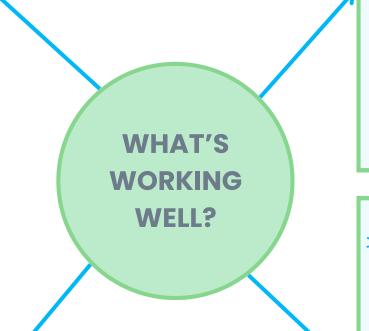


- **Partnership working** between mainstream and SEN provisions to develop PBS plans
- Specialist services audiology and dental
- 'Support first' models
- Training in schools
- Medway youth services (e.g. Shine)
- National Youth Strategy (potential for local development)
- PBS offers across Kent and Medway (0-18 years)
- STLS **Specialist Teachers**
- Mental Health Support Teams (MHST) in schools
- Training offers for family carers

Transition – moving from child to adult services

- Setting that provide support through from preschool to 19+
- Kent Special Education Needs Trust (KSENT) joint working
- **Person-centred planning** (when capacity allows)
- Families leading

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Older family carers – planning ahead

- Willingness from families to support others
- Families as lifelong advocates
- Families are knowledgeable they know their relative best



Risk of crisis at any age - additional support

- Small charities and forums able to be bespoke to individual needs
- The understanding and empathy for people/families in crisis
- Coffee mornings/drop in events
- Strength of families before they hit crisis
- Good at reacting (as a system) to crisis but not proactive





Early years – early intervention and prevention

- Postcode lottery determines availability of support and services
- Long wait times for diagnosis, NHS services such as SALT and FHCPs
- Reactive not proactive system
- Decisions based on **funding** and cost over individual needs
- System delays to prevent expenditure
- Support for families from ethnic minority backgrounds
- Limited capacity of charities to support families
- Lack of information and support
- Complex pathways to support
- Overstretched systems, funding and staffing constraints
- Lack of **respite services** for families contributes to emotional strain which is not considered
- Specific **parent training** for families of children with severe learning disabilities and behaviours that challenge
- Parent/Carer blame and trauma



Transition – moving from child to adult services

- Lack of services available post-19
- Funding disagreements/lack of funding
- Lack of staff capacity
- More proactive plans need to be in place in a timely manner as transition can be a catalyst for crisis, increasing risk of inappropriate detention
- No specific **transition team** for social care now following restructure unable to build **relationships**
- Misplaced resources
- EHCPs ceasing/only focusing on education
- Early planning is non-existent and is taking days not years ahead of 18th birthdays. Earlier referrals needed to community teams
- Lacks whole family approach
- Lack of community support results in more out of area placements - costing LA more

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Older family carers – planning ahead

- Understanding the **scope** of 'older family carers'
- Lack of future planning
- Family carers experiences over a long time traumatic, tiring
- Clear pathways for 'succession' planning, families better equipped
- Support and training for older family carers managing challenging behaviour





Risk of crisis at any age - additional support

- Assessments during crisis is unhelpful new approach is needed
- Increasing prevention methods
- Criteria review often not met until actually in crisis
- More focus on early intervention and practical, consistent approaches being taught to families
- Disjointed information and support
- Improve working with families
- Understanding **trauma** and stigma that can prevent people accessing services
- Lack of **continuity of care** (ie. with social care)
- Sharing and learning from good practice examples





Early years – early intervention and prevention

- Utilising and sharing ICS website
- Share more **information** with families
- Equipping families with the right support early on
- Joint systems approach to communication
- Data collection and compilation
- Co-production and co-delivery (including children)



Transition – moving from child to adult services

- Peer to peer support networks
- Information sharing events
- Improving communication between children's and adults services
- Continuity of care
- Trained specialists in all services
- Learning from other good practice
- Demonstrating the financial benefits of good practice examples vs the cost of negative transition causing crisis

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WHAT
ACTIONS
CAN WE
TAKE?

Key themes

- Information sharing
- Joint approaches
- Improved working systems with families
- Case studies and good practice examples
- Peer support





Older family carers – planning ahead

- Bringing people together to listen and support each other (peer support networks)
- Building connections, face-to-face engagement
- Information sharing strategies
- Feed into the Learning Disability and Autism All-Age Strategy
- Reach out to younger family members such as siblings to support the sustainable care planning work



Risk of crisis at any age – additional support

- Improve contingency planning and focus assessments on prevention
- Engage and **support families** more proactively, addressing needs earlier
- Tackle stigma and trauma, raise awareness of family carer 'burnout'
- Improve transition processes (key crisis risk stage)
- 'Up-skilling' GP's
- Raise awareness of the importance of bespoke care/support needs

Forward Together - Kent & Medway Region

Progress so far....

Shared CBF resources and reports:

1. 'Planning for the Future' Resource

Family carers:

- Connected into the CBF's family carer email network
- Provided with information for carers catch up sessions, listening ear calls and family support details
- Shared details of local parent carer forums
- Facilitated discussions with professionals working in the area to express their experiences and views

Invited professionals from the regional networks to join the CBF's Professional Email Network to connect with other professionals working with people with severe learning disabilities and behaviours that may challenge, providing peer learning opportunities.

Shared information gathered at the CoP event with leads in Kent and Medway.

Bringing in more representation from Medway to the project

Family Carer Project Worker Dean contributes to the sessions on the development of the Learning Disability and Autism Strategy for Kent and Medway to raise the issues faced by the group we are focusing on (severe learning disabilities).

Considered plans for next community of practice event including locality, how we can support more family carers to engage and to get the right information and to be more connected into services.