Lancashire Transforming Care Partnership

Learning Disability Children's Development Day

28th June 2016

Learning Disability Development Day

28th June 2016
Samlesbury Hotel, Preston, PR5 0UL
Tel: 01772 868000

Agenda

Registration from 9.00

Time	Title	Location	Presenter
09.00 – 09.15	Arrival and Registration	Canberra Suite/Main room	
09.20 – 09.40	Presentation	Main Room	Sharon Martin/ Maria Howard
09.40 – 10.00	Presentation NHS E Project Support	Main Room	Siobhan Gorry/ Sarah Jackson
10.00 – 11.00 **Choice on arrival**	Service Specification Workshop **OR** Workforce Workshop	Break out rooms	All
11.00 – 11.30	Refreshment and break	Canberra Suite	
11.30 – 13.00	Avoiding Crisis Workshop	Break out rooms	All
13.00 – 14.00	Lunch	Merchants/Private Dining	
14.00 – 15.00	Transition Workshop	Break out rooms	All
15.00 – 15.45	Developing Children’s CTRs in Lancashire	Main Room	All
15.45 – 16.00	Close and Next Steps	Main Room	Maria Howard

There were 70 attendees at the event, from the following organisations, along with Family Carers, experts by experience and self-Advocates;-

Affinity Trust

BFWH

Blackpool Council

Blackburn with Darwin Council

Chorley and South Ribble CCG

CAMHS

East Lancashire CCG

ELHT

GS Social Care Solutions Ltd

Holywell care Services

Lancashire Police

Lancashire County Council

Lancashire Care Foundation Trust

Lancashire North CCG

Midlands and Lancashire Commissioning Support Unit

NW Expert Hub

Pathways Associates

Pendle Support & Care Services

Unique kidz and co

Outcomes from the event

Service Specification Workshop

Provision of health facilitation/links with primary care services/teams

- Add in pathways around community teams to hold the ring on all service interaction
- Annual health checks only applies to learning disability not ASD, but document
- Health and social care criteria need to work concurrently or access could be difficult
- Integrated MDT teams – will assist with effective communication and collaboration
- LD teams need to sit with community teams
- Need of primary care – parenting courses open to all “riding the rapids” schools to increase
- Needs to fit with paediatric teams partnerships required
- Suggests people with ASD get on annual health check (they don’t)
- Teams need to be age specific but part of an all age service teams need to be across all ages
- Understanding and prevent challenging behaviour
- Provision of training (as a preventative service)
- Early intervention and prevention training for parents
- Roles of Social Workers and input into statutory processes e.g. DOLS
- Health and social care criteria need to work concurrently or access could be difficult

Pathways

- Add in pathways around community teams to hold the ring on all service interaction
- Diagnostic pathway to confirm diagnosis of ASD
- Entry pathways for children – what can be expected prior to accessing the service spec
- Hear LD voice in other transforming care plans/pathways
- One pathway required for children irrespective of diagnosis
- Specification not detailed enough around children’s services and pathways

MDT

- Use of established MDT tools, TAF, CAF, CPP
- MDT are not incentive enough of children’s services – education and community panel
- Integrated MDT teams – will assist with effective communication and collaboration
- Safeguarding Concerns
- Legislation for children is key difference from adults – safeguarding, Children and families act SEND, are key drivers
- Need to add in a safeguarding element – Hate crime, exploitation

Transition

- Transitions for young people with LD Primary school – secondary school, employment
- Children's is co-ordinated when transition it changes this needs to be smooth
- Person centred transition planning and bespoke transition
- If specs remain separate, I would suggest a dedicated "transition" worker to ensure smooth process

Comments on Service specification

- At the moment children's services see children, if we start separating out children with LD we could create gaps between specs that are evident within adult services. Relates particularly to SLT, OT, Physio especially if LD diagnosis not yet made
- Children specific outcomes and KPI's need to be included
- Consider children specific publications and guidance
- Eligibility criteria in the adult specification should be applied to CYP specification
- Entry pathways for children – what can be expected prior to accessing the service spec
- Finance – this is a more detailed spec and will need to be supported by equitable investment
- How does it fit with existing service specs for children's LD services
- I think we need a separate spec for children
- Is it possible to have a service spec which is appropriate for children as well which does not cover education
- Like idea of all age spec
- More emphasis needed on EHCP and the specific SEND legislation
- Need to develop specific outcomes we will work towards with children and young people that are co-developed with them
- Needs a children's specific addition
- One pathway required for children irrespective of diagnosis
- Respite needs to be addressed specifically for children – which will hopefully prevent admission to hospital or residential placement
- Spec does not place enough emphasis on role parent and reflect the facts that parents have parental responsibility are the decision makers. It is a written from a "capacity" perspective
- Specification not detailed enough around children's services and pathways
- Teams need to be age specific but part of an all age service teams need to be across all ages
- Term "autism" used in document should be changed to autism spectrum disorder

Workforce Workshop

Induction and Training

- Better training for personal assistants/services that provide direct care to children with complex challenging needs
- Changing the way we deliver training i.e. mobile apps
- Children's mental health training

- Developing a catalogue of online tools/sites that include the 3rd sector available to support training and development of professionals in a range of fields
- Gap in training for CFHS delivery of service to adults with LD who are young parents
- Improve funding/training for staff which will help recruitment
- Lack of training and development for early year providers to meet the complex medical need of children e.g. epilepsy, ng feeding, anaphylaxis
- More online training
- Need for more multi agency training opportunities to ensure more consistent practice
- Needs to be training and support for parents/school around restrictive practice and restraint
- PHB's need to have ring fenced money for training
- Provision of training offered in some areas is different for parents e.g. some Speech and language therapist training packages available in one area but not another – some local authority area few miles down the road
- Providers can't provide training to agency staff due to cost
- Training around education and health care plans
- Training to be relevant for family/carer
- Working with other agencies about LD training/communication/autism

Skills and Qualifications

- LCC only advertise internal first – people who are at risk may get the job but not necessarily have the skills to do the role
- Matching needs – providers/skills
- Utilizing skills

Pay/Salary

- Better pay for direct payment worker care agencies to support children with complex challenges needs. Hopefully recruit quality, knowledgeable staff and resilient staff
- Private provider perspective - poor pay, high turnover – attitude to work
- Private sector issue v NHS pay and terms and conditions
- Value the skill set required (reward/pay)

Positive Behaviour Support

- PBS – not enough for parents don't always get the information to access training
- PBS training in Children's services "normal ages"

Finance/Funding concerns

- Clear process and decision making from the management in social care commissioning. Parents having to wait for decisions around funding – puts additional pressure on staff
- Clearer understanding of MDT funding
- Funding new teams/roles – commissioning services – slow process

- Improve funding/training for staff which will help recruitment
- Inconsistent funding available for services
- Lack of funding
- Short breaks are limited and age restricted (Blackburn have 5-19 service) funding to Localise is inconsistent and not always including 3rd sector

Commissioner Concerns

- Commissioners driving the price down makes retention even harder for providers
- Recruitment and Retention
- Improve funding/training for staff which will help recruitment
- Service users involved in recruitment
- Slow recruitment process

Avoiding Crisis Workshop

Crisis Response Definition/Responsibilities

Mental Health

- Bespoke family training at part pf the diagnosis of Mental health disorder
- Lack of mental health services for children with LD and lack of activities
- Not addressing if Children and young people have more than one medical issue i.e. LD and Mental health
- Programmes around mental health delivered in special schools

Challenging Behaviour

- Criteria to access tier 4 beds – often children LD/ASD with severe challenging behaviour cannot access these services due to not fitting the criteria
- Support for foster carers – not much support and no training in ASD, challenging behaviour – child with attachment issues

Care

- 24 hours crisis care
- Care co-ordination needs to begin with the family – needs to be funded with PHB
- Carers/siblings carer groups – have to travel – more local provision
- De – escalation process, quick response to parent/carer/ provider when risks start to escalate
- Emergency social care beds required with a strict criteria for access (for those that don't require an admission to hospital)
- Everyone's for access criteria different care
- Health professionals need training on LD and transforming care agenda

- If requested PBS plans shared with all involved in child's care
- Improved recognition of carers
- Involve advocates – they know what's out there and can let families/carer know
- Lack of preparation for next "life stages" transitions need careful specific planning
- Multi-agency, multi-disciplinary integrated care pathway/care records
- No transition period – not accessing the right support causing issues and stress to young people and family carer
- Out of date care plans
- Parents/carers they don't know – improve local offer information
- Professionals not listening to families/carers
- Respite for CYP/family and carer
- Services to go into the home and work with families and carers to help them deal with bubbling behaviour
- Social care involvement too quick to close cases once CAMHS involvement referral – need outreach support earlier
- Somebody to talk to who will listen and care – not judge and just help One person
- Support for foster carers – not much support and no training in ASD, challenging behaviour – child with attachment issues
- Therapeutic support for parents/carers preventative

Support

- Advocacy – check in service to check everything on even-keel or if more support is required
- Appropriate levels of support in a timescale that is appropriate for the need – increasing support levels when required – referrals picked up more timely
- Better understanding of the future role of circles of support as a way of reducing crisis situations. Preferably with the circle facilitator being paid via the personal budget
- Change in regular support systems at weekends – duty workers handling crisis
- Child development centre mode :- therapists, nurses, paediatrician, nursery nurses, parent support groups
- Child leaving school and adequate plans not being in place e.g. parent leaving work due to lack of support
- Continued support for schools
- Correct support packages – social and health needs giving individuals the choice of support but with the information given
- Crisis support team required in children's LD/ASD services that match adult services
- Developing capacity within the family to cope and avoid crisis - develop strategies, develop support networks
- Early intervention and support -focusing on outcome planning
- Ensure right support, pathways and processes are in place
- Flexible model of provision to support families and to enable the young person to stay at home e.g. additional specialist support to manage behaviour, short term flexible "respite" choices, different models of in-patient assessments (short term), more local provision enhanced wrap around community support

- Having good basic support systems e.g. babysitting, childminding
- Hospital passports and crisis support plan that is recognised by all services
- Individualised crisis support plan
- Lack of appropriate support at the right time/early intervention
- Lack of sufficient planning/proactive support
- Lack of support for parents in how to help and support children
- Links to targeted support and education training opportunities
- More improved services to help educate families around parenting/boundaries and PBS support in their own home – active support and role modelling
- Need a infrastructure to support YP who fall outside of that framework
- No hand offs – everybody's business to support/prevent crisis escalation
- No transition period – not accessing the right support causing issues and stress to young people and family carer
- Not having accessible support in place early in the crisis/problem
- Parents do not engage with available systems and support
- Pathways for accessing support step up step down model
- People not being aware of support and help
- Police – helping community support policing, Early support teams
- Social care involvement too quick to close cases once CAMHS involvement referral – need outreach support earlier
- Specialist open access support for children accessed via services
- Staff not being trained to support
- Stopping of support
- Support family to let go when child is ready to take control
- Support for foster carers – not much support and no training in ASD, challenging behaviour – child with attachment issues
- Support for single parents to work – leave school – get Two days Support
- Support for social workers/community nurses
- Support groups for parents – need to signpost
- Support needs to be the hours that the individual needs
- Support Networks for families – Better sources for children that link in
- Support the family crisis can be anyone not just the service user
- Support to develop life skills/life changes e.g. school/hormones
- Supporting the families that are on the ASD pathway and haven't got a diagnosis
- TAF "wrap and support" that is not inhibited by boundaries
- The family/child's needs are assessed and reviewed regularly to ensure support/services etc. are provided as/when required
- Therapeutic support for parents/carers preventative
- Training and parental support very early in the process
- Unexpected crisis – need to know what support is available before hand to prevent escalation of the crisis.
- Unfair distribution of funding/services for some families - some get more support than others

CTR

- One electronic system for all services for better communication
- Request CTR -> cry for help from family
- CPA need to discuss CTR
- CTR's not available

Police Involvement

- Training for police around crisis management for children with LD/ASD improve knowledge and understanding

Cause

- Changes in routine/environment – house, school, ill health, lack of respite, change of circumstances, breakdown of care package, change in care/carer causes crisis
- Courses (specialist) can make a huge difference but what about the families who aren't eligible because their child hasn't a diagnosis
- Everyday problems – debt, job any problem that causes stress
- Funding panel no clear date of when funding panel occurs. This causes anxiety for parents – some parents have to wait 3 months for approval
- Not involving child in referral makes initial assessment difficult and can cause crisis
- Parenting courses/groups sometimes it's the parents issues that cause the crisis – parents want to "fix it"
- When services stop because a child is "too old" or they've had it for as long as they can

Training and Awareness

Skills

- Support to develop life skills
- Training and skills for practitioners and also for young people around self-management/self-awareness/regulation

Resources

- Lack of resources
- Respite inclusive community resources – preventative providing stimulation
- Triggers
- Help families to learn the triggers for behaviours
- Knowledge of triggers

Safeguarding

- Not knowing procedures to be followed (e.g. Safeguarding) when incidents
- Lancashire safeguarding guidance is in place – this should be the same for managing a crisis, should be a universal pathway that covers a crisis as part of safeguarding guidance.

Carers/Social Care/prevention

G.P

- Lack of involvement in CAF/ Assessment process for medical professionals – GP's/consultants

Family

- Bespoke family training at part of the diagnosis of Mental health disorder
- Care co-ordination needs to begin with the family – needs to be funded with PHB
- CYP damaged home – relocate family until fixed
- Developing capacity within the family to cope and avoid crisis - develop strategies, develop support networks
- Family breakdown lack of support, lack of early intervention – unrealistic expectations
- Family support groups
- Having a named person to help the family to navigate complex info and systems
- Isolation from Family/peers
- Local beds/facilities min of 8 to be viable – LD in crisis sent to Newcastle – impact on family
- Local services so patients can have access to family/security/comfort
- Looking at the needs of the individual over the needs of the family
- More funds required to sustain quality of family life for children with LD/ASD and their families
- No transition period – not accessing the right support causing issues and stress to young people and family carer
- Pathways that involve the whole family
- Planning proactive work and appropriate funding to meet child and family's needs
- Request CTR -> cry for help from family
- Respite for CYP/family and carer
- Support family to let go when child is ready to take control
- Support the family crisis; it can be anyone not just the service user
- The family/child's needs are assessed and reviewed regularly to ensure support/services etc. are provided as/when required
- Provider
- Crisis can arise when what is perceived to be needed differs from what service providers offer or where levels of needs are assessed as lower than they are perceived to be. Service and need are incompatible
- De – escalation process, quick response to parent/carer/ provider when risks start to escalate

Respite

- Flexible model of provision to support families and to enable the young person to stay at home e.g. additional specialist support to manage behaviour, short term flexible "respite"

choices, different models of in-patient assessments (short term), more local provision enhanced wrap around community support

- Not having access to respite or extracurricular leisure activities
- Respite – too much of a reduction in Lancashire in respite provision
- Respite for CYP/family and carer
- Respite services working with families on strategies not just the provision of the respite – outreach, home working

Social Care

- Clarity around roles health, social care, education – 1 person Parents Carers
- Emergency social care beds required with a strict criteria for access (for those that don't require an admission to hospital)
- Social care involvement too quick to close cases once CAMHS involvement referral – need outreach support earlier

Commissioning: Funding/processes/systems

Funding

- Funding panel no clear date of when funding panel occurs. This causes anxiety for parents – some parents have to wait 3 months for approval
- Key times – need good and effective planning e.g. school holiday/Christmas so funding can be approved in advance
- Lack of co-ordination/ responsibility regards funding
- Lack of funding/approval for needs (incoherent approach)
- Planning proactive work and appropriate funding to meet child and family's needs
- Unfair distribution of funding/services for some families - some get more support than others
- Very few children meet criteria for CHC funding – child's complex needs communication behaviour, health they trigger and assessment but then don't meet criteria
- Why is funding health/social provision not a one pot budget

Processes/Systems

- Change in regular support systems at weekends – duty workers handling crisis
- Develop systems that are good for the individual to follow
- Ensure right support, pathways and processes are in place
- Having a named person to help the family to navigate complex info and systems
- Having good basic support systems e.g. babysitting, childminding
- Information sharing across agencies
- Integrated care records
- More innovative flexible use of personal budgets and direct payments for times of crisis
- Multi-agency, multi-disciplinary integrated care pathway
- Parents do not engage with available systems and support
- Personal budgets can be used more effectively

- Pro-active integrated planning
- Unclear on the services and systems to approach or navigate when in crisis, where would you present? How well equipped are the services to manage these children and families

Transition Workshop

Pathways

- Complex difficulties team - Blackpool example of panel working, multi-disciplinary team discuss options, pathway and support
- GP Knowledge needs improving on signposting and referral pathways – if over 16 willing to refer for ASD
- Pathway for apprenticeship/guide into work
- Pathway for mainstream hospital services
- Pathway to occupy time
- Pathways can be improved by having a seamless pathway that works from 0-?
- Pathways to be designed to meet Thrive model so that even when in one quadrant can access services
- Run pathways parallel – different stations for needs

Providers

- Post 16 providers need to improve their offer to YP
- Understanding the responsibilities of providers outside of the send agenda e.g. Equality act and ensuring these are fulfilled as well as SEND reforms/Agenda

Joint Working

- Adult teams continues not to be commissioned for working with adults with ASD – they have to access MH services
- Bigger age range challenges (potential) working with groups of CYP you have not worked with before
- Peer networking
- Services collaboratively working together
- Working differently -> assessments for EHCP's has shorter timescales advices not completed in a timely manner

All Age Service

- Applying for EHC after age 19 – children's LD services finish at 18, CAMHS finished at 16
- Change in role for parents, as child is given more autonomy/choice in adult services
- Continuity of services within specific provision i.e. in service and across partnership
- Early intervention services i.e. child action NW, Bernardo's, school counsellor, holding too much risk, need better support from CAMHS/MH

- EHC plans are often written by “children’s” services for “adults” services to implement and may not reflect adult priorities
- Environments not suitable for all age all needs
- Expectation that all workers are familiar with the SEND agenda – so much going on in adult services there isn’t the time to dedicate to understanding requirements
- Family view – Access to services i.e. CAMHS .Parents have asked for referrals to CAMHS but waited 18 weeks for the appointment
- Gap in CAMHS services 16-18
- Gap in services some end at 16years and nothing until 18years. ASD no adult service unless mental health associated
- Giving young people what they need when they need It therefore more flexible services
- Looked after children with LD and autism at greatest risk of needing services to fight for their rights to access community specification
- Looking at adolescent services (transition to ensure young people are accessing age related services
- PBS not embedded in Children’s services
- PHSE for special schools at a younger age for relationships and sexual relationships -> Improvement of sexual health services
- Relevant information not being shared between services
- Services collaboratively working together
- Services often end 16/18 so difficult to smoothly encompass services for child and adult up to age 25
- The services need to be based on need not age
- When to introduce adult services
- Planning
- Complex difficulties team - Blackpool example of panel working, multi-disciplinary team discuss options ,pathway and support
- GP Knowledge needs improving on signposting and referral pathways – if over 16 willing to refer for ASD
- Pathway for apprenticeship/guide into work
- Pathway for mainstream hospital services
- Pathway to occupy time
- Pathways can be improved by having a seamless pathway that works from 0-?
- Pathways to be designed to meet Thrive model so that even when in one quadrant can access services
- Run pathways parallel – different stations for needs

CTR

- CTR alignments into 1 day reviews incorporating review/care plan reviews – one stop shop
- CTR process for CYP needs to be linked to SEND processes for EHCP’S (assessment and review)

Training

- Need for funding/access for supported internships, training apprenticeship support, employment
- Sexual appropriate training
- Specific individual training
- Staff training to be young person focused
- Training employers to understand the people with LD
- Transition training for staff
- Welsh sex education training on an individual basis

Support in Health, Education and Parental

- Advocacy quality and committed so that young people are supported and empowered when families can no longer support or when YP no longer want family involvement
- AMHS does not work to the same model as AMHS – crisis not support then is there a specialist service for them to access
- Complex difficulties team - Blackpool example of panel working, multi-disciplinary team discuss options ,pathway and support
- Develop workforce so they are confident and competent to support individuals and families in transition
- Early intervention services i.e. child action NW, Bernardo's, school counsellor, holding too much risk need better support from CAMHS/MH
- Ensure local community schemes are available to prevent isolation i.e. support groups
- Ensure support for LD development is recognised as an achievement and a listed outcome measure
- Forensic support for adolescents
- Getting timely/quick referrals for babies/young children so that they are able to access services (including education services) at the earliest opportunity e.g. sensory support
- Having to justify needs/why you need support when you enter adult services, after having had professionals in children's services who know your child and have seen their progress over the years
- Housing – appropriate accommodation (supported living)
- Life skill support
- Need for funding/access for supported internships, training apprenticeship support, employment
- Raise awareness with local employers and colleges "collective support"
- Risk of isolation if not able to access studies, employment support placement
- Skill set support
- Stopping the gaps in services to minimise issues in transition/transition support
- Support for children/families as they transition to nursery/early years provision to ensure their needs are met but where support has moved from being in the home to being in the setting, parents are still able to access support services to support them in meeting their child's needs

- Support staff to prevent burn out – build resilience, mentally healthy workplace. Staff turnover and continuity of care
- Supporting children/young people who have additional needs but may not meet the criteria for EHCP. Ensuring their needs are identified and appropriate provision/support interventions are put in place by universal services
- Supporting people to stay safe
- T/C programme needs to also support the building of appropriate community based children's services
- Use 3rd sector more effectively f/c support, benefits, housing
- Use of transition support documentation as trialled in Southampton called "ready, steady, go"

SEND

- A lot of paperwork required for EHC plans this is confidential information -> data protection -who is responsible? Care co-ordinator? SEND co-ordinator?
- CTR process for CYP needs to be linked to SEND processes for EHCP'S (assessment and review)
- How flexible are academies with respect to SEND
- Lack of knowledge and learning on job around EHC for mainstream schools – a lot of children are still not transferred to an EHC from an SEND
- Making sure parent/carers/professionals are aware of SEND agenda
- No accurate numbers of post 16 SEND
- Send 0-25, CAMHS 0-16, LD 0-18
- Send agenda focused around education provision
- Send agenda key stakeholders may not all be engaged in the transforming care work
- Send doesn't cover universities to 25
- SEND inspections
- SEND reps on any of the LD work stream groups?
- The SEND agenda is outcome based but what is an outcome? It should not just be education based
- Understanding the responsibilities of providers outside of the send agenda eg Equality act and ensuring these are fulfilled as well as SEND reforms/Agenda