Equal Lives

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Disability North



- We are a disabled people's organisation our Trustees board is led by disabled people and parent/carers and 50% of our staff have some form of lived experience either a long-term health condition, disabled, neurodiverse or are parent/carers
- We have been providing direct payment support for 20 years and are the commissioned service for Newcastle. This includes PHB's and Education budgets
- Our independent support service is open to anyone across the Northeast and Cumbria
- Our payroll supports just over 600 Direct payment recipients.
- We provide PA training, Direct Payment employer training and carry out access audits and provide inclusion training.
- We provide a full welfare benefits service from benefit checks to form filling and tribunal appeals
- Our Community Care Advice service works alongside families and individuals to ensure their rights are upheld
- We partner with national organisations such as TLAP, ILG community and The National Direct Payment Forum, Disability Rights UK, and feed into policy work with the DHSC, DFE and work with local partners such as Newcastle University on research

Preparing For Adulthood is a Journey

It should be a golden thread running through everything

Chapter 8 of the SEND Code of Practice is entitled "Preparing for Adulthood from the Earliest Years" it says that when a child is very young, or SEN is first identified, families need to know that the great majority of children and young people with SEN or disabilities, with the right support, can find work, be supported to live independently, and participate in their community. All professionals should encourage these ambitions right from the start.



The better the preparation, the better the journey, the better you arrive and enjoy the destination





Growing up!

Transitions needs to be on everyone's agenda.

Good coordination and planning at local level and involvement across health, education, social care and local community

If we are going to keep trying to fit round circles into squares we will fail.

We need to see the young person, their aspirations and work alongside them and their family

Where can we support?

Where are the potential gaps?

What are the cliff edges at each stage?

What will good look like?

It starts with young person and their family and good communication

So often the labels and needs overshadow the young person. The maze of services for some young people and families are complicated and overwhelming.

















Transition through the eye of a Parent/Carer











"If you have a young person who has a learning disability but also uses a wheelchair there is no provision within the county."

"There are not enough post 16 support services and there is lack of knowledge from practitioners around post 16 provision."

"There is a lack of support from the LA in post 16 education transition I am furious that I still do not know where my daughter is going for sixth form, going to panel for a third time".

The children with disabilities team were praised for positive transitions

Real Life Experience

Parents felt that aspirations and the potential of their young people are being overlooked

Parents commented on positive transitions from the children with disabilities team to adult social care. One social worker being described as always working with the young person at the Centre.

"Information around welfare benefits was not always available and practitioners were not picking up on eligibility for higher rates"

"It was a huge cliff we fell off resulting in mental health crisis and then leading to an autism diagnosis, there was no support. Transition planning needs to include those without EHCPs"

"No one bothers to read my young person's Person-Centered Support Plan"



"Transition seems to be a word which means we will take away what is working as you are an adult now. It means loss and stress for parents already burdened with the full-time role of carer"

One parent explained that her child who is year 11 and now studying for her GCSE's and only last week did she finally have a meeting with SENCO (mainstream school) Parent/Carers felt that for autistic people who were diagnosed in their 16-20's there was no support or help and everything was aimed at younger children.

"Sadly, transition is lacking, the need for it is not understood and most services pay lip service to it. The reality is families are left to support their disabled child".

"There is no one to join up the dots and support the young person and their family at such a difficult time"

Real Life Experience

"NO post 16 provision so tricky"

"There is a lack of policy around this and where there is it is inadequate."

"We are dealing with different teams, numerous individuals many of whom don't have an adequate understanding of autism and its impact on young people"

"There is a real lack of post 16 provision"

One parent/carer spoke of having to be a good detective trying to find out information

"I did a self-referral into adult social care for a needs assessment for my daughter and found the entire process excellent."



Why is Early Preparation Important?

- Good, early preparation and having the right support at the right time means less reliance on services post 18
- Early preparation helps parents to navigate the systems and get things in place in a timely manner, it can help to identify any gaps
- Parents can prepare for each stage and support their child/young person effectively
- Keep reviewing the destination things change







What Can we do? 'Nothing about us without us'



- Plan Together work out the end goal. Ask
 what is it you want to do and how can we
 support you in this? What tools do you need?
 Listen to their aspirations, focus on their
 strengths
- Prepare Ask how are we going to get from A to B? Who is needed to support you? What is needed? Where are the gaps and how can we fill them? Be brave, be aspirational think outside the box
- Produce when everyone works together with the voice of the young person at the centre and involved in the preparation the outcomes can be amazing.

Coproduction, Clarity, Consistency, Communication



With the young person at the centre, together plan and provide the support they need to achieve their outcomes.

Offer flexibility and adaptability to meet the changing and diverse needs of the individual

Ensure the quality and safety of the services and advice provided

Promote inclusion and empowerment of the individual in their communities, education, employment, and social activities as well as in the self direction of their support to meet their outcomes

What Good Looks Like

Good local connections of what is available to meet outcomes

Think outside the box

Respect the choice and control of the individual

Good clear and timely communication

Know what their strengths are and what they want to do

Encourage a culture of Bravery and Aspiration

Sign posting to ongoing support

Effective, clear and consistent processes and approach



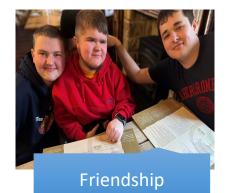
Principles of Good Transition

- Planning and decision making should be carried out in a person-centred way
- Support should be co-ordinated across all services
- Planning should start early and continue up to age 25
- Young people should get the support they need
- Young people, parents and carers must have access to the information they need
- Families and carers need support
- A continued focus on transitions across our local areas.



This is What Good Transitions Can Achieve



















Thriving not Surviving