

Talking points

The NNPCF is a membership organisation and our mission states that “we aim to empower our members to ensure that their voice is heard at a local, regional and national level.”

Working with our membership we have identified a number of key “talking points” - these are topics and themes that are the most important to our membership and the ones that have been prioritised by the NNPCF.

Based on feedback from our membership and from other partners and stakeholders, the “talking point” summarise:

- The lived experience of our members about each topic,
- What is working and what is not working, and
- What we would like to see changed.

The talking points have been created using a range of feedback which includes:

- Surveys (including the SEND surveys)
- Feedback from our annual conferences
- The topics raised at regional meetings
- Themes and topics raised by our membership on social media
- Face to face conversations with our membership

This is the latest version of the **Preparing for Adulthood Talking Point**.

Preparing for Adulthood

Preparing for Adulthood from the earliest years is a key element of the SEND reforms Code of Practice. Chapter 8, gives clear guidance to **all** professionals working with children and young people with SEND but in particular to those who work with young people aged 14 and over. This includes children and adult social care practitioners as well as health practitioners.

High aspirations for all is a key to success and all work being done with children and young people should bear in mind the 4 themes of preparing for adulthood:

- Education and employment
- Health and Wellbeing

- Being part of the community, having friends and relationships
- Independent living and housing options

These outcomes must be considered holistically, with the right focus on all elements to meet the personalised outcomes of each young person.

Families report a number of consistent issues across the country:

- Whilst there are often good, co-produced preparing for adulthood strategies and intentions, provision of services is lacking across the board.
- Joined up working across adult and children's services is limited in many areas
- There is frequently poor planning that is not started soon enough
- Information about preparing for adulthood is limited and confusing both nationally and locally.
- The quality of EHC plans is variable, and too many contain weak or no contributions from care services.
- Areas that have successfully implemented the government's reforms are jointly commissioning the services that parents need and this leads to better outcomes for young people.

This message is echoed by Amanda Spielman, Her Majesty's Chief Inspector for Ofsted in her annual report 2017/18 who states that *'in the second year of our local area SEND inspections, we have seen a continuing lack of coordinated 0–25 strategies and poor post-19 provision.'*¹

The cliff edge

Families describe their young people approaching school leaving age as "the cliff edge". Whilst at school, they understand the provision and support their young person is receiving and can align this with the outcomes for their young person. However, upon leaving school the offer from many, if not most local areas is less clear and very often families are unable to see how the services and provision available will serve to deliver the best possible outcomes for their young people. This is because information about services is often poor and too frequently, the

¹ <https://www.gov.uk/government/publications/ofsted-annual-report-201718-education-childrens-services-and-skills/the-annual-report-of-her-majestys-chief-inspector-of-education-childrens-services-and-skills-201718>

services and support parents believe their young person needs are just not available.

Forums also describe lack of information regarding the Mental Capacity Act, Deprivation of Liberty (DOLS) and deputyship.²

Education Health and Care Plans for the post 19 age group

As a result, many families seek to retain an education health and care plan (EHCP) after the age of 19 believing that educational provision is the only viable option for their young person. Frequently parents will understand that options other than education may better suit their young person but a lack of provision and information mean they do not believe this will actually be delivered.

From September 2014, EHC plans replaced Learning Difficulty Assessments (LDAs) for young people in further education. Children and young people aged 16-19 years old account for 22% of children and young people with a statement or EHC plan as at January 2019. This represents an increase year on year over the period from January 2014 (10%) to January 2018 (22%), remaining at this level in January 2019. The percentage of young people aged 20-25 has similarly increased since the introduction of EHC plans in 2014, rising to 5% of all plans in 2019.³

Post-16 SEND demand is projected to rise. The forecasting model for London projects that the number of 16 to 18 year olds with EHCPs will rise by 5% between 2018 and 2022. The volume of 19 to 24 year olds with EHCPs is projected to remain broadly static in the same time period.⁴

² http://www.legislation.gov.uk/ukpga/2019/18/pdfs/ukpgaen_20190018_en.pdf

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/805014/SEN2_2019_text.pdf

⁴ https://www.london.gov.uk/sites/default/files/london_send_post-16_review_0.pdf

Despite the published latest data by the Department for Education, many families continue to report that EHCPs are being withdrawn even if their child's education outcomes have not been met. In determining whether to withdraw a plan a local authority must have regard to whether the educational or training outcomes specified in the plan have been achieved⁵.

The NNPCF recognize the pressures on SEN Funding and have seen an increase in concerns from forums that their local areas cannot deliver the legal requirements of the Children and Families Act with constrained resources. This message is shared by the LGA who in a recently published report highlight a raised parental expectations and aspirations of the young people as well as the extension of EHC plans to age 25 as contributory factors to the financial pressures faced by Local Authorities.⁶

The NNPCF would also like to see local authorities take into account the, quality and relevance of non-education services available to a young person's outcomes when assessing whether to cease an EHCP. If no appropriate non-educational provision is available, the young person should continue in an educational setting with an EHCP.

Often families are only offered part time education provision for their young person (often 3 days a week). Families report that frequently, no or inadequate provision is offered for the other days.

The NNPCF would like to see local authorities consistently providing the required 5 day a week packages with the required follow up from the DfE and inspectors and strongly champion for a coproduction approach as a way of delivering services more effectively.

⁵ Department for Education. SEND: 19 to 25 year olds' entitlement to EHCP plans. January 2017
<https://www.gov.uk/government/publications/send-19-to-25-year-olds-entitlement-to-ehc-plans/send-19-to-25-year-olds-entitlement-to-ehc-plans>

⁶ <https://www.local.gov.uk/about/campaigns/bright-futures/bright-futures-childrens-services/bright-futures-send-funding>

Outcomes for Young People

Education outcomes for young people with SEND continue to be not as good as their peers without SEND. For example, 9% of young people with EHCPs in London were not in education or training after key stage 4, compared to 5% of those without SEND.⁷

A lack of planning

There is not enough planning by schools with parents and young people from year 9 onwards which in turn impacts on the young people getting their voices heard as well as the aspirations of their families for their future.

The NNPCF would like to see greater focus on preparing from adulthood from the earliest ages – to quote one forum “PFA begins at birth”.

Some local authorities have adopted the four PFA themes and integrated them into their EHCPs from year 9 onwards. We would like to see this practice rolled out in all local authorities.

Good intentions but a lack of provision on the ground

There is a significant gap between projected demand and existing supply of education places Post 16. Even where the provision does exist, it may not be in the most convenient place for the young person. For example in London, 44% of young people with EHCPs cross local authority boundaries for their post-16 provision.

Many parent carer forums report that their local area has good quality, co-produced preparing for adulthood strategies with some stating that transition representatives, PFA officers and employment co-ordinators have been appointed (For example All age disability strategy in Calderdale, PFA strategy in Bedford Borough). However, many report that services on the ground are often

⁷ https://www.london.gov.uk/sites/default/files/london_send_post-16_review_0.pdf

lacking. Areas commonly identified are low numbers of supported internships, apprenticeships and employment opportunities for young people with SEND. In addition, availability of appropriate housing is also highlighted with low stocks, little or no choice on what is available.

If EHCPs are completed effectively they could be used as part of the evidence base for commissioning both at an Individual level – planning from year 9 to ensure that each young person with an EHCP has Preparing for Adulthood outcomes stated, and that specific post-16 provision is in place to help them meet these outcomes and at a strategic level – Data from EHCPs could be brought together in a single data source to provide aggregate data for commissioners. For example London Borough of Islington has introduced a commissioning sub group to their EHC statutory decision making panel and Bexley Voice has coproduced a parent Transition planner for families

Local offers need to be better focussed on preparing for adulthood services. The NNPCF would like to see an increased focus from local authorities, the DfE and regulators on the availability of information about local services and the identification of gaps through the local offer.

Age appropriate services

Many parent carer forums report that adult social care services in particular are overwhelmingly focussed on old people’s care. Young people with SEND are often offered services that are not appropriate for them. Those offered housing with older people or offered respite services with older people are reluctant to use these services because they do not meet their needs or help to deliver their desired outcomes.

The NNPCF would like to see more age appropriate services for young people with SEND delivered across the country.

Co-ordination between adult and children’s services

Parent carer forums report very patchy co-ordination between adult and children’s services in many local areas. This is amplified by the differing ages at which a young person becomes an “adult” across different services and different

pieces of legislation with different services transitioning at different ages ranging between 16, 18, 19, and 25. Very often there are gaps in provision.

This means that there is often a lack of clear accountability in local areas about who is responsible for preparing for adulthood.

The NNPCF would like to see a named individual in each area identified as the local PFA officer who is responsible to co-ordinating the provision of services across a local area to prevent gaps in provision. As noted above many areas are moving towards this.

Pathways into employment

Parents report that the pathways into employment for their young people are confusing and at times difficult to access. There are many different routes available such as:

- Study programmes
- Supported internships
- Traineeships
- Apprenticeships
- Access to work

However, families do not necessarily understand the differences between these programmes, who provides them, how long they last, where they are delivered. In addition, often information about what is available locally is very poor.

NDTI has published some information on pathways into employment.⁸

The NNPCF would like to see a clear national guidance that cover these different pathways and outlines which may be relevant for their circumstances and how to access them. We must also recognise that work may not be the right outcome for all young people with SEND. Those young people for whom employment, education or training is not the right answer, should be offered alternative choices and meaningful day opportunities.

For further information please see the Employment Talking Point.

⁸ Preparing for adulthood

<https://www.preparingforadulthood.org.uk/downloads/employment/routes-into-work-guide.htm>

Health and Wellbeing

Forums share that parents lack confidence in the transfer from children's health to adults. They report that adult health services frequently do not have a great understanding of the young people with SEND and this is often reflected in the availability of appropriate services.

Forums have also have raised concerns about the lack of GP engagement with the community of SEND young people including access to Learning Disability Health Checks.

People with a learning disability have worse physical and mental health than people without a learning disability. On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population; and the life expectancy of men with a learning disability is 14 years shorter than for men in the general population (NHS Digital 2017)⁹

The learning disabilities health check scheme is designed to encourage practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer these patients an annual health check, which includes producing a health action plan.

The NNPCF would like to see more joint working from Year 9 onwards with regards to health services from community's teams to the acute hospitals including a focus on the role of GPs.

The NNPCF have worked with CONTACT and Bromley Parent Voice to develop resources to raise awareness of the Learning Disability Health Check.

⁹ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme/learning-disabilities-health-check-scheme-england-quarters-1-and-2-2017-18>