



SHROPSHIRE Parent
And
Carer
Council

DATE & TIME	Friday 15 th Sept 2017 - 10am – 1pm
LOCATION	Central Baptist Church, Shrewsbury
TYPE OF MEETING	Board – Public Record
ATTENDEES	Sarah Thomas, Anne Lanham, Natalie Hughes, Angela Price Visitors: Jeannette Griffiths, Jo Lewis
APOLOGIES	Zara Bowden, Mike Thomas, Julie Davenport

AGENDA ITEM
<p>1. Introductions & Apologies</p>
<p>2. Minutes & Actions No actions outstanding Financial Update End of year accounts for 16/17 have been produced for AGM. Grants 2nd DfE payment received and discretionary grant for newsletter and leaflets. Governance Noted Data Protection requirements changing – ST booked onto workshop in Nov</p>
<p>3. Update reports;</p> <ul style="list-style-type: none"> • 0-25 Emotional Health & Wellbeing Service Requested meeting with new commissioner – raise concerns about lack of coproduction with parent carers and lack of information about the neurodevelopmental and LD pathway • SEND Strategic Board Provide written feedback on Shropshire SEND Strategy and Board Terms Of Reference – received request for PACC to co-chair Communication and Participation work stream – Agreed ST will Chair. • Short Breaks Met with AFC re community short breaks and discussed working together to develop new service – proposed PACC hosts a short break user group for parent carers Discussed concerns about lack of progress in transitioning families to new overnight provider with Shropshire Council Lead – A family meeting agreed in principle but still awaiting confirmation of date – ST to Follow up Emailed lead inspector for Ofsted inspection requesting opportunity to contribute to inspection AL to attend Short Break meeting on 21st Sept. • Transition and adult social care ST meeting with Director of adult social care on 4th Oct – will follow up restructuring of ASC team, development of new LD strategy and to provide feedback on ASC experience New staff in Post 16 Team – have been asked to introduce PACC to them – date to be arranged ST attending regional Preparing For Adulthood workshop on 18th Sept in B’ham

<ul style="list-style-type: none"> • CWD Register ALL In register to be extended to become CWD register – waiting for proposal about how this will be actioned and who will take on lead role
<p>4. Communications work;</p> <ul style="list-style-type: none"> • Website New site live – calendar updated and new section active – Blog site set up will post first blog shortly – receiving a steady flow of new members via website • Newsletter Articles from; Enable, Transition Lead, and young person re Uni experience. Requested articles from AFC and Mencap re new contracts and Post 16 Lead about Post 16 team developments • Monthly Updates Sept update drafted
<p>5. Upcoming work / events;</p> <ul style="list-style-type: none"> • Community Games and Local Offer Live – 24th September • AGM and Open Meeting 2018 – 10th Nov • NNPCF Annual Conference – 27th & 28th Nov - Manchester • Regional training with Steve Broach – 18th Oct • IPSEA Training – ST & NH – 29th Sept • Working with Parents Supporting Parents – discussed extending model to other areas
<p>6. Feedback Received</p> <p>Lack of info and understanding about Adult Social Care financial assessment process Requests for social care assessment being inappropriately refused Families valuing Buddies group – a chance to speak to other parents, nice to know that there is something for them when they are older</p>
<p>7. AOB Joined by Kelly Kubilius – Transition Practitioner</p>
<p>8. End of closed meeting.</p>
<p>9. Open Participation Meeting – Transition Discussion See Notes Below</p>

Open Participation Meeting; One additional parent carer joined this meeting

Prior to Kelly Kubilius joined the meeting there was a brief discussion about what the parent carers felt were the most important skills for their child to learn to help them prepare for adulthood. The responses are briefly listed below and not surprisingly focus on life skills and developing confidence / independence. There was a further discussion about the lack of opportunities offered by schools in general to develop in these areas and that parent carers feel that in the main this falls to them.

Skills needed when preparing for adulthood;

Social skills – Playing games, being with others, making choices

Reduce tendency to isolation – need to feel comfortable with being out in the community

Develop confidence – out in community – road safety, speaking to people that you haven't met before (e.g in shops) – also feeling comfortable with who you are
Practical Skills - make a sandwich, wash own hair etc.

Kelly joined the meeting and introduced herself and her role. The role sits with Adult Social Care and so in the main she will have direct contact with young people who will need or are likely to need support post 18, but she also has a role providing strategic oversight of the transition process in Shropshire. This will involve working closely with the Post 16 SEN Team, the Disabled Children's Team, Early Help and health services such as the new Emotional Health and Wellbeing Service.

There was a recognition that currently the Social workers in the Adult Team don't know the full range of what is available for young people in SEND in Shropshire post 18. Kelly also acknowledged that families have identified this as a barrier for practitioners as well as families. In response to this Kelly will initially be focusing on being able to provide much more information proactively to families, on what is available across all aspects of life / support as young people go through transition. The intention is that this will enable a hard copy document to be produced, but this information will also be available via the Shropshire Local Offer and Shropshire Choices. Families and social workers will have access to the same info. In addition to this Kelly informed the meeting that there had been a launch of the Shropshire transition protocol for practitioners and service providers. This document is available on the Shropshire Local Offer but it is recognised that currently it is not a very accessible document. It is currently being rewritten in a parent carer friendly format.

At this point, there was a discussion about the need for written information to be supported by opportunities for discussion and questions. Parent carers present also asked how this will fit with the EHCP process and expressed the hope that systems would be joined up. The discussion also raised the need to provide support for parent carers as their child goes through transition. This is a major change in life for everyone and currently there is little or no support or preparation for families so that they can respond positively to this change. There was an extended discussion about the impact of early life experiences on both parent carers and young people and how this can negatively impact on preparation for adulthood. It is important that schools and other settings work to understand the parent carers perspective and do not just see parent carers as an obstacle to be overcome. There was also feedback about the benefits that families get from coming together and supporting each other and a request that opportunities were explored to ensure that this happens during transition

Parent carers raised the need to ensure that young people were supported to be able to communicate their feelings and wishes as they grow and that services should build a comprehensive picture of a young person that is used to inform transition. Currently the lack of communication between services and stages tends to mean that there is poor continuity in understanding of an individual and families feel that they are constantly having to tell their story and prove themselves.

Two specific questions were asked;

1. What consideration is being given to improve the transition experience for young people with high health needs and how are you linking with specialist health teams such as, the community nursing team, continuing health care etc?

Kelly welcomed this being raised and acknowledged that it was an area that required special attention. She is building links with all teams that currently provide support to young people who might require adult social care and will ensure that the needs of young people with high health needs is considered. Kelly informed the group that she has plans in place to visit Hope House to discuss how they provide support in transition to this group. Kelly was also made aware that there was a lack of respite for young people who need nurse led respite provision and that families often have to go out of area to access this.

2. What happens if a young person clearly has social care needs, but says during the assessment that they don't need or want social care support, their family can look after them - if the family say they can't go on doing that?

In response to this situation Kelly suggested that it would be beneficial to explore the possibility of the young person spending time away from home in a gradual way and that assuming eligibility for this could be supported by Adult Social Care. There was a discussion about the importance in such circumstance of building up a relationship with the young person and the family so that there is an understanding of everyone's perspective and concerns.

Kelly thanked everyone for their interest

Close of meeting.