Transition of Children and Young People with Disabilities to Adulthood Consultation Responses Positive Responses

Theme	Respondent	Comment
Welcomes early intervention to provide support	Council for Catholic Maintained Schools (CCMS)	
Welcomes integrated planning, multi agency approach	CCMS, PHA, Northern Ireland Rare Diseases Partnership (NIRDP), Women's Aid Federation Northern Ireland (WAFNI)	PHA- long standing problem that needs involvement of adult services
Welcomes a focus on rights	CCMS, Northern Ireland Rare Diseases Partnership (NIRDP)	
Support development programme for disability awareness	CCMS, PHA, Northern Ireland Rare Diseases Partnership (NIRDP). Women's Aid Federation Northern Ireland (WAFNI)	CCMS- important to demonstrate benefit for children and young people as well as teachers
Support Personalised Budgets, integrated plans and passports	Community Child Health (BHSCT), Women's Aid Federation Northern Ireland (WAFNI), Disability Action	Women's Aid Federation Northern Ireland (WAFNI)- Passports should be complementary rather than record of numerous agency functions

Welcome recognition of the need for provision of adequate support into adulthood	Northern Ireland Rare Diseases Partnership (NIRDP)	
Welcome recognition of mental health issues	Northern Ireland Rare Diseases Partnership (NIRDP)	
Welcome recognition that transition planning occurs at too late a stage	Northern Ireland Rare Diseases Partnership (NIRDP)	
Welcome the 'can do' focus	Northern Ireland Rare Diseases Partnership (NIRDP)	
Welcome information on domestic and sexual violence	WAFNI	
Welcome information on children with disabilities on the Child Protection Register	WAFNI	

Welcome participation in community	Women's Aid Federation Northern Ireland (WAFNI)	
Welcome recognition as a child or young person first	Women's Aid Federation Northern Ireland (WAFNI)	
Welcome proposed link to Sport NI Disability Strategy	Women's Aid Federation Northern Ireland (WAFNI)	

Feedback from children and young people

Respondent	Comment
Disabled Children & Young Peoples Participation Project (DCYPPP)	ELA • Young people should have the right information at the rights stage • Variation in school experience across the region, one good example was someone who had access to a transition worker since 3 rd year and was now going to university after support from principal and university. Many did not experience as positive an experience • Transition office in each local area LSS • Have a transition worker in each school to give training on disability awareness • Transition planning should be based on outcomes planning so it is meaningful • Agree with the importance of integrated working EEEW • Stress the importance of employment opportunities and being supported into this employment
	 CPCS Really value their opportunity to participate- other young people need to be involved in the same way and in a way that is meaningful, not tokenistic
	 Healthy Physiotherapy needs to continue after school stops, based on assessed need Good coordination to ensure provision of equipment for those with complex health needs

In line with best practice, the group will feed back directly to children and young people about how their views have been heard.

Feedback from Parents

Respondent	Comment	Action
Transitions Parent Reference Group	 Healthy More detail on integrated plans needed, driven from the top, meaningful, remembers all children with disabilities, includes parents as partners There should be representation from Children's Law Centre or Guardian Ad Litem What will be the format of passport information and who will own/secure it? 	The Chair of the group met with the Parents Reference Group on November 27 th 2012 to discuss their feedback. Given the strategic nature of the group, the detail will follow in the implementation of the action plan
	 ELA Important to develop plans to deal with the problem rather than tracking numbers only Difficult to see how the needs of severely disabled young people are going to be met Home tuition is aspirational and denies other needs such as socialisation 	Agree A person centred planning process will ensure inclusion of all severities of disabilities Noted
	 LSS The promotion of rights is often tokenistic Awareness raising among agencies/schools/parents/children and young people More provision for children and young people with disabilities-programmes sometimes do not want to accept them Class sizes too big No suitable playground equipment in some circumstances More severe punishment for perpetrators of hate crimes What is meant by 'link' with SBNI 	The rights of children and young people are the framework upon which the CYPSP is basing its work. Noted, agree Noted Outside the remit of this group It means ensuring that safeguarding

	issues for children and young people with disabilities is on the agenda of SBNI
 Ensuring family support is aspirational and in reality provision was patchy More money needed to do this or risk Outcomes Groups priorities 	Noted Noted
becoming so diluted that they will not make much difference- or go to small community groups who deliver support on the cheap • Are parents and families not already resilient after having to fight for	Noted
everything?	1.0.00
 Believe mapping/scoping had been done and it was time for affirmative action- many up to date reports available More meaningful to scope Adult Centres and the problems there 	Noted, detail of implementation will follow Noted
Not manageable and needs measurable milestones	Noted Agree
 Short breaks review needs to happen- stop talking about it. Its aspirational again System stigmatises families- postcode lottery 	Noted
 Don't use the word 'exciting'- 'high standard' or similar would be better Situation worse for young adults, need a change in legislation and that could take 3 years 	This wording has been changed Agree
 Children with a disability are all children by law Why look to the UK when reviewing employment opportunities? 	To learn from best practice as wide as
Battle between urban/rural in Northern Ireland	possible Noted
 Examples of good practice in giving young people the opportunity to experience work and learning e.g. Glencraig, Mourne Grange and Dr. B's 	Noted and useful
There is a requirement to educate employers	Noted

 CPCS Personalised budgets good in theory if timely access is possible Who can access personalised budgets and who will make sure the young person understands the process At the moment schools are given money from the Board (new special education review). This comes under "additional needs" and has to be very thinly spread at the Principal discretion. 	Noted and agree, the detail will follow in the implementation
LSRR	
 Not enough will to make change happen, need to start taking action Group agreed that it would require a large amount of money to make a meaningful difference. One parent told how they knew a mother who was offered a place in an old people's home for her disabled child 	The mutli agency, integrated nature of this group includes the will of all relevant agencies and organisations.
Other issues for the group was the development of CAMHS	Noted, an issue for the EBD Sub Group, with which this group will link closely
The group identified their priorities as follows:	
High Level Outcome: Healthy	
Action 1 – Develop integrated plan including the use of passports	The group welcomes the priorities identified by this parent's groups and notes the similarity with the areas identified by the group.
High Level Outcome: Enjoying, Learning and Achieving	
Action 1 – Track the number of young people moving into further education,training and employment	

Action 2 - Examine home tuition High Level Outcome: Living in Safety and with Stability Action 1 – Promote awareness through training in disability awareness, Human Rights, UNCRC and the UNCRPD High Level Outcome: Experiencing economic and environmental wellbeing Action 1 – Scoping information to determine expected demand and creating an integrated point of access Action 2 – Review short breaks services Action 3 – Review employment opportunities High Level Outcome: Contributing positively to Community and Society Action 1 – Ensuring a person centred approach through self directed support including individualised budgets and direct payments High Level Outcome: Living in a Society that Respects their Rights Action 1 – Integrated/multi agency approach to individual assessment.

Action 2 – Develop integrated commissioning statement	
Action 3 – Roll out of training on Human Rights, Disability Awareness, UNCRC and UNCRPD	

Constructive Suggestions for Change

Respondent	Comment	Action
	General Issues	
Positive Futures	Information from children and young people should be written in a format that children and young people will understand- care needs to be taken to ensure that statements from professionals are not attributed to children and young people	Noted, will be changed accordingly
Craigavon Borough Council	 Many ongoing developments that include children and young people with disabilities e.g. Sport NI Active Communities Inclusive Fitness Initiative Sport and Leisure Users Groups 	Noted and useful, thank you
Dungannon Borough Council	 Are aware of or have been involved in the following: Transition of children and young people with disabilities from 	Noted, the group welcomes the ongoing work

	education to health (Children's Commissioner) Welfare Reform, the age of assessment at 16 rather than 18, and further exceptions on housing allocation and room allowance for disabled children Respite/Short breaks and TYC Options for independence and support programmes. Good practice such as Fit for U and Active Communities Council discussions regarding lifelong learning courses Transfers from schools Extending Sure Start models to all children with disabilities	The group will link with Child Care Partnerships
Community Child Health (BHSCT)	 Priority to developing an 18+ service to transition to similar to the Cystic Fibrosis Service Plan ahead to know numbers transitioning next year Consider training needs of staff if providing a transitions worker from age 14- training needs analysis should be done Need to map ongoing regional work to avoid duplication 	Noted Agree Noted Agree
Northern Ireland Rare Diseases Partnership (NIRDP)	Transition issues for young people, carers and families are compounded when they face a rare disease	Noted
Women's Aid Federation Northern Ireland (WAFNI)	Question need for two plans given the huge overlap between them	Given the importance of the issue transition, it was considered necessary to have a separate group
Early Years	 Recommend the following as practice for smooth transition: Interruption of needed service is avoided Child, family and service providers are given opportunities to prepare for changes that may occur Planning based on strengths of child as well as needs 	Noted and useful, thank you

	 Families informed of rights and options 	
	 Families enabled to provide input into child's education 	
	programme	
	 Most appropriate and supportive environment identified 	
	 Child is emotionally and practically prepared for new environment 	
	 Continuity of curriculum and routine is facilitated from one setting 	
	to the next	
	 The child receives support in the new setting 	
	 Families involved in transition process 	
	 Child's adjustment to the new setting is evaluated 	
	 Ongoing communication and collaboration between 	
	professionals, the child and the family	
	A key overarching recommendation therefore is the investment in early	Noted
	years services	Agree
	Link with DHSSPS Allied Health Professions in Northern Ireland 2011-	Agree
	2016	Croup has established along working
	Track SEN progress as with the children and young people with	Group has established close working links with the Children and Young
	disabilities action plan	People with Disabilities Sub Group
		People with Disabilities Sub Group
		Agree, the group acknowledges the
	Greater monitoring and reporting mechanisms and more detailed	timeframe for the action plan
	timescales	
	More reference to bullying and discrimination. Early Years has much	Noted and useful
	practical experience in this area including The Media Initiative for	Noted and userui
	Children Respecting Difference Programme, Faces and Spaces-	
	Children's Shared Space Programme and Keyhole Autism Training for	
	Pre-Schools	
Regional Inter-agency	Where do the needs of people with diabetes, arthritis or palliative care	The outcomes based planning process
Implementation	needs fit into this plan?	for children and young people will
Group on Children	More detail on implementation is needed	ensure inclusion of children and young
with Complex		people with complex health needs
Physical Health Care		
Needs		
Reference Group:		

Transition from Children to Adult Services Northern Ireland Hospice	Where do the needs of young people with long term conditions or palliative care needs fit into this plan?	As above, the outcomes based planning process for children and young people will ensure inclusion of children and
		young people with complex health needs
	Healthy	
Positive Futures	Quantitative indicator 'rates of parents/carers experiencing mental health/ stress' identified but no actions that would likely improve this apart from integrated plans etc which are not enough- possibly addressed by improved family support under EEEW	The group recognises the interconnectedness of the outcomes and as a framework, it is likely that an impact in one area will also impact another.
Children's Palliative Nursing Special Interest Group	Issue of passport excludes the needs of young people with life limited conditions. Also excludes regional work carried out on this issue	The outcomes based planning process for children and young people will ensure inclusion of children and young people with complex health needs
Regional Inter-agency Implementation Group on Children with Complex Physical Health Care Needs Reference Group: Transition from	 More balance between physical and mental health emphasis Comments re AHP services should include 'timely' access because of issues regarding complex assessment processes and waiting lists Integrated plans should be relevant to individuals and consistent with regional assessment processes Who will be responsible for integrated plans and how will they work? More information required on passports including: Who will responsible for reviewing and updating? 	As above, the outcomes based planning process for children and young people will ensure inclusion of children and young people with complex health needs

Children to Adult Services	 Will include urgent medical information e.g. end of life decisions Current bulky format or electronic Will it link to ongoing national passport work How will it work in multi agency format- coloured sections? Who is responsible for keeping it? Should determine the effectiveness of clinical information before 	The strategic nature of the plan means that detail will be forthcoming when the group begins to implement the plan
	 No mention of the 3 regional workshops held in 2010 about the Transition of Young People with Complex Physical Healthcare Needs. These workshops identified issues regarding: medical support, budgets for continued care packages at transition, hospital admissions in adult settings, development of a pilot ward area to support young people in adult hospital, Identification of a medical/clinical lead to support young people to transition from child to adult acute services. Community Paediatricians and GPs will be included in the integrated planning process, education of adult healthcare staff, lack of regional approach to transition age from child to adult acute hospital services, development of a health passport to do away with repeating information at clinics etc. but also to inform hospital admissions (especially emergency). 	Noted and useful
PHA	Pg 4- change AHP reference to 'there is a need to ensure that young people continue to access services and supports available in children's services into adult services, including AHP services, as appropriate	This has been changed accordingly
Northern Ireland Hospice	 No mention of the 3 regional workshops held in 2010 about the Transition of Young People with Complex Physical Healthcare Needs. These workshops identified issues regarding: medical support, budgets for continued care packages at transition, hospital admissions in adult settings, development of a pilot ward 	Noted and useful

	area to support young people in adult hospital, Identification of a medical/clinical lead to support young people to transition from child to adult acute services. Community Paediatricians and GPs will be included in the integrated planning process, education of adult healthcare staff, lack of regional approach to transition age from child to adult acute hospital services, development of a health passport to do away with repeating information at clinics etc. but also to inform hospital admissions (especially emergency Clarification is required as to who will adopt the role Transition worker and the area of focus- currently focus on education and employment Should address response times for wheelchairs Integrated plans should be relevant to the individual and include other regional assessments Should also clarify how integrated plans will be developed, implemented and reviewed Who will review and update passports? And will it include resuscitation issues, end of life decisions or seizure management/ emergency response plans etc Clarify what is meant by 'not a health record' Clarify other areas including: Format of passports- electronic? Coordinate with other planned passports eg PCC, PHA and RCPG The effectiveness of clinical information for those with long term complex health needs	Given the strategic nature of the group and the action plan, the detail will follow in implementation. The group will develop a glossary of key terms for the action plan for ease of reference
Women's Aid Federation Northern Ireland (WAFNI)	How will integrated plans be reviewed and how will they involve children and young people	The detail will follow in implementation

Disability Action	More detail on passports, what has been done so far, what is next and the level of involvement of children and young people	The detail will follow in implementation
Health and Social Care Board	 Is it realistic to develop passports for each young person Will one document cover multi agency aspect What is the criteria for ensuring young people access a transition worker at 14- is this achievable for every young person? 	Given the strategic nature of the group and the action plan, the detail will follow in implementation.
	Enjoying, learning and achieving	
Council for Catholic Maintained Schools (CCMS)	 Important to determine why young people with disabilities are leaving school with fewer qualifications Should consider home tuition as a last option 	Agree Noted, agree
Positive Futures	 Happy to share best practice re participating in Duke of Edinburgh Award Consideration for inclusion of young people in social and leisure activities in local communities- link with our documents eg Review of Lakeland Family Service, Creating Opportunities and Changing Lives: Best Practice Manual and an Inclusion Manual (On website) 	Noted and welcome Noted and welcome
Women's Aid Federation Northern Ireland (WAFNI)	Should be more emphasis on what types of educational opportunities will be in place to support transition e.g. career guidance, job skills etc Should be a focus on relationship education, especially as young people with disabilities may be particularly vulnerable and need to know the difference between healthy and abusive relationships. Link to 'Helping Hands' and 'Heading for Healthy Relationships' programmes	Noted and welcome examples of good practive
Disability Action	To ensure equality of opportunity regarding training, this text should	Agree

	include special schools	
Health and Social Care Board	Clarify what is meant by the Qualification Credit Framework	The group will develop a glossary of key terms to be included in the action plan
	 Evidence needed for the statement 'Young People in special schools may not be encouraged to achieve as much as those in mainstream or learning support For the last point under qualitative information- do we need to consider examples of positive areas? Has the group not already linked with education members to track young people through education as part of their integrated plan Can we achieve diversity and disability awareness for all primary and 	This has been changed accordingly Noted The multi-agency, integrated nature of the group means cooperation is possible not only with education but
Regional Inter-agency Implementation Group on Children with Complex Physical Health Care Needs Reference Group: Transition from Children to Adult Services	General statements. Who will be responsible for collating information and producing 'Good Practice' model	The Group has identified these areas as part of its ongoing work
Northern Ireland Hospice	 Clarification needed regarding developing a good practice model, collation of information and its implementation How will this outcome be promoted for children with complex health and palliative care needs? 	Given the strategic nature of the group and the action plan, the detail will follow in implementation. Outcomes, person centred focus will ensure inclusion of all conditions

	T	
Agree with the coordinated approach and has established Transition service with NHSCT and DEL with action plans for 14+ age	Noted and welcomed	
Legislation and process for sharing of data among agencies is urgently	Noted, agree	
Pg 7 point 3 in qualitative information- anecdotal evidence suggests that pupils with learning difficulties who come from a more supportive	This has been changed accordingly	
 Aware of the lack of appropriate and relevant courses available for young people with disabilities, the majority of whom are in SLD schoolshoping to address by working with Northern Regional College in the coming year NEELB has developed a process to highlight to the NHSCT those pupils in year 10 with significant needs who will fit the criteria for disability, so they know of their existence from age 14. 	Noted and would welcome updates. The group is keen to identify and link to ongoing work	
Living in Safety and with Stability		
It is not clear what families can expect that will lead to strengthening of family support and resilience	Noted	
While incidence of hate crime may be higher, it may not be the experience of every young person with a disability- the information presented suggests it is	This has been changed accordingly	
Keen to be involved in training for service providers and policy makers	Noted and welcomed	
Training on hate crime must be included to encourage reporting of incidents	Agree	
	 service with NHSCT and DEL with action plans for 14+ age Legislation and process for sharing of data among agencies is urgently required Pg 7 point 3 in qualitative information- anecdotal evidence suggests that pupils with learning difficulties who come from a more supportive background do achieve academically than those in mainstream Aware of the lack of appropriate and relevant courses available for young people with disabilities, the majority of whom are in SLD schoolshoping to address by working with Northern Regional College in the coming year NEELB has developed a process to highlight to the NHSCT those pupils in year 10 with significant needs who will fit the criteria for disability, so they know of their existence from age 14. Living in Safety and with Stability It is not clear what families can expect that will lead to strengthening of family support and resilience While incidence of hate crime may be higher, it may not be the experience of every young person with a disability- the information presented suggests it is Keen to be involved in training for service providers and policy makers Training on hate crime must be included to encourage reporting of 	

Regional Inter-agency Implementation Group on Children with Complex Physical Health Care Needs Reference Group: Transition from Children to Adult Services	How will steps be implemented and effectiveness measured	Given the strategic nature of the group and the action plan, the detail will follow in implementation.	
Northern Ireland Hospice	 How will these steps be implemented and evaluated How will this outcome be promoted for children with complex health and palliative care needs 	Given the strategic nature of the group and the action plan, the detail will follow in implementation.	
	Experiencing Economic and Environmental Wellbeing		
Positive Futures	 Need to consider additional challenges faced by those living in rural conditions And also the poor economic outcomes linked to caring for a child or young person with a disability More work needed on 'day opportunities' and the benefit of this for young people. Currently focussed solely on short breaks Qualitative information mentions social and leisure opportunities but no associated actions Link with , not only DARD, but other relevant organisations re transport 	Noted, the focus on the child or young person will account for extraneous factors such as these Agree A review of short breaks will include social and leisure opportunities Noted	
Northern Ireland Housing Executive	Note that further work is required to sensitise the housing allocation system to support the transition of young people from an accessible	Welcomed	

	family home to their own home- ongoing work currently	
Belfast City Council	Currently employ young people with learning difficulties, keen to explore more opportunities	Welcomed
Disability Action	Re transport- link with Translink and other community transport services	Noted and agree
Regional Inter-agency Implementation Group on Children with Complex Physical Health Care Needs Reference Group: Transition from Children to Adult Services	Actions and implementation milestones are important steps but how far in advance is information needed to influence change?	Noted
Northern Ireland Hospice	Actions and implementation milestones are important steps but how far in advance is information needed to influence change?	Noted
Contributing Positively to Community and Society		
Northern Ireland Hospice	The capacity for personalised budgets, including the ability to purchase health care support, needs to be addressed in this plan	Agree, it is included
Regional Inter-agency Implementation	Include the needs of those with complex health needs who are often the most excluded	Outcomes, person centred focus will ensure inclusion of all conditions

Group on Children with Complex Physical Health Care Needs Reference Group: Transition from Children to Adult Services			
Disability Action	How will children and young people be involved in these actions	Children and Young People represented on the Sub Group	
Belfast City Council	More use could be made of the Belfast City Council Youth Forum	Noted and welcomed	
PHA	No mention of 'community access' approaches to promote inclusion in community outside the home	Noted	
Positive Futures	Link to Transitions regarding supporting young people into employment	Agree	
	Living in a Society which Respects their Rights		
Positive Futures	Needs to be an inclusion of the issues regarding restraint/restrictions	Outside the remit of this group	
Belfast City Council	 More information of disability awareness training- who would do it and has there been any consultation or contact with relevant professionals or the community sector- may be able to contribute Worth identifying how organisations currently include consideration for disabilities in their plans Where did information regarding recreational activities on pg 20 come 	Detail will follow in implementation, welcome the potential to link into existing work Information provided by the experience	

	from? No actions to address it either. BCC believes its facilities are accessible to all	of group members, parents, children and young people
Disability Action	Advocates Disability Equality Training rather than Disability Awareness Training	Noted