. We would recommend that this network is set up as soon as possible to build upon the positive engagement, hope and enthusiasm that was present in the project workshops and focus groups.

The group could meet on a monthly basis online (to facilitate engagement across the east and west midlands) to share learning from complex cases, share examples of good practice, and to build on the sharing of adapted and relevant resources. Clear terms of reference and information sharing/ confidentiality agreements would need to be designed and implemented. This could be supported by 6- monthly or yearly networking events face to face, where services could share areas of good practice; coproduction would need to be a central part of such days.

7 Develop a shared resource of easy read and accessible information for autistic people and people with learning disabilities for use across the CJS pathway. There are many pockets of good practice currently and some of the necessary accessible documentation has already been created by services.

This resource would include videos, service user stories, easy read documents and links to relevant websites and would include specific information including (but not limited to); understanding autism and learning disability, understanding rights, understanding the process of court hearings, understanding prison transfers, and the roles and responsibilities of specific agencies involved in an individual service users care.

The shared resource would be most effective if its development is built on work by the staff network (as above, recommendation 6) with a funded post to support this development. Any resources developed as part of this work should have co-production at the centre and could include a paid co-production lead role alongside a professional lead role (which may most appropriately be a SALT).

A process would also need to be designed and implemented to ensure that information within the resource remains relevant and up to date, and to ensure mechanisms are in place for storage of and sharing of resources as well as developing a capability to add to existing resources as these are developed.

8 Develop a directory of services, across geographical areas and the different areas of the CJS and stages of the pathway. This directory would require quality assurance measures to be in place and would include inclusion and exclusion criteria of each service; location of service; contact details; opening hours; clear referral process and links to any referral forms, including where these should be sent. An accessible version of this, with information relevant to service users should also be compiled and made available to service users.

Additional key areas of systemic change

Additional key areas of systemic change addressed in the change points from this project that are needed include:

9 Develop a comprehensive and whole-systems approach to developing an evidence- based psychometric measure to screen for autism and learning disabilities in the CJS. Current tools are inadequate, but creating such a tool requires cross- system collaboration, significant research and funding to develop.

10 Develop a universal training package for staff working in the CJS, with co-production at the centre. Training provision would need to include a high level of co-production with autistic people and people with learning disabilities with lived experience of the CJS.

This training would need to include introductory training in working with autistic people and people with learning disabilities in the CJS for all operational and non- operational staff, specific training in working with complexity in autistic people and people with learning disabilities in the CJS, including the importance of listening to and working with families and in trauma- informed care.

The training would need to include access to ongoing mentoring, supervision and support from expert clinicians to develop staff learning, to generalise skills in services and to support the individual needs of service users.

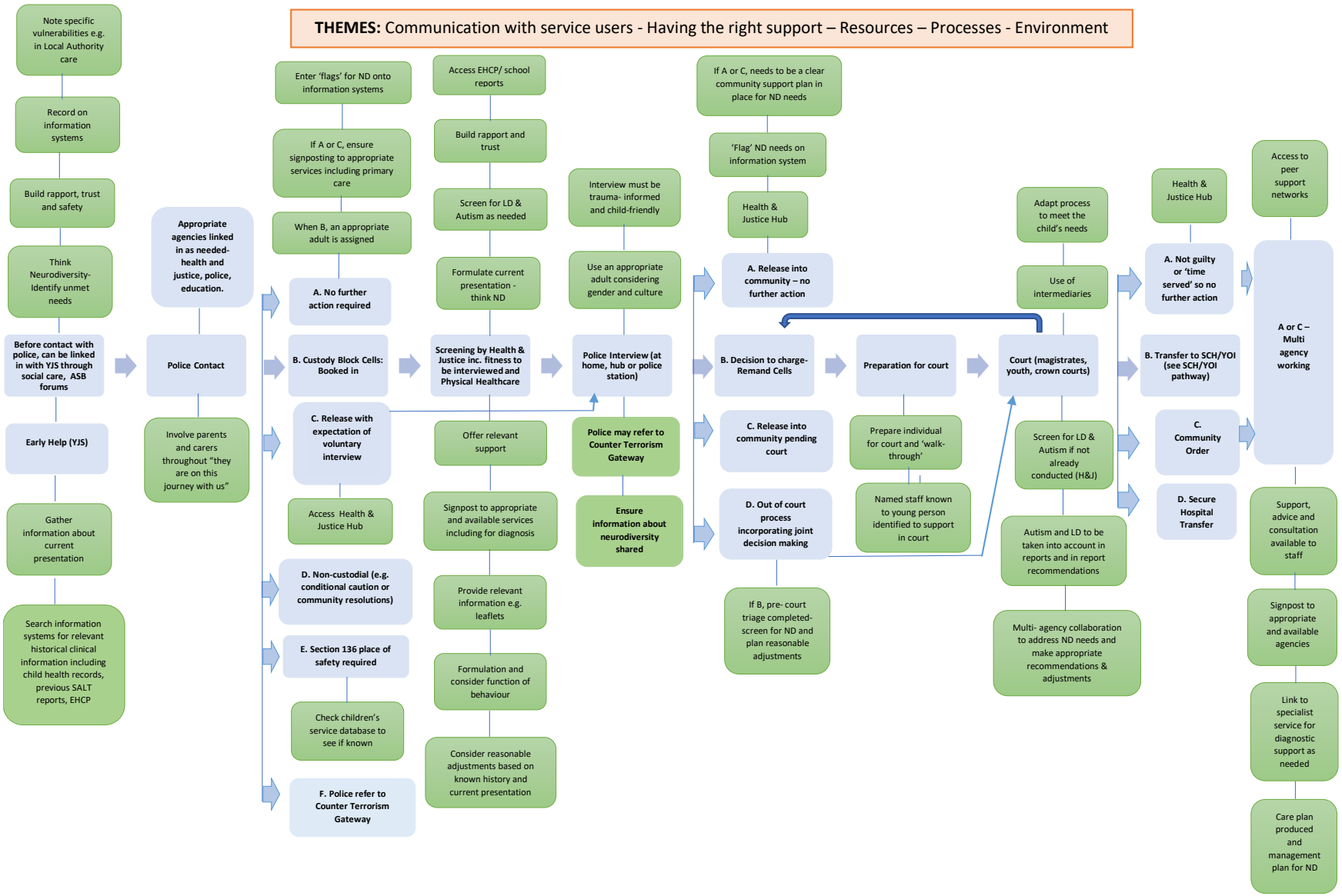
11 Develop comprehensive and fit- for- purpose information sharing systems and information sharing guidelines across services and geographical areas. Guidance in using these systems would be required and relevant staff training, including in understanding how risk, mental capacity and consent are relevant to information sharing.

Quality Assurance and Research Opportunities

This is an evolving area of research and service development, and it is important that any services developed are evaluated effectively and that results are disseminated to support the learning of other services. There is ample opportunity to undertake specific research projects in multiple areas regarding this project, and we would recommend that potential research opportunities are considered when designing and implementing services. Any such research projects should be co-produced by autistic people and people with learning disabilities in the CJS.

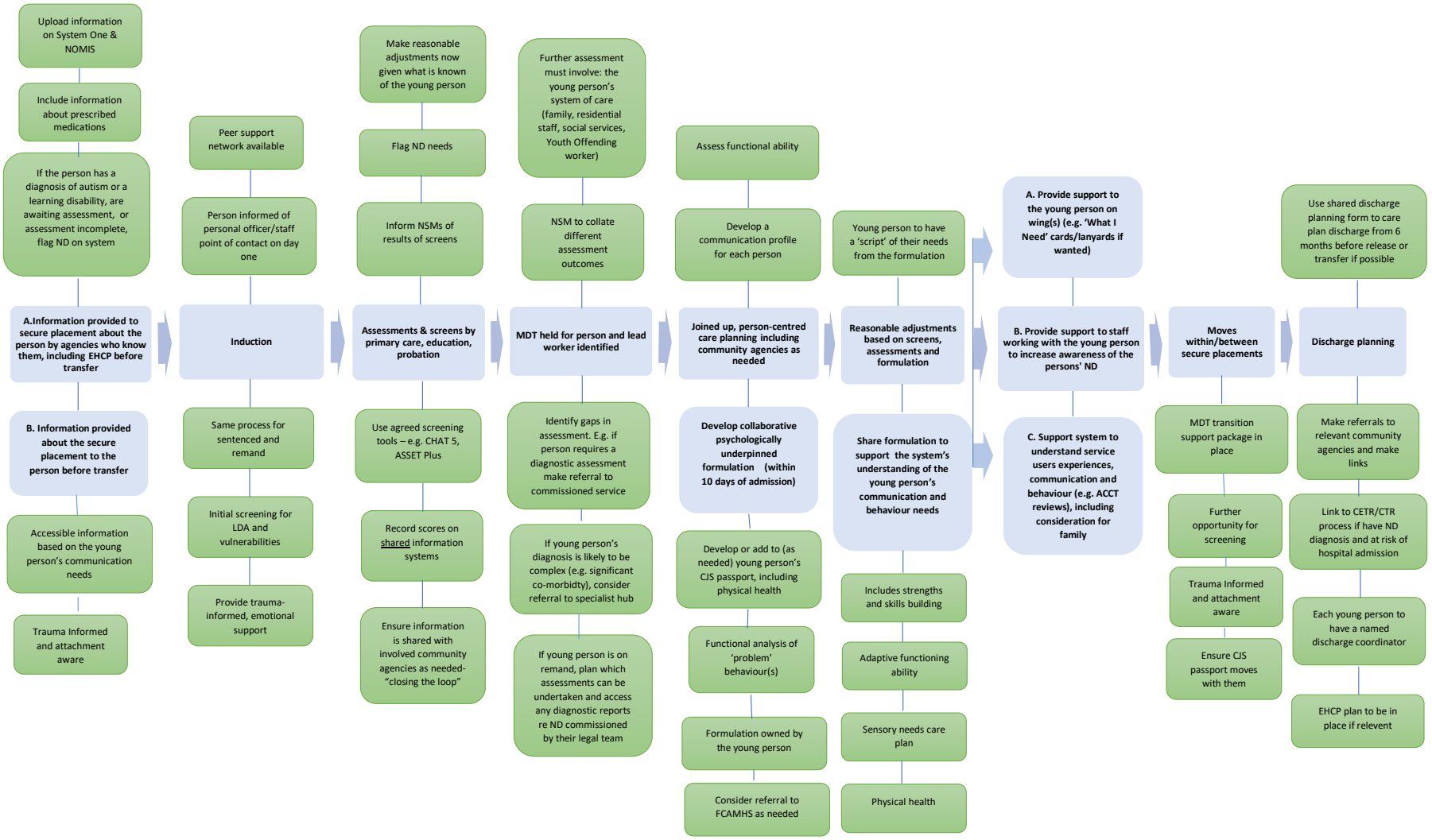
Police and The Courts: Child LDA Pathway

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



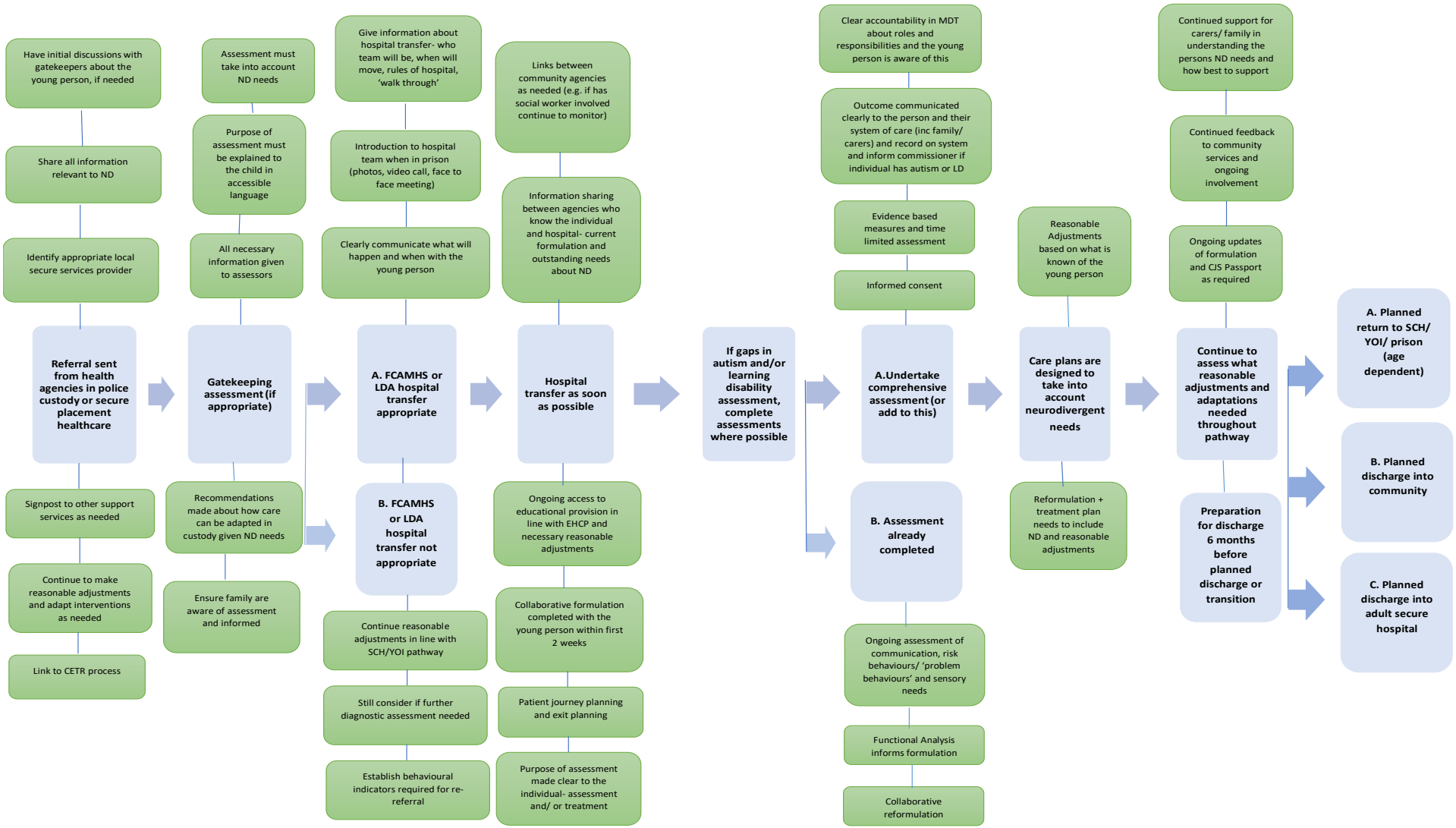
Youth Custody: Child LDA Pathway

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



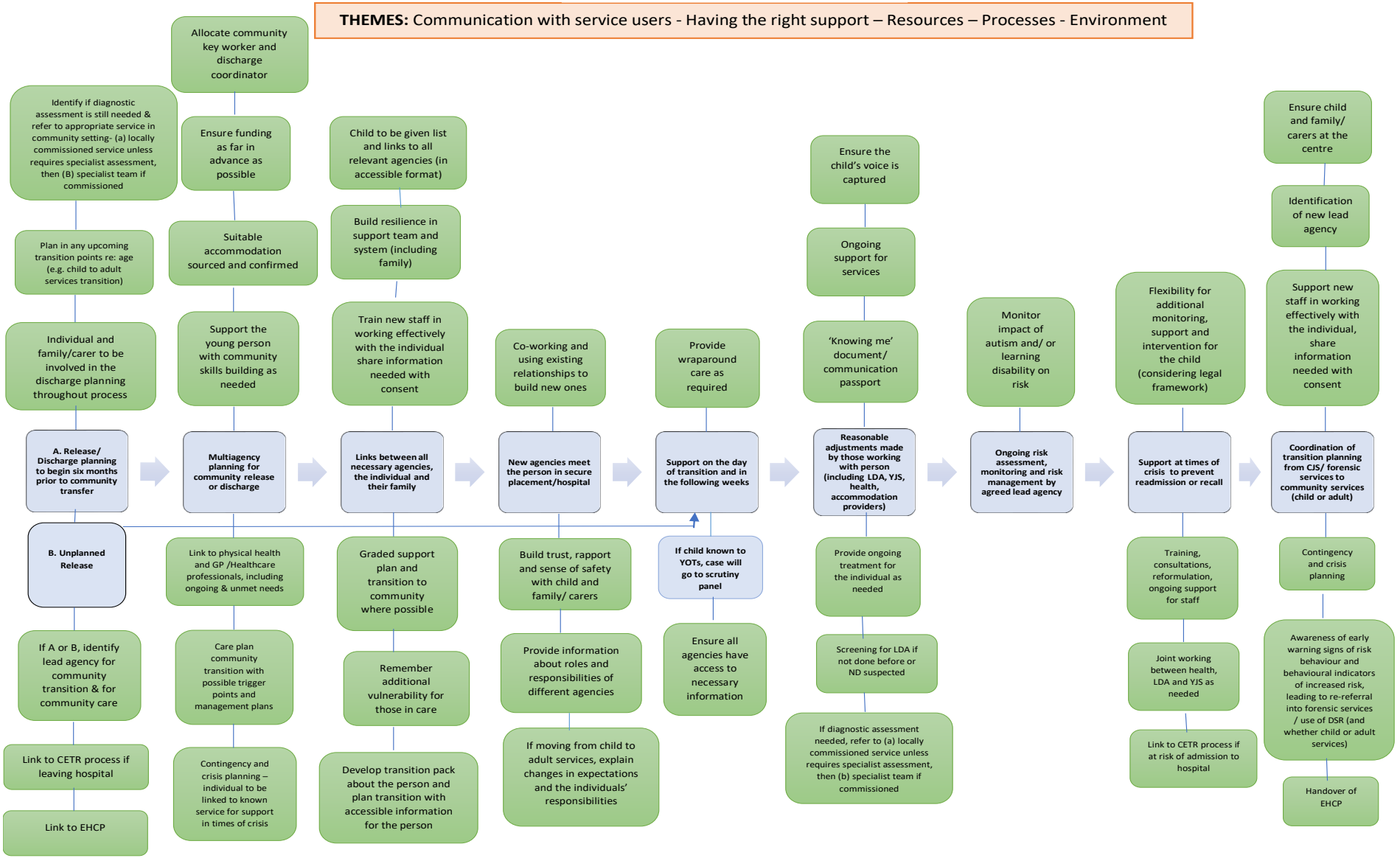
Secure Hospital: Child LDA Pathway

PRIMARY THEMES: Communication-Having the Right Support- - Resources - Processes-Environment



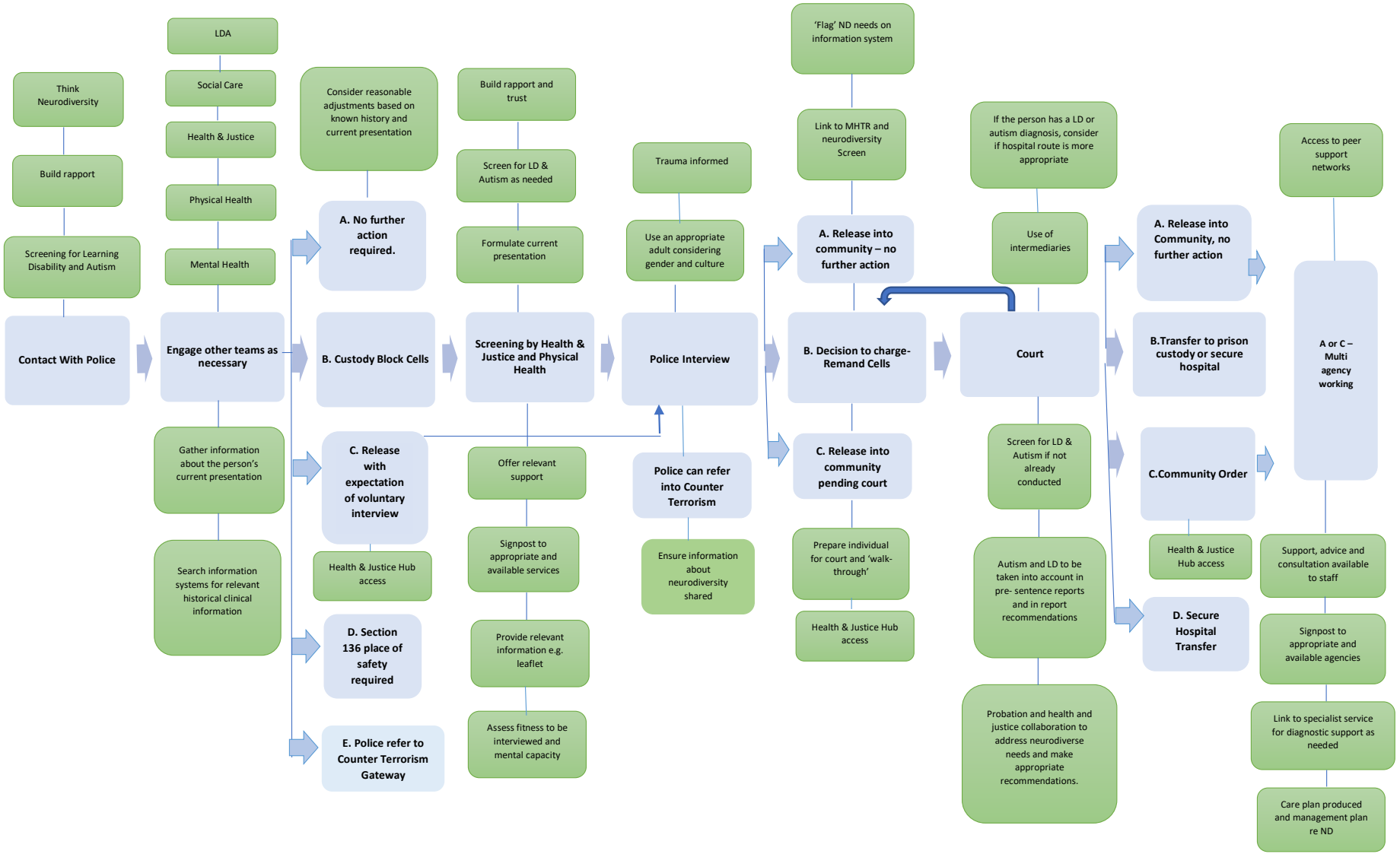
Community Release: Child LDA

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



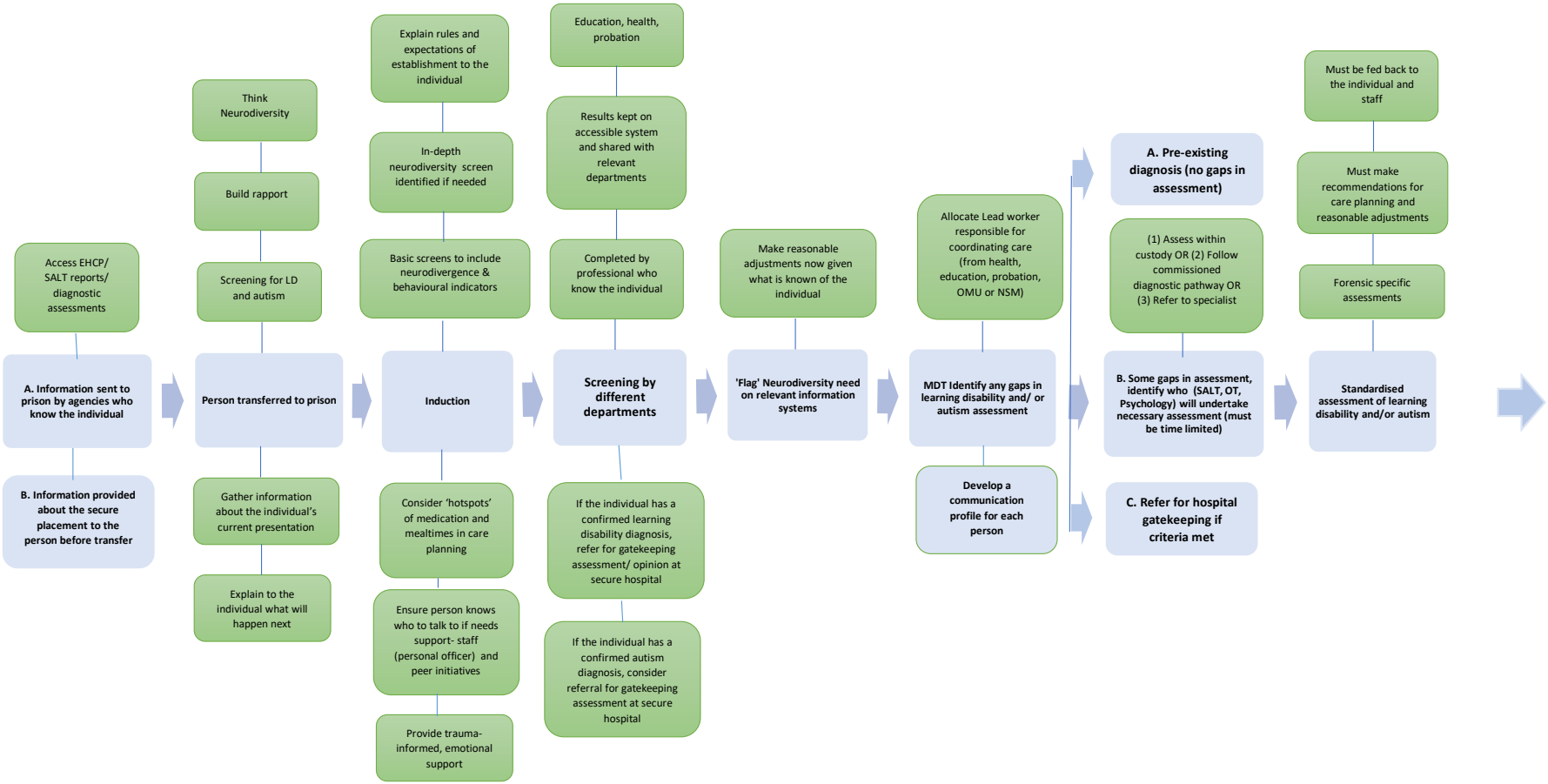
Police and The Courts: Adult LDA Pathway

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



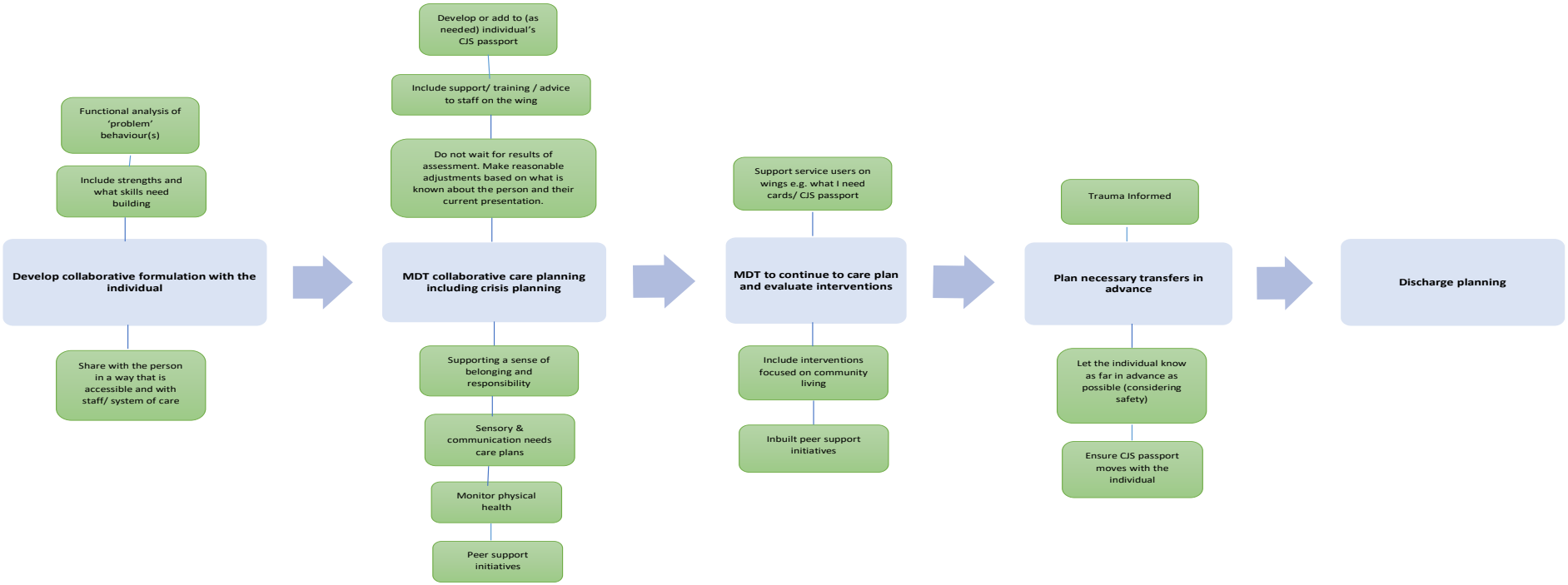
PRISON CUSTODY : ADULT LDA PATHWAY

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



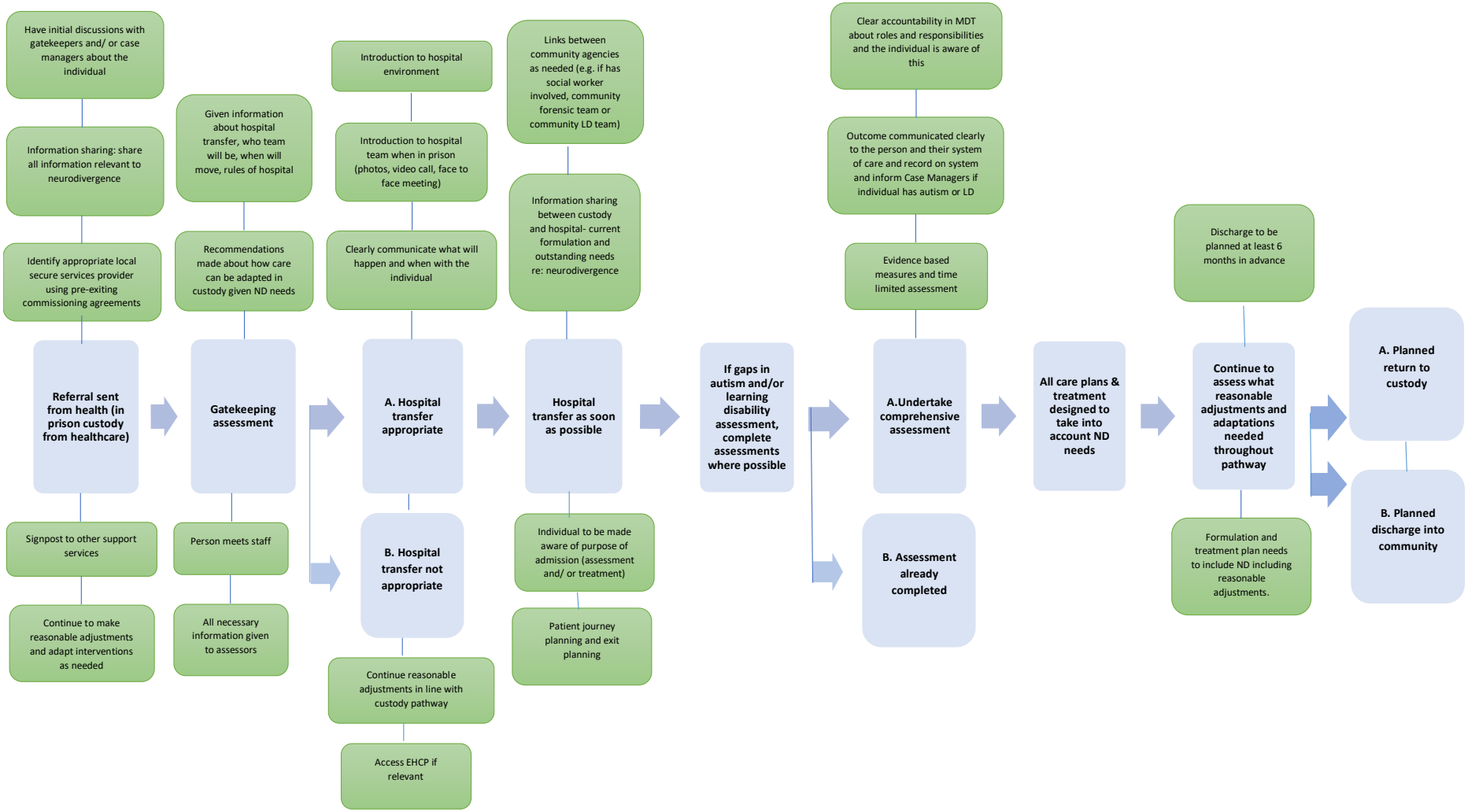
PRISON CUSTODY : ADULT LDA PATHWAY

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment



Secure Hospital: Adult LDA Pathway

PRIMARY THEMES: Communication-Having the Right Support- - Resources - Processes-Environment



Community Release: Adult LDA Pathway

THEMES: Communication with service users - Having the right support – Resources – Processes - Environment

