

Topic of Importance – Preparing for Adulthood

More parent carers are coming forwards with a range of issues, questions and concerns relating to what could broadly be termed 'Preparing for Adulthood' (PfA). PfA covers the needs of children and young people with Special Educational Needs and Disabilities aged between 14 and 25 and is based around moving between childhood and adulthood towards independence. Areas often focussed on are employability, independent living, health and community participation. Recently work has been around developing strategies for Parent Carers and SEND children around at a much earlier stage in their lives prior to age 14, including PfA work within early years settings, under the Earliest Years (PfA Review).

What are parents telling us?

Mainly from contact with parent carers via social media (FVP Chatroom) and email, phone contact to the main charity office similar themes are being raised by a range of parent carers.

1. There are concerns over changes to benefit, primarily the DLA ending and the related concerns over:
 - a. Whether a young person will qualify for PIP
 - b. How to apply for PIP
 - c. Lack of understanding over appointeeship
2. There are also corresponding concerns on the impact on household finances, especially where a young person is in the family home aged between 16 – 18 and 18 - 25
3. There is anxiety over social care charges relating to support via adult social care
4. Lack of knowledge/ awareness/ understanding around what is available in terms of home care support (respite/ domiciliary care/ independent living)
5. Concerns around how much families are involved in decision making
6. Lack of knowledge/ awareness/ understanding around what is available in terms of home care support (respite/ domiciliary care/ independent living)
7. Concerns around how much families are involved in decision making
8. Concerns that families are not aware of the support available and where to find information.

Where we get our evidence from

1. Contact with parent carers via Facebook
2. Email/ phone requests from parent carers for signposting, information and advice
3. Attendance at external and internal Forums and Workshops
4. Feedback from training and other activities
5. Responses to surveys

How have FVP responded

To investigate some of these themes further a small scale survey with a focus on independent living was developed and shared via the FVP Chatroom.

This survey elicited a small response from 7 parents. From these responses we were able to report on the age, gender and needs for the young people concerned and the key areas of concern raised by both parents and the young people themselves.

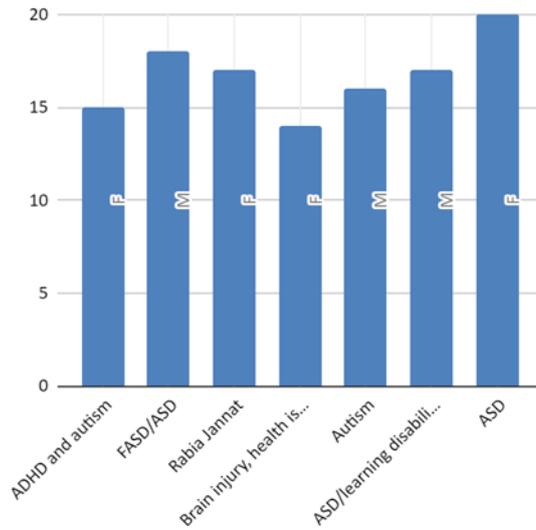


Fig 1: Age, gender and Identified Need for Young Person

Count of If your young person has not moved to adulthood yet are you anxious about this?

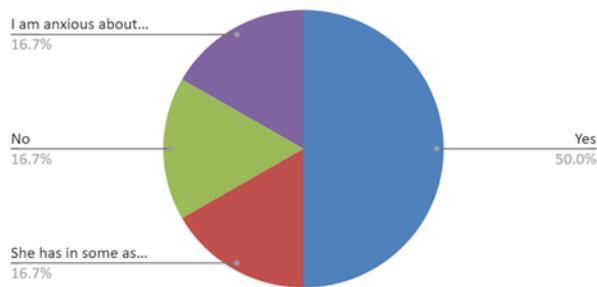


Fig 2: Anxiety pre transition

Count of What options are you aware of for independent living for your young person??

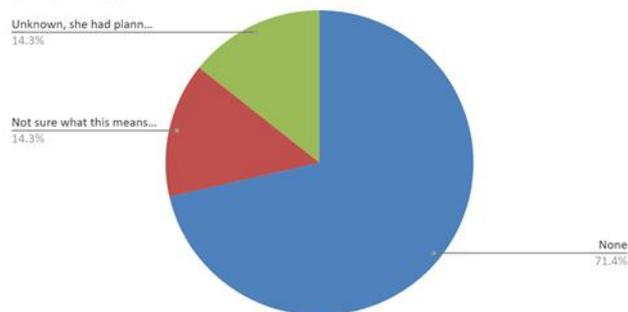


Fig 3: Awareness of Options Available

On a scale of 1 to 5, 1 being very poor to 5...

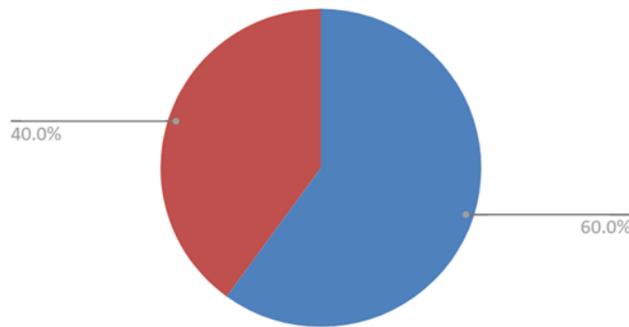


Fig 4: Experience post transition

Parents and young people were able to respond to a series of questions around “Preparing for Adulthood” which enable us to identify their current and future concerns and experiences.

The issues raised were:

What does Preparing for Adulthood mean to you?

- *“Preparing for them to be able to live independently”*
- *“Looking at the young person's needs and what support they need, based on their disabilities and SEMH difficulties, and making a plan for their future, with them at the centre, not trying to fit them into a predefined box, and making necessary adjustments”.*
- *“It means preparing to support her. Helping her and providing her with the benefits she needs because as she is growing the medics are moving away from her”*
- *“Everything, it's so important that we can help her get ready for this”*
- *“Getting ready to start an independent life, leaving home”*
- *“Teaching her life skills, social skills and how to make life decisions since she doesn't want to go to University anymore or until she deems it safe. Also, our helper to do the PIP update retired...”*

What does Preparing for Adulthood Mean to your young person?

- *“How to make friends because I have none now and what to do with my life”*
- *“A future career”*
- *“Being scared, and not feeling prepared for what is expected of them.”*

When asked about the services that they would like to see offered to alleviate concerns around their young person's transition to adulthood, comments included:

- *“Using the EHCP process to facilitate preparing for adulthood outcomes and provision. Appropriate assessments, for example in advance of 17th birthday, so that a young person with complex needs does not have to try to find in with 'standard' transition process”*
- *“More support calls and sessions to help her”*
- *“Support that is more suitable for her developmental age”*
- *“A cry ally someone to contact me to inform of what the next stage is”*
- *“Education/mental health/social”*
- *“Help with writing PIP update”*

Other issues that parents said were important to both themselves and their children:

- Being able to make independent life choices, without the need for parents of extended support network “interfering”.

- Concerns about transition to post 16 education - specifically whether the new setting would be adequately prepared and able to provide consistent support.
- Concerns that support being offered was appropriate to enable the young person to understand and engage - i.e. to be

Other Sources of Information/Feedback from Parent Carers

- Attendance at Caring Together Focus Group on developing Support for Parent Carers and PfA Transition
- Attendance at external Forums where PfA has been raised as an issue
- FVP Open Forum for Young People attending Lime Academy Orton

Summary of Findings

- Parents on the whole are anxious about their children's transition in adulthood and they are unaware of some of the initiatives available to support them and their children
- Parents would like their children to experience an adult future which is independent and free from the input of themselves (where appropriate) and a wider support network.
- Concerns around managing finances - support is required for the maintenance of individual financial support, such as PiP and other benefits.
- Some children/young people will need ongoing support into their futures - who can provide this if not the parent?
- What happens when a young person on a EHCP reaches the age of 25?
- Will post 16 Education settings be adequately informed about the young persons needs and be able to provide the continuity of support required for the young person to engage and develop?
- Parents are not aware of the The Preparing for Adulthood from the Earliest Years (PfA Review)

Where FVP have shared this talking point

1. FVP Website
2. FVP Social Media Channels
3. FVP E-News
4. Peterborough City Council Decision Makers

Next Steps and Areas for Consideration

1. FVP to feedback these concerns at PfA Steering Group and appropriate sub group meetings.
2. Regular updates on the progress of PfA policies and initiatives to be shared with parent carers via FVP media channels.
3. Provision of further surveys and workshops/forums across the range of PfA issues to gain further information on areas of concern and also areas where policies and services are working well. These will then be communicated to PCC PfA Steering Group.
4. LA to consider concerns/ issues/ views of parent carers and work with commissioned services to facilitate parent carer input into the transition process.
5. LA to share PfA guide already developed more widely.
6. LA to look at key concerns such as changes to household income and explore ways to help parents prepare.

Timescales

1. PCC to provide a response within three months of this being presented to the SEND project board
2. This ToI to be posted on the Local Offer and FVP website within one month of production