



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



An Ghníomhaireacht um
Leanaí agus an Teaghlach
Child and Family Agency

**Joint Protocol for Interagency Collaboration
Between the Health Service Executive and
Tusla – Child and Family Agency to Promote
the Best Interests of Children and Families**

December 2020

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List of Abbreviations

AJWG: Area Joint Working Group

AoN: Assessment of Need

CEO: Chief Executive Officer

CAMHS: Child and Adolescent Mental Health Service

CDNM: Children's Disability Network Manager

CDNT: Children's Disability Network Team

CHO: Community Healthcare Organisation, HSE

CPW: Child Protection and Welfare Service, Tusla

DCYA: The Department of Children and Youth Affairs

GDPR: The General Data Protection Regulation.

HIQA: The Health Information and Quality Authority

HSE: Health Service Executive

IFSP: Individual Family Service Plan

MoU: Memorandum of Understanding

PPFS: Prevention, Partnership and Family Support Service, Tusla

Section 1 – Introduction

1.1 Background

In March 2017 the *Disabilities Protocol Group* signed off on the *Joint Protocol for Interagency Collaboration between the HSE and Tusla to Promote the Best Interests of Families* – hereafter referred to as the *Joint Protocol (2017)*. This protocol established clear expectations as to joint working by both agencies to promote best outcomes for children known to either or both agencies. It also established structures to ensure the effective management and governance of individual cases from local level (i.e. Area Joint Working Groups [AJWGs]) up to the National HSE/Tusla Oversight Group.¹ Its implementation from September 2018 was influenced by ongoing challenges highlighted by both agencies and by the Ombudsman for Children’s recommendations in particular, Molly’s case (Ombudsman for Children, 2018) & Jack’s case (Ombudsman for Children, 2020; Appendix A).

While the *Joint Protocol (2017)* provided significant guidance about how the two agencies should work together, there were on-going challenges that resulted in further issues being raised to management in both agencies and to the Ombudsman for Children. These challenges included the following:

- Clarity regarding the cohort of children and young people to whom the protocol referred;
- Funding of residential placements for children and young people with complex needs;
- Differing perceptions of the responsibilities of each agency;
- How to ensure smooth transitions to adult services; and
- Clarity in relation to the structures for resolution of disputes in respect of funding or case management responsibilities.

A series of workshops were held during 2018 and 2019 across all Health Service Executive (HSE) Community Healthcare Organisations (CHOs) and Tusla, Child and Family Agency (Tusla) Regions/Areas. These were intended to ensure a consistent implementation of the *Joint Protocol (2017)*. A further national workshop was held in February 2020 to review the implementation and to address any issues arising. This workshop was attended by representatives of both agencies (including the Chief Executive Officers); both the Department of Health and the Department of Children and Youth Affairs; and by the Office of the Ombudsman. This workshop helped identify ambiguities and proposed amendments to the *Joint Protocol (2017)*.

1.2 Purpose of this Protocol

The purpose of this revised Joint Protocol – hereafter referred to as the *Joint Protocol (2020)* – is to describe how the HSE and Tusla will work together to provide a person-centred pathway to meet the needs of children with a complex disability and their families.

¹ The HSE/Tusla Oversight Group consists of Tusla’s National Director of Services; the HSE National Heads of Operations; and the HSE’s and Tusla’s National Leads for this *Joint Protocol (2020)*.

1.3 Cohort of children

This *Joint Protocol (2020)* applies to children with a complex disability in statutory care² (e.g., foster or residential) or those inappropriately placed in other settings (e.g., long-term placement in respite; acute hospital beyond medical need).

1.4 Complex Disability

Complex disability typically denotes children with a moderate-to-severe or enduring physical, sensory, mental health or intellectual impairment. However, some children with both a mild intellectual disability and co-morbid presentations may also be assessed as having a complex disability.

Both the HSE and Tusla agree that from a disability perspective,³ complex needs refer to 'one or more impairments that contribute to a range of significant functional difficulties that require the services and support of an inter-disciplinary healthcare team' (*National Policy on Access to Services for Children and Young People with Disability and Developmental Delay, 2019, p.17*). The *Disability Act 2005* (Part 1 Section 2) defines disability as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.' In Part 2 Section 7 of this Act (p.10), 'substantial restriction' as noted above is further defined as (a) permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes; and (b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability.

1.5 Underpinning principles

The provision of care to children with a complex disability will be guided by a suite of key operational principles.

Table 1. Key principles for providing Tusla and health-related services to children in care.

Principle	
Accountability	<ul style="list-style-type: none">• Services will be answerable to children / young people / families / carers and the State.
Accessibility	<ul style="list-style-type: none">• Services will be accessible in a timely manner;• Children with a complex disability in State care will access HSE services in the same way as other children.⁴
Assessment	<ul style="list-style-type: none">• All children in care will have been formally assessed by an appropriate professional;

² Statutory care refers to children formally received into the care of Tusla under provisions of the *1991 Child Care Act* by virtue of care proceedings or voluntary parental consent. Formal state care is separate from arrangements/placements such as residential provision solely to meet a child's disability care needs that to date are not subject to statutory regulation.

³ From a social care perspective, complex need can include vulnerabilities and complicating factors within the child's family that impact significantly on their day to day care.

⁴ The person who is carrying out parental duties should have no bearing on a child's eligibility or access to services. In other words, Tusla is not responsible for funding required disability services generally provided by other agencies any more than any parent.

	<ul style="list-style-type: none"> • Children in care will have their needs consistently reviewed using the statutory Child in Care review process.
Communication	<ul style="list-style-type: none"> • Services will communicate in a timely and respectful manner with children / young people / parents / carers; • All agencies will consult appropriately with each other, especially when planned actions focused on improving outcomes for service users may impact on other agencies; • A national data sharing agreement will facilitate inter-agency sharing of information on a need-to-know basis.
Early intervention	<ul style="list-style-type: none"> • Early intervention will be facilitated by competent professionals providing support services to children and young people who are deemed to be at risk (due to their complex disability) and/or to their families, and to those children and young people who are in care.
Managed transitions	<ul style="list-style-type: none"> • The transition from State care to Aftercare or independent living for children and young people with a complex disability (including mental health) will be jointly managed so as to address their identified needs (e.g., via pervading the necessary supports) and provide continuity of care. Such transition planning will commence at the child's sixteenth birthday or before.
Maximise efficiencies	<ul style="list-style-type: none"> • In the context of finite resources, services will operate in an efficient and value-for-money manner so as to maximise the outcomes for children / young people / families.
Parental consent	<ul style="list-style-type: none"> • Where there are no child protection concerns, the HSE needs parental consent, preferably from both parents / guardians, to accommodate a child with complex disabilities in a residential placement.
Person-centred and participation	<ul style="list-style-type: none"> • Services will ensure that children / young people / families will be at the forefront of involvement and decision making concerning their care and intervention planning; • While receiving a child formally into State care should be seen as a measure of last resort, if parents have effectively abandoned parental duties, the best interests of children / young people will be the guiding principle to ensure their interests and welfare are being appropriately protected.
Prevention	<ul style="list-style-type: none"> • No child / young person with a complex disability (including a mental health issue) will be taken into State care as a consequence of insufficient service provision (e.g., disability services, CAMHS).
Prioritisation	<ul style="list-style-type: none"> • Children with a complex disability (including a mental health issue) in State care will access Acute Hospital; CAMHS; Disability; Primary Care and specialist services in the same way as other children; • Regarding accessing to these services <ul style="list-style-type: none"> ○ The degree to which identified needs are complex will determine prioritisation (relative to other children needing these services); ○ An 'in care' status must be an additional vulnerability factor that needs to be considered relative to children not in care
Service coordination	<ul style="list-style-type: none"> • In respect to children in care, a named professional from either Tusla (i.e. their assigned Social Worker or Social Care Worker) and/or the assigned health services service co-ordinator (as required when there are complex healthcare needs) will assist children / young people / parents / carers in navigating the healthcare system to meet their identified needs.

Supported decision making	<ul style="list-style-type: none"> • Senior managers will support clinical decision making by trained and competent front-line clinicians; and • While decisions should be made by front line clinicians, management support should be available but not undermine clinical / professional judgement in decision making.
Timely decision making	<ul style="list-style-type: none"> • All decisions should be made in a timely manner and in the best interests of the child.
Working together	<ul style="list-style-type: none"> • Different agencies must work together to meet the needs of children / young people / families / carers in a holistic manner

1.6 Memorandum of Understanding (MoU)

In 2020 the Department of Health and the Department of Children and Youth Affairs (DCYA) signed off on a set of agreed principles in relation to the future responsibilities and funding for children in care or transitioning out of State care. The HSE and Tusla have since signed off on a MoU that is based on these principles. This MoU provides greater clarity in respect of the funding of children in care cases and related clinical/case management responsibilities. It also provides a commitment to children who are not in State care but who fall within the active remit of both Tusla and the HSE. The key components are set out below:

1. While subject to the Estimates process, the cohort of cases in the care of Tusla who had reached and who would reach the age of 18 years in 2020 jointly identified in 2019 by the HSE and Tusla would transfer from Tusla to the HSE (e.g., funding, clinical and case management);
2. All current cases of children with complex disability needs under the age of 18 years (not aged out) will be funded on a 50:50 basis between the HSE and Tusla with effect from 1st October 2020. Tusla will retain case management and governance where this is currently the case and HSE will retain case management and governance where this is the case, until the child reaches the age of 18 (ages out) when the HSE will assume full clinical and case management responsibility.
3. All children referred to above and any new cases will, upon turning 18 years (i.e. ageing out), transfer in full (cost and case/clinical management) to the HSE at age 18 years.
4. A process will be agreed as to when the HSE should take over the funding on a phased basis. This agreement will form part of an estimates bid in conjunction with the DCYA.
5. Any new cases of children in care requiring additional specialist care or services coming on stream, as above will be funded, on a 50:50 basis, until the age of 18 years (ageing out). At the age of 18 years the HSE will assume responsibility for clinically managing care and full funding *subject to available resources*. Prior to age 18 years the management of the case will be agreed by both agencies as per this *Joint Protocol (2020)* i.e. agreed at local operational management level based on the needs of the child. It is anticipated that if the child is in the care of Tusla by order of the Child Care Act 1991 (as amended), Tusla will take the lead role up to the age of 18 years.
6. Children who are not in care but fall within the active remit of both Tusla and the HSE will receive a fully coordinated and joined-up assessment, care plan and interventions as agreed in a joint meeting of operational and clinical personnel from both agencies. This is as per this *Joint Protocol (2020)* and where one agency is clearly leading (as agreed) the other agency will make

available its expertise and resources to assist the lead agency to demonstrate the maximum integration of service delivery as mandated by the Joint Protocol.

7. A process is to be established between the HSE and Tusla at the CHO/Area Manager level to jointly assess and agree cases that are to be included on the National Ability Support System (NASS)⁵ as appropriate.

⁵ The NASS is a database that has replaced both the National Intellectual Disability Database, and the National Physical and Sensory Disability Database. While the HSE and the Health Research Board (HRB) are the Joint Data Controllers for the NASS, the HRB manages its day-to-day operational database management, support and hosting.

Section 2 – Policy and Legal Context

While Appendix D provides a list of policies and legislation that informs this *Joint Protocol (2020)*, this section highlights key policies and an easy reference summary of the key legislation underpinning this protocol.

2.1 Generic Policies

- a) *Children First: National Guidance for the Protection and Welfare of Children* (Tusla, 2017)

This national guidance document underpins all inter-agency work in relation to the protection and welfare of children. It was launched on October 2017, and is a primary reference for all professionals in relation to their legal obligations to keep children safe and how everyone should be alert to the possibility that children with whom they are in contact may be being abused or at risk of being abused. The *Guidance* outlines the roles of the main statutory bodies involved in child welfare and protection: Tusla – Child and Family Agency, and An Garda Síochána. It contains details of how to report a concern about a child and is intended to assist anyone whether a member of the public, a professional, employee or volunteer, in identifying and reporting child abuse and neglect, and to deal effectively with these concerns. It also sets out the statutory responsibilities for mandated persons and organisations under the *Children First Act 2015* (Government of Ireland, 2015) and provides information about how the statutory agencies respond to reports of concerns made about children.

- b) *Meitheal – A National Practice Model for all Agencies working with Children, Young People and their Families* (Tusla, 2013)

One of Tusla’s functions under the *Child and Family Agency Act 2013* (Government of Ireland, 2013) includes maintaining and developing support services, including support services in local communities in order to support and promote the development, welfare and protection of children and to support and encourage the effective functioning of families.

The Partnership, Prevention and Family Support (PPFS) Service in Tusla is delivered directly by Tusla staff and indirectly by a range of agencies based in local communities across the country. These agencies include family support centres and other community based child and family support services and youth services. PPFS services are designed and have been developed to support children and families in need and to prevent the children and families from needing child protection and welfare services. The model which is most often utilised is the “Meitheal” model. Meitheal is about preventative support where children have unmet additional and/or complex needs. In this model, a Lead Practitioner identifies a child's and their families’ needs and strengths and then, if the identified needs require it, brings together a team around the child to deliver preventative support that is outcomes-focused, planned, documented and reviewed over time.

https://www.tusla.ie/uploads/content/Tusla_Meitheal_A_National_Practice_Model.pdf

2.2 HSE Policies

There are a number of significant HSE policies that underpin how the HSE services will work internally together.

- c) *HSE National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* (HSE, 2019)

This policy (HSE, 2019) provides a referral pathway to services for children with disability or developmental delay. Children with 'non-complex' needs will be referred to Primary Care services and children with 'complex' needs to Children's Disability Network Teams (CDNTs). Non-complex needs are defined as one or more impairments giving rise to functional difficulties that result in mild restrictions in participation in normal daily living. Complex needs refer to one or more impairments that contribute to a range of significant functional difficulties that require the services and supports of an inter-disciplinary team.

This policy includes a requirement for a geographically-based Integrated Children's Services Forum (ICSF). This is a meeting of relevant services and disciplines across different HSE services (i.e. Child and Adolescent Mental Health Services [CAMHS], Disability, Primary Care), and representatives of other services as required in line with the child's needs (e.g., Acute Hospital Services; Tusla, Child and Family Agency; Education). These fora provide 'a mechanism for deciding where the child or young person's needs will be best met at any particular time, where it is unclear as to the pathway for a child or young person to receive service(s)' (HSE, 2019, p.22).

The implementation of this internal HSE protocol is essential in the context of this *Joint Protocol (2020)*.

d) *HSE Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services* (HSE, 2017)

The primary goal of this internal joint working protocol is to standardise guidelines regarding the management of cases between Acute Hospital Services, Child and Adolescent Mental Health services (CAMHS), Disability Services and Primary Care Services. More specifically, its primary recommendations include:

1. Ensure clarity of roles and responsibilities of each service;⁶
2. Ensure there is inter-agency cooperation in the sharing of information in a confidential manner as appropriate to support a child's health care needs;
3. Facilitate timely access to services to prevent duplications of referrals and in turn waitlists;
4. Make referral processes more seamless and timely by services collaborating and ensuring open communication channels between parents, service users, and the services themselves;
5. Hold consultation meetings for cases where more than one service will be involved in the care of individuals;
6. Conduct joint assessments for cases where there is a significant possibility of a differential diagnosis or co-morbidity; and
7. An Integrated Children's Service Forum in each area will provide a mechanism that will allow services to discuss cases whose needs are unclear or complex.

The implementation of this internal HSE protocol is essential in the context of this *Joint Protocol (2020)*.

e) *HSE Primary Care Strategy*

This strategy (Department of Health & Children, 2001, p.15) defined primary care as 'an approach to care that includes a range of services designed to keep people well,

⁶ An Acute Hospital working group will clarify the integrated role of the Consultant Paediatrician (0.5 WTE General Paediatrics / 0.5 WTE Community) in relation to geographical areas / populations.

from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social wellbeing’.

Primary Care services play a central role in co-ordinating and delivering a wide range of integrated services in collaboration with other HSE-funded services. Primary care teams are the central point for service delivery that actively engages to address the medical and social care needs of its defined population in conjunction with a wider range of Health and Social Care Network services.

f) HSE Progressing Disability Services for Children and Young People

This national programme (HSE, 2013) aims to provide equitable access to services for all children with a disability through a consistent structure of services across the country. Coterminous with Community Healthcare Networks in each of the nine CHOs, geographically defined Children’s Disability Network Teams will provide services to children with complex needs who have a wide range of disabilities including, but not limited to, intellectual disability, physical disability, sensory disability and autism.

g) Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders (HSE, 2018)

In his role as the Minister of Health, Simon Harris commissioned a review of Irish health services for individuals with ASD. Informed by nearly 400 submissions, over 200 of which came from parents and carers, the resultant HSE report made 36 recommendations. These included timely access to diagnostic assessment by shifting away from highly intensive ASD assessments towards a tiered approach to assessing ASD; and that assessments can take place in primary care with the facility to access more specialist services dependent on presentation. More specifically, the assessment-related recommendations were:

1. Introduce an assessment pathway where all referrals to Primary Care services with query ASD are triaged, resulting either in determining whether ASD is present or absent (as supported by consultation with secondary care colleagues) or onward referral to secondary care services.
2. Introduce a tiered approach to assessment in secondary care services whereby the required intensity of a diagnostic process is determined by the complexity of presenting symptoms and clinicians’ judgement of these symptoms.
3. For co-morbid presentations (e.g., query ASD with moderate-to-severe mental health issues) different secondary care services (e.g., Children’s Disability Teams, CAMHS) will undertake conjoint assessments.
4. Formulate evidence-based guidelines for how privately sourced ASD diagnostic assessments are conducted, and evaluate whether these are adhered to and whether such out-sourcing provides value-for-money.

h) Sharing the Vision: A Mental Health Policy for Everyone

Published by the Department of Health and Children (2020), *Sharing the Vision* is the successor to *A Vision for Change* (Department of Health and Children, 2006). It carries forward those elements of the original policy that still have relevance in-light of expert opinion. It incorporates new recommendations as appropriate to enhance national policy, while simultaneously aligning with the ten-year vision for reform and transformation of Ireland’s health and social care services encapsulated in the

Sláintecare Report (Government of Ireland, 2017).

2.3 Tusla Policy

i) *Tusla National Leaving and Aftercare Policy and Implementation Plan (2017)*.

Section 45 of the *Child Care Act 1991* places a statutory duty on Tusla to form a view in relation to each person leaving care as to whether there is a “need for assistance” and if it forms such a view, to provide services in accordance with the legislation and subject to resources. Young people who have had a care history with Tusla are entitled to an aftercare service based on their assessed needs. The core eligible age range for aftercare is from 18 years up to 21 years. This can be extended until the completion of a course of education in which a young person is engaged, up to the age of 23 years. The introduction of the *Child Care Amendment Act 2015* has strengthened the legislative basis for the provision of aftercare services and imposes a statutory duty on Tusla to undertake an assessment of need for an eligible child or eligible young person. The aim is to create an explicit, as opposed to implicit, statement of Tusla’s duty to satisfy itself as to the child’s or young person’s need for assistance by preparing a plan that identifies those needs for aftercare supports. This Tusla policy document states how Tusla will provide a comprehensive Aftercare service for young people leaving the care of the state.

2.4 Relevant Legislation

The primary legislation that underpins the responsibilities of Tusla regarding taking children into care is the *Child Care Act 1991*. Appendix D lists most of the legislation and regulations that are relevant regarding how best to respond to the needs of children in care. The below bullet points summarise and provide some of the more critical interpretations from the *Child Care Act 1991*, the *Health Act 2007*, and *Child and Family Agency Act 2013*. Drawing from these interpretations, Appendix E profiles a number of challenging scenarios (e.g., where a child with complex disabilities remains in an Acute Hospital beyond medical need) and how to manage these.

- 1. Tusla are the only state body who can take a child into care.** There is no lawful authority for another State body such as the HSE, or a local authority to take steps to take a child into care. Even the Gardaí do not receive a child into care in an emergency – under section 12 of the *Child Care Act*, they deliver the child to Tusla. Tusla cannot delegate this function to other State Bodies.
- 2. Where a child is in Tusla’s care, he/she can be placed in a disability placement.** Only Tusla shall decide how a child in its care can be accommodated. There is a clear legal pathway identified by the *Child Care Act* to permit a placement in a disability residential setting.
- 3. The threshold for receiving a child into care is high.** There must be some form of child protection risk to the child’s health, development, and welfare – which would be avoided if the child was received into care. Similarly, there must be a risk that the child’s needs will not be met unless the child is received into care. The existence of, or likelihood, a negative impact on the child by the parents’ actions, or inactions, are relevant.
- 4. A Child is received into care by Tusla in one of two ways: voluntary care, or by court order.** Voluntary care, is by agreement with both parents, and must be

on the basis of informed consent from the parents. Where such consent does not exist, there is a duty on Tusla to make an application to court.

5. **An application to court will not necessarily be granted.** The application will be contested, and parents have procedural and constitutional rights that must be respected. Tusla are often put on “strict proof” meaning every part of their case must be in oral evidence, and open to cross examination. The court must be satisfied not only that the threshold has been met (*i.e. an avoidable risk to the child’s health development and welfare*), they must also satisfy the court that it is necessary, and proportionate to bring this application i.e. nothing other than care will do, and that other options have been considered.
6. **“Abandonment” of a Child does not necessarily reach the threshold for an interim care order.** There have been situations where a parent has refused to accept a hospital discharge of their child or where children are not collected from school or respite services. These cases are often linked to a parental perception that they are not able to care for their child or that they are not receiving adequate support (e.g., respite etc.) to enable them to care for their child.⁷ While abandonment has yet to be defined legally, the threshold for State care may be met if the parent has abdicated their parental responsibilities (e.g., never visits; never engages in the process of assessment; nor is never available to clinicians to make decisions).

Alternative scenarios include where the parent *is* actively involved in all decisions and has not abdicated their parental responsibilities but cannot allow their child to return home until supports are in place – that may not reach the threshold for an interim care order. It is a matter of degree, and there is no clearly defined rule. An assessment and interagency cooperation will assist in identifying how the child’s needs can best be met.

7. **Absence of threshold for court order does not mean no intervention.** Tusla Act 2013 notes that Tusla has a responsibility to take children into care where necessary. However, other responsibilities include making all reasonable efforts to prevent children coming into care; promoting proper family functioning; and promoting the development, welfare and protection of children. This does not exclude children with a disability, or the families of children with a disability.
8. **The HSE can accommodate a child in a disability placement – with parental consent.** Such a child is not “in care.” Instead the child is receiving support with parental consent. The parent is in full control, and if he/she wants the return of the child it must be facilitated (*subject to the usual child protection concerns, and medical advice*). Any such parental consent must be informed and active. The ‘Jack’ report points out that reasonable efforts must be obtained in order to ensure that both parents consent.
9. **HSE “home sharing” placements are not regulated and are not on a legislative footing.** This is a matter which will need future attention. Until placements are regulated and there is a related legislative footing, some form of inspection or

⁷ For a variety of reasons, some parents decline home-based supports such as in-home respite. A potential alternative model of respite would be after school care up to 8pm Monday to Thursday.

monitoring is necessary by the HSE, possibly in accordance with whatever arrangement they have made (e.g., Section 39). One of the failings recognised by the 'Jack' report was that the mother did not know of the Expert Group's concerns in 2016.

- 10. Tusla are required to facilitate and promote enhanced interagency cooperation.** This is to ensure that services for children are co-ordinated and provide an integrated response to the needs of children and their parents. Tusla Act recognises that there are disciplines and expertise that other State bodies have, and Tusla must call upon them to promote the needs of children.
- 11. Disputes at all levels between the HSE and Tusla should be addressed via this *Joint Protocol (2020)*, rather than through the court system.** It is inappropriate for one State Body to seek an order compelling a service from another State Body in a court setting. This *Joint Protocol (2020)* provides pathways for arbitration and mediation of any dispute.

2.5 Ward of Court proceedings

Wardship proceedings can be initiated for a number reasons that are valid and required. It is however inappropriate to initiate Wardship proceedings to force either agency to fulfill their obligations under the legislation, regulations or this protocol. The system for escalation of unresolved issues to the AJWG and Regional Management must be utilised to resolve inter-agency disagreements. This applies to all HSE services (including the Acute Hospital Groups), and to all regions and areas within Tusla.

No case should be referred into the Courts or Legal system without being escalated as per this *Joint Protocol (2020)* and without agreement of the HSE and Tusla National Leads for implementation of this *Joint Protocol (2020)*.

Section 3 – Level #1: Local Joint Working with Individual Cases

3.1 Inter-agency Collaboration

Where there is a reasonable expectation that cases will require both health service and Tusla, Child and Family Agency input, staff in each agency must fully commit to proactively identifying these cases and engaging in joint working regarding clinical meetings, statutory reviews and service provision, dealing with issues, etc. At local level, decisions should be made by the practitioners from both agencies involved in managing each case. Tusla practitioners and first line managers will liaise as appropriate with the appropriate HSE personnel and managers (e.g., Children's Disability Network Managers/CDNT) to identify and resolve any issues in line with best practice, this *Joint Protocol (2020)* and the 2020 MoU (see Section 1.6). Likewise, health service personnel will engage with the Tusla department managing each case (e.g., PPFs; CPW).

All children in statutory care (subject to a care order)⁸ are allocated a Tusla Social Worker who oversees the implementation of the care plan for the child. The assessment of the child's may require the HSE services to meet the health care needs of the child. From a healthcare perspective, children with non-complex needs⁹ will be referred to their local HSE Primary Care Team, while those with complex needs¹⁰ who require more specialist care will be referred to the appropriate specialist service (e.g., Acute Hospital; CAMHS; CDNT (Disability); palliative care services). As these Primary Care and specialist services are not otherwise available within Tusla both agencies must work together in a timely and proactive manner to facilitate the best potential outcomes for children in care with a complex disability. Such joint working will also be required for those vulnerable individuals with non-complex disabilities.¹¹

Informal consultation for advice and direction in regard to specific expertise must be provided as appropriate by practitioners and colleagues in the various HSE services and Tusla. Where a practitioner has concerns or identifies a need for intervention from another HSE service or from Tusla, she/he must liaise with the relevant practitioner and agree a process for inter-agency engagement and collaboration. In the event of specific issue such as High Court cases, HIQA inspections, Ombudsman for Children recommendations, etc., the appropriate managers will work collaboratively to implement the required service improvements.

Joint working will be governed by the requirements of *Children First* (Tusla, 2017) and this *Joint Protocol (2020)*. When issues of child welfare and protection arise, early engagement should be as immediate as the same working day where harm has occurred, or within one week where an emergency child protection plan is required or Court matters need to be addressed. The fundamental principle is that both agencies are committed to optimal engagement in the best interests of the child, and the minimisation of avoidable and inappropriate applications to the Court.

Expanding beyond the HSE and Tusla, proactive engagement is required with other

⁸ Children who are in voluntary care are jointly managed by the child's parent(s) and Tusla.

⁹ Those with one or more impairments giving rise to functional difficulties that result in mild restrictions in participation in normal daily living.

¹⁰ Those with one or more impairments that contribute to a range of significant functional difficulties that require the services and support of an inter-disciplinary team.

stakeholders. The latter includes voluntary providers, representatives from statutory teams, and other services (i.e. educational support staff, etc.) to ensure that all agencies work together to ensure the best possible outcome for each child and their family.

Likewise, HSE CHOs need to ensure full implementation of the HSE (Internal) *Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services* (CAMHS; 2017) so as to ensure that different HSE services work in a collaborative manner with regard to children in care. (please see page 8 above)

3.2 Care Planning

An interagency meeting can be called by **any** HSE service or Tusla, Child and Family Area to develop or update a joint care plan. Once convened such meetings will consider a range of issues including:

- Identification and agreement as to the Lead Agency and the ‘service coordinator’ professional;¹¹
- Identification of treatment interventions that need to be delivered;
- Notification to line management when an identified need cannot be met;
- Committing to make all reasonable efforts to resolve identified issues, while ensuring minimal delay in responding to the needs of the child; and
- Where line management cannot resolve an identified issue (e.g., due to lack of resources or some other impediment), escalation of the issue to the next level (e.g., Area Joint Working Group) as per this *Joint Protocol (2020)*.

The Care Plan or an addendum thereto, needs to clearly show which agency / service is dealing with each intervention element; the actual intervention/service being provided; resources; costs; and the funding agency.

3.3 Child in Care Review meetings

Under the Child Care (Placement of Children in Foster Care) Regulations 1995, Part III, social workers, in consultation with the children, their families, foster carers/residential centre and significant others draw up comprehensive, written care plans for children before they are placed or in the case of an emergency placement, within 14 days. Periodic reviews of the Care Plan for children in the care of the state take place within legally defined time limits.

While cases of children in care might, be discussed at a HSE-led Integrated Children’s Services Forum for initial signposting as to what services may be required to provide assessment and intervention, subsequently these cases will be reviewed at a statutory Tusla-led ‘Child in Care Review’ meeting. The latter will be attended by stakeholders critical to meeting the needs of each child and his/her family. In cases where a child in care has a (complex) disability, relevant HSE service front line nominees who are familiar with the child in question will attend a ‘Child in Care Review’ meeting; and the format of these meetings can be adjusted as appropriate (e.g., incorporate into each meeting a sub-section on the health care needs of each child).

To ensure appropriate attendance at Child in Care Review meetings, Tusla first line

¹¹ A nominated health service or Tusla, Child and Family professional will provide a generic ‘service coordinating’ function for each child with a disability in care. Other terms used to describe a similar function include ‘key working’ and ‘care coordinator.’ This individual will help to streamline contact (e.g., coordinate appointments) and ease the pressure on families to engage with a multiplicity of staff.

managers will liaise with the appropriate HSE managers (e.g., CAMHS; Children's Disability Network Managers; Primary Care Managers).

3.4 Aftercare Planning Process

Tusla, Child and Family Agency Local Aftercare Steering Committees (that include relevant health service professionals¹² and other service providers) manage aftercare planning for both short-term and long-term supports up to the age of 21 years (or 23 years if remaining in education or training) for young people in care presenting with complex needs aged 16-to-18 years. Care planning during this transitory period is a necessity to ensure the necessary supports are in place on discharge from statutory care and commencing adulthood. As per Tusla's *National Leaving and Aftercare Policy and Implementation Plan (2017)*, planning needs to commence with referral to the Local Aftercare Steering Committee on the young person's 16th birthday.¹³ This process provides a forum for highlighting those in most need of services after their 18th birthday and informs services of budgetary provision and resources required in advance. Also, both agencies need to collaborate closely when non-statutory placements are being sought for children and young people with additional complex health care needs. Late entrants to care post 16 years of age with complex health needs may pose a planning challenge and may require an immediate or more urgent interagency response.

Some young people turning 18 who have been in foster or residential care may be more vulnerable due to the impact of a complex disability (including mental health difficulties), addiction issues, and/or complex health care needs etc. A strong multi-agency collaborative approach is essential for this cohort of young people including, appropriate notification of abuse concerns for vulnerable young people leaving the child in care system to the relevant health services and the HSE Safeguarding and Protection Team. It is important that this collaborative approach in aftercare planning process incorporates the capacity of Tusla's aftercare service to co-ordinate safeguarding planning and share information on any known safeguarding risk factors about their current/proposed carers or living arrangement.

Effective collaboration and information sharing also applies to children turning 18 years who are subject to a child protection plan and who would be deemed a vulnerable adult post 18 years of age. Sharing of information may also include young people known to Tusla who may pose a safeguarding risk to vulnerable adults (i.e. in the family home).

Where a child with a complex disability, approaching their 18th birthday, needs residential supports, both agencies need to work together to assess the placement needs of the child and plan jointly to meet those needs.¹⁴ There are a range of options which may need to be considered including the child remaining in the current placement if this is both desired and deemed appropriate. Consideration should be given to how the placement is funded with reference to the HSE/Tusla Memorandum of Understanding (2020). Other placement

¹² For example, Occupational Guidance Officers are well placed to contribute to Aftercare Steering Committees.

¹³ See Appendix D – Process map for consideration in cases concerning the ongoing welfare and support needs of a young person entering adult services.

¹⁴ Ideally there should be a review process for a ward of court application for all children in State care who are ageing out, and who have a moderate / severe / profound intellectual disability.

options may include sheltered housing; supported lodgings; Home Sharing;¹⁵ and independent or semi-independent living etc.

3.5 Communication

Clear and professional communication standards enhance joint working. The local professionals involved in joint working will determine the process and protocols needed with regard to communication, that will be based on existing local arrangements/systems and take cognisance of local, area, regional and national requirements. Information handling policies and data protection regulations will be adopted under agreed terms of reference to support this protocol in each local area. A National Data Sharing Agreement will be drafted as soon as reasonably practicable. Referrals between professionals will be acknowledged and engagement, response or decision will commence within agreed timelines from receipt of the referral. Where a decision has been made regarding the most appropriate service provider, this decision will be communicated to the referrer and copied to the relevant health service / Tusla Area without delay, detailing the rationale for the decision. If the service provider to whom the referral is made is not in a position to provide services that are considered critical to the safety of the child and family, that service provider must notify the referrer immediately and the case must be escalated appropriately.

3.6 Confidentiality and Information Sharing

Each service will ensure that the highest professional standards are maintained in relation to confidentiality, and any information sharing will have the appropriate informed consent. In this regard, all relevant personnel will be cognisant of the requirements under *Children First* (Tusla, 2017), *Safeguarding Vulnerable Persons at Risk of Abuse* (HSE, 2014) and other obligations in relation to freedom of information, data protection and the *General Data Protection Regulation* (GDPR; European Commission, 2018).

Even in the context that Tusla, will share its register of children in care with a disability¹⁶ with the HSE on a quarterly basis, some health services may not immediately be aware that a child is in State care. Hence, it is important that both agencies communicate on a need-to-know basis around what children with a complex disability are in care at any given time. It is also important that other key agencies involved in providing health care are given appropriate information in the context of meeting children's care needs.

3.7 Identifying Lead Agency and Coordinating Professional

Where children are in the care under the *Childcare Act 1991*, the lead agency will be Tusla. For children who are not in the care under this legislation, a lead agency and 'service coordinating' professional must be mutually agreed. The Lead Agency will most likely be identified firstly and will normally be the service that has the largest involvement in a case. There will be recognition that the identified 'service coordinating' professional and Lead Agency may change over time depending on the circumstances of the case. Consideration will be given to which professional or service provider will be the long-

¹⁵ Home Sharing can take several forms including (1) Home Sharing 'Short breaks'; (2) Home Sharing 'Contract Families' whereby a contracted family offers regular short breaks; (3) Home Sharing 'Shared Living' families that is similar to a foster placement arrangement (HSE, 2016).

¹⁶ Tusla's National Child Care Information System (NCCIS) records several types of disability (i.e. mental, psychological, personality disorders; other; physical disability; sensory disability; and specific learning disability) according to different levels of severity (i.e. mild; mild-to-moderate; moderate; moderate-to-severe; severe).

term care provider and a decision will be made in this regard. As agreed with the Lead Agency, all professions and agencies are obliged to remain involved in the management of the case and to actively contribute to the required service solutions. There are times when a joint co-ordination approach may be required on certain complex cases. The 2020 MoU further clarifies each agencies responsibilities under this section (see Section 1.6).

3.8 Management of Costs

The arrangements for funding of services and placements are clearly established in the 2020 MoU (see Section 1.6). At the individual client level, interventions will be provided from each agency's existing resources and all services identified in the Care Plan will make provision for the service within the allocation of their resources.

Each HSE Chief Officer should consider delegating to a senior manager the authority to make all funding decisions related to all cases (whether they are escalated or not). The purpose of this recommendation is to ensure timely and efficient decision making with regard to cases under consideration.

Each Tulsa Regional Service Director will make such decisions (or nominate a senior manager to do so).¹⁷ Each nominated manager will operate within a rule set for signing off on budgets (e.g., up to a certain budget threshold; the principle that the geographical area of origin maintains the responsibility for funding any out-of-area placements, and for the planning and funding of adult placements wherever the appropriate location is agreed to be).

3.9 Escalating of Disputes

In situations where differences arise in relation to the management of a case and a local joint decision cannot be agreed, the practitioners from the different HSE services / Child and Family Agency Areas must make every effort to resolve them so that appropriate interventions can proceed. Where this cannot be agreed (e.g., due to a lack of resources or some other significant impediment), the matter must be escalated as per this *Joint Protocol (2020)* to the Area Joint Working Group (AJWG i.e. Level #2).

Where significant additional resources are required and needs cannot be met within existing local or regional resources (and all alternatives have been explored), local practitioners can submit a business case for relevant cases (through their respective line management structures) to their HSE Chief Officer and Tulsa, Child and Family Agency Regional Service Director (i.e. Level #3) for resolution. At a minimum, such a business case must include details of the issues, actions to date, options and costing where appropriate; and be co-signed by all relevant parties. Where additional funding requirements cannot be met at this level, further escalation is required to HSE National Heads of Operations / Child and Family National Director of Services (i.e. Level #4). Please refer to the 2020 MoU for further details of funding arrangements (see Section 1.6).

¹⁷ All decisions need to be informed by presenting need and are dependent on available resources which are finite.

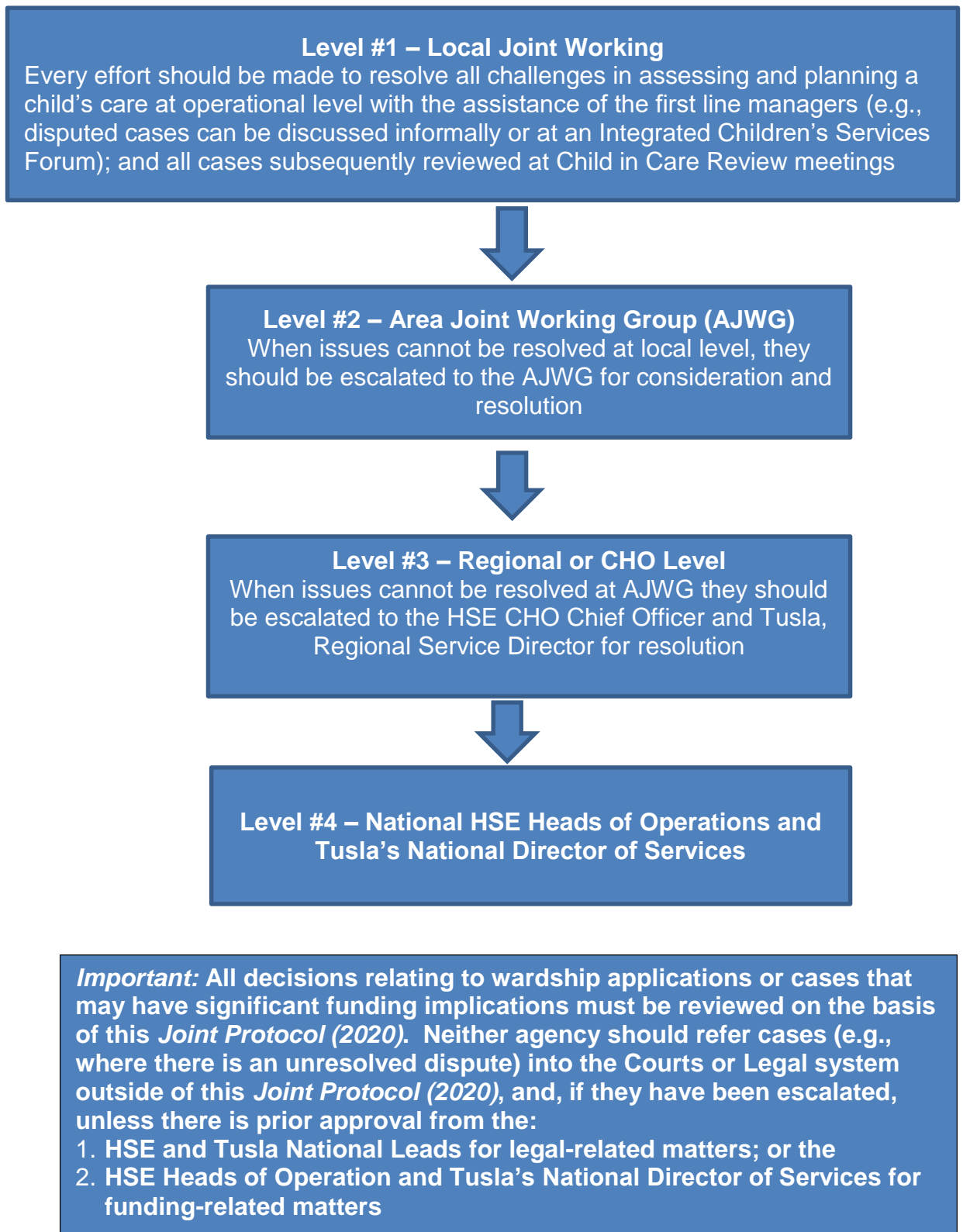


Figure 1. Flow chart for addressing issues related to this *Joint Protocol (2020)* for children in care with a complex disability.

Section 4 – Level #2: Joint Working at CHO / Area Level

4.1 Purpose and Function

The purpose and function of the Area Joint Working Group (AJWG) is to ensure that joint working at a local level is effective and efficient to improve outcomes for children and families. It also acts as an early warning system where senior managers in partner services/agencies are alerted to issues at the earliest possible opportunity; and it ensures that actions taken are in line with national policy.

Objectives:

- Identify most important priorities and ensure that different health services and Tusla, Child and Family Agency Areas coordinate their efforts and develop shared responses;
- Identify what each health service / Tusla, Child and Family Agency Area is doing in their area with associated gaps and blockages and agree solutions;
- Ensure individual complex cases that are unresolved by local joint working are managed appropriately i.e. referred back to local practitioners with direction or recommendations for further resolution or addressed by the AJWG in regard to specific issue (e.g., decision on funding / resources or approach to Court);
- Ensure joint issues such as aftercare will be routed through this process;
- To identify gaps in service provision with a view to informing strategic planning in both organisations; and
- In exceptional cases where a situation cannot be resolved at this level, to escalate the matter to the CHO Chief Officer/Tusla Regional Service Director level. The AJWG must evidence all reasonable attempts to resolve, in a timely manner, outstanding issues before escalating the matter to the CHO Chief Officer/Tusla Regional Service Director level.

4.2 Complex cases

Practitioners involved in joint working on individual complex cases can refer unresolved matters for advice or submit a business case agreed locally in accordance with this protocol to the AJWG.

4.3 Terms of Reference

- Provide oversight and appropriate co-ordination of specific cases, e.g. where more than one health service / Child and Family Agency Area is involved; cases involving Court proceedings, the Ombudsman, HIQA; etc.
- Identify children already known to other services
- Agree priority recommendations
- Identify lead agency and coordinating professional(s)
- Ensure associated local assessment process and guidelines are adhered to
- Clarify management of resources and budget
- Agree priority recommendations and roles especially for a young person transitioning to adult services where there may be any safeguarding issues

4.4 Membership of Area Joint Working Group

An Area Joint Working Group consisting of representatives from Tusla, Mental Health, Disabilities, Primary Care services will meet on a monthly basis or less as referral rates indicate to discuss unresolved cases escalated to it. Staff representatives at the appropriate levels will be identified from each of the health services and Tusla as follows:

- Acute Hospital Group: Representative
- Child and Family Agency: Area Manager and managers from CPW, Children in Care and PPFS as deemed appropriate by the Area Manager
- Disability: Disability Services General Manager¹⁸
- Mental Health: Business Manager
- Primary Care: Operations Manager/Community Health Network Manager nominee

4.5 Chair

Joint Chair: Area Manager, Child and Family Agency and HSE CHO Head of Service (i.e. Mental Health, Disability and Primary Care).

4.6 Area Level Process

- Monthly meetings will have minutes taken and shared as appropriate, with a mechanism for addressing emergencies
- Referral as appropriate to other agencies in specific cases
- Care options to be explored based on consideration of the business case including presentation of clinical need
- Recommendations made for local practitioners to implement
- Management of costs/joint budgets – existing resources
- Review mechanism will be established

4.7 Escalation to HSE Chief Officer / Tusla Regional Service Director Level

There is an expectation that decisions will be made at local team level regarding the provision of access to appropriate, available services. If this is not possible for whatever reason then a business case must be prepared, identifying options and costing where appropriate, and signed by all relevant parties. The business case will be progressed to respective HSE Chief Officer and Tusla, Child and Family Agency Regional Service Director for decision. In exceptional cases, where agreement cannot be reached, representations may be made to national management level. The HSE CHO Manager and Tusla Regional Service Director will designate an appropriate manager within their respective offices to make decisions in respect of funding of services to avoid unnecessary delay under the protocol and the MoU (see Section 1.6).

¹⁸ Section 38 / 39 agencies also need to actively participate in Area Joint Working Groups, while others such as Children's Disability Network Managers may be asked to contribute.

Section 5 – Level #3: Joint Working at HSE Chief Officer / Tusla Regional Service Director Level

5.1 Purpose and Function

The overarching role of the HSE CHO/Tusla Regional Service Director Joint Working Group is to provide a mechanism to address capacity issues (resources human or financial); for dispute resolution; to ensure an early warning system is in place; and to ensure actions taken are in line with national policy.

5.2 Referral Pathway

Referrals to the HSE CHO / Child and Family Joint Working Group are received in regard to unresolved issues at Area level (i.e. Level #2; see diagram in Section 3.9)

5.3 Terms of Reference

- Oversight of costs/joint budgets
- Review of individual cases where issues cannot be addressed at Area (AJWG) level
- Sharing and dissemination of good practice
- Review and action as appropriate of reviews/reports (HIQA, Ombudsman, etc.)

5.4 Membership

- Tusla, Child and Family Agency Regional Service Director and other Managers (as required and deemed appropriate by the Regional Service Director)
- HSE CHO Chief Officer
- HSE CHO Head of Primary Care Service
- HSE CHO Head of Disability Service
- HSE CHO Head of Mental Health Service
- HSE Acute Hospital Group representative¹⁹

5.5 Chair and Authority of Final Decision Making

Joint Chair (i.e. Child and Family Agency Regional Service Director and HSE CHO Chief Officer).

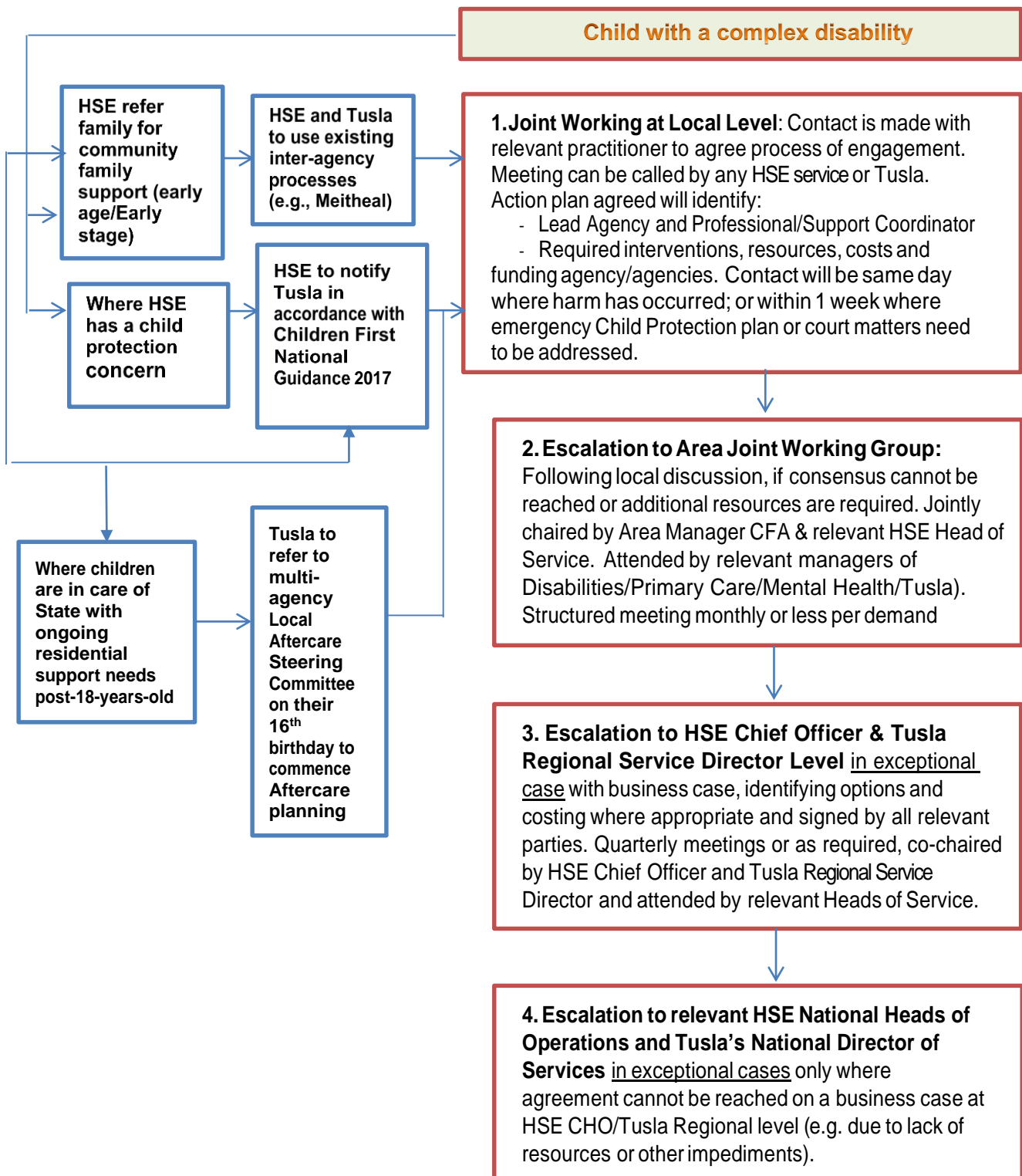
5.6 Escalation process

The HSE CHO Chief Officer / Tusla Regional Service Director Joint Working Group will review all business cases submitted by the AJWG for decision. In exceptional cases where agreement cannot be reached on a business case, the case will be escalated to the relevant HSE National Heads of Operations and the Child and Family Agency National Director of Services.

¹⁹ Many of the acute hospitals in an Acute Hospital Group serve a number of CHO areas.

5.7 Protocol Process

The following diagram represents the working protocol as a flow chart. As part of the process there will be quarterly meetings, minutes taken, and shared as appropriate, with a mechanism for addressing emergencies (see also diagram in Section 3.9).



Section 6 – Level #4: HSE National Heads of Operations / Child and Family National Director of Services

Responsibility for exceptional cases that have been escalated and remain unresolved will rest with the relevant HSE National Heads of Operations and Tusla, Child and Family Agency National Director of Services to agree a resolution on unresolved disputes.

6.1 Tusla, Child and Family Agency Register

Tusla will retain a register of children in care with a disability. This register will be shared with the HSE on a quarterly basis to ensure that the HSE are constantly updated on the evolving needs of this cohort of children. This sharing of information will be governed by a robust Data Sharing Agreement. Furthermore, the HSE will be notified by Tusla, Child and Family Agency when a child reaches their sixteenth birthday so that appropriate planning can be made for onward care as required. While Tusla may notify the HSE sooner a child's sixteenth birthday (where it is deemed appropriate), it must notify the HSE of the pending transition when the child turns 16 years old.

There is a broader requirement for HSE to be aware of the numbers of young people in Tusla's care requiring onward residential or long-term adult family placement (based on appropriate assessment of their disability needs) so that that HSE can factor these costs into the annual Estimates process.

6.2 Management of escalations

All decisions relating to wardship applications or cases that may have significant funding implications must be reviewed on the basis of this *Joint Protocol (2020)*. Neither agency should refer cases (e.g., where there is an unresolved dispute) into the Courts or Legal system outside of this *Joint Protocol (2020)*, and, if they have been escalated, unless there is prior approval from the:

1. HSE and Tusla National Leads for legal-related matters; or the
2. HSE Heads of Operation and Tusla's National Director of Services for funding-related matters.

Section 7 – Implementation Plan

In order to embed this protocol into everyday practice staff must be made sufficiently aware of its existence. Each Area/Region will take responsibility to implement the protocol at operational level with clear endorsement by HSE CHO Chief Officer's senior management groups; Hospital Group Chief Executive Officers (CEOs); and Tusla Regional Service Directors.

In addition, an implementation plan will be developed that will address the following:

1. HSE Chief Officers, Tusla Area Managers and Hospital Group CEOs will jointly organise implementation workshops with relevant stakeholders and staff personnel;
2. Relevant ongoing training will be provided to ensure collaboration and relationship building;
3. Required additional resources will be identified to address unmet need and to support implementation of the local cross divisional resolution structures and the 17 Local Area Aftercare Steering Groups;
4. Required additional resources will be identified to support young people with disabilities moving to appropriate adult accommodation and provision after their 18th birthday;
5. The National HSE/Tusla Oversight Group will continue to oversee implementation of this *Joint Protocol (2020)*; and
6. Existing early intervention family support pathways and approaches for children, young people and their families with complex disability will be reviewed.

Section 8 – Evaluation and Audit

Ongoing evaluation and review of this *Joint Protocol (2020)* will be necessary to ensure its successful implementation and to evidence that it is meeting its intended objectives.

The National HSE/Tusla Oversight Group convened by the National HSE Management Team in partnership with Tusla, will meet on a three-monthly basis to monitor, assess and recommend revisions as necessary based on analysis and the experience at local and regional level. The Group will also provide on-going support to local CHOs / Hospital Groups / Tusla areas. This Group will include HSE service representation from Acute Hospitals; CAMHS; Disability; and Primary Care.

8.1 Work Programme of National HSE/Tusla Oversight Group

The work programme of this group will include:

1. Track the roll-out of implementation plan including briefings and workshops at local level. Audit levels of engagement and collaboration at local level and measure if this *Joint Protocol (2020)* is working effectively at front line in a consistent and standardised manner;
2. Advise Area Joint Working Groups on how interagency challenges in areas such as child protection/welfare threshold criterion, role clarification, referral responses and capacity constraints could be addressed;
3. Consider future joint learning opportunities and further work in relation to the inter-agency challenges and opportunities;
4. Consider further developments to strengthen local collaboration;
5. Support local / regional structures in profiling the various cohorts of children that fall under this *Joint Protocol (2020)*;
6. Support local / regional structures in implementing the HSE/Tusla MoU (see Section 1.6); and
7. Work with local / regional structures in monitoring expenditure and providing an evidence base for funding projections.

Section 9 – Potential Work Processes

To illustrate the intended implementation of this *Joint Protocol (2020)*, the following profiles how to manage case examples that have previously challenged practitioners and managers. These solutions are based on best practice having regard to both this *Joint Protocol (2020)* and the Memorandum of Understanding; and should be utilised to resolve future challenges. In the unlikely event that practitioners and first line managers cannot resolve the issues related to specific cases, these need to be escalated to the Area Joint Working Group as per this *Joint Protocol (2020)*.

#1 Early Intervention for children with a complex disability

Where the health services are supporting a child with a complex disability, providing comprehensive help at an early age or at the early stages of the intervention can prevent the child's needs overwhelming families over time. Where the health services identify the need for additional support for the family in their day-to-day care of their child, as the lead agency, they need to work together with Tusla's PPFS service to see how the child can be supported from the range of community family support services that are in place. Where appropriate a Meitheal could be convened with the consent of the family:

https://www.tusla.ie/uploads/content/Tusla_Meitheal_A_National_Practice_Model.pdf

#2 Required additional support

Where a family is feeling overwhelmed as a result of caring for a child with a complex disability or for a child with a non-complex disability where there are additional vulnerabilities (e.g., parental mental health difficulties), additional family support may be required. In such instances, both agencies (i.e. Tusla's PPFS service) need to work together to assess the specific unmet additional needs of the child and his/her family. This could take the form of an application for a Meitheal assessment to a Tusla Child and Family Network Co-ordinator. Informed by assessment findings, both agencies need to work together to compile a family support plan or IFSP. The responsibility for delivering on the plan needs to be agreed between the professionals in both agencies. A lead practitioner, typically the individual who has the most day-to-day contact with the child and his/her family, will be assigned to coordinate related supports. Relevant health services could also provide a wide continuum of supports.

Where there is a significant resource implication in the delivery of the care plan, the operational managers need to agree the arrangements for funding the plan from existing resources. Where this is not achievable, the care plan needs to be referred to the AJWG (i.e. Level #2) for discussion and resolution; or, if necessary, to regional structures (i.e. Level #3).

https://www.tusla.ie/uploads/content/Tusla_Meitheal_A_National_Practice_Model.pdf

#3 Parent unwilling or unable to take a child home

Where the parents of a child with a complex disability are either unable or unwilling to care for their child in their home, no child should remain in an inappropriate setting (e.g., acute hospital or respite placement) beyond medical need. For example, to minimise any delay in a child's discharge from hospital (beyond medical need), both health services (including, where appropriate, the Acute Hospital manager) and Tusla must actively engage with the child's parents and each other to identify the most appropriate supports for the child.

Critical to these discussions is for a nominated health service contact who has a good working relationship with the family to meet with the parents to ensure the immediate safety and welfare of the child; and to understand their reluctance to take their child home. Every effort should be made to use all resources available to support the family in whatever way possible.

Where the health services have exhausted all options in relation to resolving the situation and where the parents remain either unable or unwilling to care for their child in their home, the health services will have to consider their responsibilities under *Children First: National Guidance for the Protection and Welfare of Children* (Tusla, 2017). However, one of the underpinning principles for Children First is that a proper balance must be struck between protecting children and respecting the rights and needs of parents/guardians and families. The reasons for the parent refusing to take the child home need to be considered carefully in this regard.

If a referral is made, the assigned Tusla Social Worker will conduct an assessment that will include exploring what support the family is seeking. This could include wrap-around support (e.g., including respite); or possibly an alternative care placement for their child (e.g., foster care; residential placement) under a voluntary Care Order. Where parents are requesting an alternative care placement with Tusla, Tusla (in consultation with the health services) will assess whether a placement under the *Child Care Act 1991* is appropriate and in keeping with the best interests of the child.

A child cannot be considered to have been abandoned if the parent or parents continue to be present and to advocate for appropriate services including support and respite for the child to assist the parents in caring for the child.

If there are no child protection issues, the health services will take the lead responsibility. In situations where a parent abandons a child (see Section 4 and 8 of *Child Care Act, 1991*) with a disability or complex health care need, both agencies need to work together to identify and support an appropriate placement for the child. Consideration should be given to the most appropriate legal option to support the child in an alternative care placement (i.e. voluntary care or a care order).

Where there is disagreement between the health services and Tusla practitioners (e.g., Social Workers; therapeutic staff) as to which agency has to lead on a particular case and the appropriate course of action (e.g., who funds a care placement), the matter must be immediately escalated to the local AJWG (i.e. Level #2) for discussion. If there is no resolution at AJWG level, the matter must be escalated to regional level (i.e. Level #3) for consideration as per this *Joint Protocol (2020)*.

The cost of the service provision including any placement may have to be shared as per the HSE/Tusla MoU (see Section 1.6).

#4 Young adult with a non-complex disability

There may be cases of young adults with a non-complex disability that do not technically fall under the remit of this *Joint Protocol (2020)*. For example, a just turned 18-year-old with a mild intellectual disability – a case that would typically be appropriate to HSE Primary Care Services – who has been in voluntary care with Tusla for a number of years due to reported behaviours that challenge his / her care. For such young adults, Tusla will have the lead responsibility to support and, where

appropriate, identify an appropriate aftercare placement. The health services through appropriate services also need to assist and support these young adults in respect of their health and social care needs.

#5 Aging out and foster care case

If a child in foster care reaches the age of 18 years and is in education or training, Tusla may provide an aftercare allowance that can sustain the foster placement as an aftercare placement subject to fulfilling the requirements of the regulations and guidance. However, if the young person is not in education and training, Tusla and the health services must assess the young person's placement needs and explore all options for the young person's continued placement. All options need to be considered, including, as guided by the young adult's preferences, continuation of the foster placement (as funded by the health services); sheltered housing; supported lodgings; some variant of Home Sharing; or independent or semi-independent living etc.

#6 Wardship proceedings and aging out in care

Young people in care will have a care plan which will be reviewed on a regular basis. The decision to make an application for wardship for a young person leaving the care of the state should form part of the discussion at the Child in Care statutory review when the young person is 16/17 years old; and is centred on whether the young adult lacks capacity and will be capable of managing his/her own affairs and will require long-term adult residential care. The Child Care Amendment Act 2015 places a responsibility on Tusla to prepare an aftercare plan following an assessment of need.²⁰

Where these concerns in relation to the young person's capacity when they reach adulthood, it is vital that these young people are identified in care at an early stage (when the young person is 16/17) so that the assessment of need under the *Child Care Amendment Act 2015* is multi-disciplinary and that the appropriate personnel from the health services are involved. Where Wardship proceedings are being actively considered the young person should also be referred for discussion to the (local) Area Aftercare Steering Committee that is a multi-disciplinary, multi-agency forum for planning, implementing and monitoring a comprehensive, integrative aftercare plan for young people/young adults in receipt of aftercare. If necessary, where there is dispute, cases may be escalated as appropriate in line with this *Joint Protocol (2020)*, in the first instance to the AJWG (i.e. Level #2).

#7 Complex disability dispute

In the event where there is a dispute in respect of the complexity of a child's needs and whether they reach the threshold for consideration under this *Joint Protocol (2020)*, a second opinion from an agreed professional may be jointly sought and the assessment findings from this second opinion should be accepted. If necessary, such cases may be escalated as appropriate in line with this *Joint Protocol (2020)*, in the first instance to the AJWG (i.e. Level #2).

#8 Aging out and aftercare plan dispute case

On occasion there may be health service/Tusla disagreement as to what supports a young adult with a complex disability in a residential placement needs when they turn 18-years-old. For example, Tusla might want the health service to continue to fund

²⁰ This 'assessment of need' is different from the 'Assessment of Need' legislated for under the Disability Act 2005.

the young adult's existing residential placement, whereas the health service might assess the child as needing a different type of residential placement or different supports altogether (e.g., no residential placement). To minimise the possibility of inter-agency disputes and delays in providing care, the (inter-agency) Leaving and Aftercare Steering Committee needs to actively review the needs of such children when they turn 16-years-old. This will necessitate both agencies working together during the two-year transition period up to the young adult's eighteenth birthday to agree what supports will be offered to them when they turn 18-years-old. If agreement cannot be reached at an early stage during this two-year period, or if the health service notes that it does not have the budget to fund aftercare arrangements (e.g., a residential placement), the case needs to be escalated to the AJWG (i.e. Level #2) long before the child turns 18-years-old. If such cases cannot be resolved at the AJWG, they must again be escalated, in the first instance to regional structures (i.e. Level #3).

#9 Cross Area / Region Placements

Where a child is placed in a geographical area/region which is not within their area of habitual residence, it is incumbent upon the placing agency (i.e. either the health service or Tusla) to ensure that the new area is aware of the child's placement and that both geographical areas work together to ensure that this *Joint Protocol (2020)* is implemented in the interests of achieving the best outcomes for the child. This is likely to involve the placing agency liaising with both the health service and Tusla managers in the new area, including ensuring that an incoming child is not placed at the bottom of an existing waiting list (e.g., for assessment / intervention). As per this *Joint Protocol (2020)*, where agreement cannot be reached, all stakeholders need to consider accessing the AJWG (i.e. Level #2) and, if necessary, regional structures (i.e. Level #3) within the new area/region.

#10 Voluntary care placements

Where a child with a complex disability is placed in a residential setting outside of the Child Care Act 1991 with parental consent, intervention will be as per the child's Individual Family Support Plan. Ideally the latter will address how to re-integrate such children back into their naturalistic supports of their family-of-origin and extended family in a manner that protects them and ensures their safety. While Tusla will be not responsible for reviewing such placements, they will be available to the relevant health services for informal advice and consultation in relation to applying best practice standards to the oversight and review of the child's placement. If parental consent is withdrawn and there are reasonable grounds for concern that this will result in harm to the child, consideration must be given to submitting a report to Tusla (as per *Children First: National Guidance for the Protection and Welfare of Children 2017*).

Appendix A – Recommendations from Ombudsman for Children (2020) re. ‘Jack’ case

The Ombudsman for Children made a suite of recommendations specific to a child noted as “Jack” (a pseudonym) and more generally to children who were in an acute hospital setting beyond medical need. The latter included:

1.	The local HSE disability team will convene a multi-disciplinary meeting to include all services involved with Jack and his family.
2.	HSE Disability Services will immediately and systemically review all cases where a child remains in hospital settings beyond their medical need
3.	Children with significant disabilities require a coordinated integrated approach in assessing their needs. HSE Disability Services will devise a framework for a holistic assessment of both the child and their family’s circumstances.
4.	HSE Disability Services will engage with the Department of Health to ensure services and funding are in place to support the right of children with disabilities to grow up at home with their families.
5.	HSE Disability Services will conduct a national review of the current need for alternative care for children with disabilities whose parents or carers are not willing, or not able, to provide for their on-going care.
6.	A new protocol will be put in place to manage disagreements and complaints between the HSE Disability Services and acute hospitals
7.	Tusla should immediately issue a guidance to all social work areas, that child protection and welfare referrals about children with disabilities must be assessed and managed the same as all other referrals and in accordance with national policies & procedures

Appendix B – Brief description of services including roles and responsibilities

The following is a high-level overview of services provided by the HSE and Tusla. More detailed information regarding the provision of specific services, referral pathways, contact points, etc., is available for Tusla on www.tusla.ie. Information about the HSE at local primary care centres, other service delivery centres and offices, the internet, etc. Staff in the respective organisations will continue to have access to and avail of all the existing sources of information in relation to the range and extent of service provision.

In implementing this *Joint Protocol (2020)*, it is imperative that staff in the respective organisations fully commit to proactively engaging in joint working regarding clinical/professional meetings and service provision, dealing with issues, etc.

1.0 Tusla Child and Family Agency

1.1 Functions

The Child and Family Agency is the dedicated State agency responsible for improving wellbeing and outcomes for children. Tusla has responsibility for child welfare and protection services, family support, educational welfare and a range of other services, including those relating to domestic, sexual and gender-based violence. Under the Child and Family Act 2013 the Child and Family Agency is charged with:

- Supporting and promoting the development, welfare and protection of children, and the effective functioning of families;
- Offering care and protection for children in circumstances where their parents have not been able to, or are unlikely to, provide the care that a child needs. In order to discharge these responsibilities, the Agency is required to maintain and develop the services needed in order to deliver these supports to children and families and provide certain services for the psychological welfare of children and their families;
- Responsibility for ensuring that every child in the State attends school or otherwise receives an education, and for providing educational welfare services to support and monitor children's attendance, participation and retention in education;
- Ensuring that the best interests of the child guide all decisions affecting individual children;
- Consulting children and families so that they help to shape the agency's policies and services;
- Strengthening interagency co-operation to ensure seamless services responsive to needs;
- Undertaking research relating to its functions and providing information and advice to the Minister regarding those functions; and
- Commissioning services relating to the provision of child and family services

Given Tusla's role in strengthening inter-agency cooperation to ensure seamless services responsive to need, it is recognised that those children with complex needs, particularly those with moderate and profound disabilities, require additional specialist services and expertise that are not available in Tusla. Joint working between Tusla and the various HSE services is critical and a collaborative approach is the key to

achieving positive outcomes that meet the needs of the child and family.



Figure 2. Tusla's seventeen Areas based in four geographical Regions.

1.2 Operational Divisions

Tusla provides a broad range of family support, child protection and services to children and families in the community and children in care. These services are provided within structures which reflect the geographical regions and areas of the country and, within those areas, the types of services.

1.2.1 Prevention, Partnership and Family Support

The PPFS service in Tusla is delivered directly by Tusla staff and indirectly by a range of agencies based in local communities across the country. These agencies include family support centres and other community based child and family support services and youth services. PPFS services are designed and have been developed to support children and families in need and to prevent the children and families from needing child protection and welfare services. The model which is most often utilised is the "Meitheal model which calls upon a broad range of people and agencies (including the HSE) to come together to support the child and family. Full details of the family support services can be accessed at <https://www.tusla.ie/services/family-community-support/>

1.2.2 Child Protection and Welfare Services

Child Protection and Welfare Services are designed to ensure the protection of children from abuse and neglect. While all agencies (including the health services) have responsibilities for highlighting concerns in respect of the neglect or abuse of a child, Tusla, Tusla has the lead responsibility for the assessment and interventions to address any neglect or abuse of a child or children. For specific information relating to reporting a concern about a child, please refer to www.tusla.ie

The *Signs of Safety* is the Tusla Child Protection and Welfare service's national approach to practice. It is a strengths-based, safety-organised approach to child protection casework which aims to work with the strengths, resources and existing support networks that exist within families in their risk assessments. The aim of the intervention is to build safety for children who have suffered, or who are at risk of suffering on-going significant harm of abuse i.e. physical, sexual, emotional abuse and/or neglect. A Safety Plan is created with the family and the safety network. It is monitored and reflected on by everyone involved and refined over time. Where the Safety Plan cannot adequately provide for the safety of the child, Tusla can make an application to the courts to receive the child into statutory care under the Childcare Act 1991.

1.2.3 Alternative Care Services

The Child and Family Agency has a statutory responsibility to provide Alternative Care Services under the provisions the Child Care Act, 1991, the Children Act, 2001 and the Child Care (Amendment) Act, 2007.

Children who require admission to care are accommodated through placement in foster care, placement with relatives, or residential care. A care order can take the form of

- An Emergency Care Order (up to 72 hours or three days);
- An Interim Care Order (for up to 21 days or longer by agreement); or
- A Full Care Order which can last until the child reaches the age of 18 years.

In addition, services are provided for children who are homeless or who are separated children seeking asylum. The Agency also has responsibilities with regards to adoption processes.

Foster care is the preferred form of alternative care for children in Ireland as it is deemed the most appropriate substitute to a child living with their own family; and it also conforms with both the constitutional and UN Convention aspirations. Where a child cannot be cared for in a foster family, residential care is used. At the time of publication of this *Joint Protocol (2020)*, 92% of children in care in Ireland were cared for in foster care; and approximately one third of these foster families were related to the child involved (i.e. relative or kinship foster placements).

The threshold for admission to care is deliberately set at a high level as the Constitution and the UN Convention on the Rights of a Child identify a family as the most appropriate placement for a child. In this context, Tusla will always endeavor to maintain a child with their family unless to do so will result in neglect or abuse that will have an adverse impact on their health, wellbeing and development.

An admission to care by voluntary agreement is a formal arrangement that involves the parent giving informed consent. In these cases, the parent continues to make all

significant decisions in the child's life and works in partnership with Tusla to achieve the best outcomes for the child. Voluntary consent to care is not sufficient for long-term planning for children in care.

1.3 Tusla Leaving and Aftercare Service

Aftercare services are support services that build on and support the work that has already been undertaken by many including, foster carers, social workers and residential workers in preparing young people for adulthood. Tusla Aftercare Services work within a legislative framework. There is a nationally standardized policy framework which clearly defines the eligibility of access to aftercare services, the nature and level of the services available, the terms and conditions for the allocation of aftercare workers, financial supports, and arrangements for the closing of aftercare supports, and specific guidelines to cover particular aspects of aftercare provision.

1.4 Key Tusla Inter-Agency Fora

There are a number of associated processes in place, or being developed which will assist inter-agency collaboration. These include:

- Children and Young People's Services Committees²¹ – a service delivery framework²² which will promote the routing of referrals to and through Tusla and their partner funded family support agencies;
- National Leaving Aftercare Policy and Implementation Plan - outlining the Agency's commitment to and provision for the preparation of young people for leaving and Aftercare; and
- Where they have yet to be formed, the HSE CHO level Residential Services Executive Management committees will be established. These will have a key role in any future requested disability residential placements.^{23,24}

While this *Joint Protocol (2020)* has been agreed between the HSE and Tusla, the principles apply equally to all entities that are funded by the HSE (i.e. Section 38 and Section 39 agencies, where appropriate and relevant; and to agencies that are funded by Tusla under Sections, 56, 57, 58, 59 of Tusla Act 2013, where appropriate and relevant).²⁵ The overarching principle is that the collaborative partnership is all inclusive

2.0 Health Service Executive

The HSE is structured into several services i.e. Acute Hospitals; Disability; Health and Well-Being; Mental Health; Services for Older Adults; and Primary Care. The services that are most relevant to this *Joint Protocol (2020)* are CAMHS; Disability; and Primary Care. The Acute Hospital sector is often involved with children with complex healthcare needs and are also also involved with children who remain in

²¹ DCYA is promoting the development of Children and Young People Services Committees to ensure one is established in every county. This *Joint Protocol (2020)* has been considered within that development.

²² Tusla has developed a service delivery Protocol that determines the route of referrals from the point of entry to the final outcome. An element of this will be local Area pathways with considerable reliance on community services and non-statutory providers. This *Joint Protocol (2020)* has been considered in light of this development.

²³ An 'emergency placement' request may take anywhere from 6-9 months to source and provide.

²⁴ Where appropriate, these committees could merge with and form part of the Residential Care Decision Forums.

²⁵ Service Arrangements may need to be amended and updated to reflect the obligations of this MoU (see Section 1.6) on Section 38s and 39s.

hospital beyond medical need pending identification of an appropriate onward alternative care placement.

There are 9 HSE CHOs geographically spread across the country.

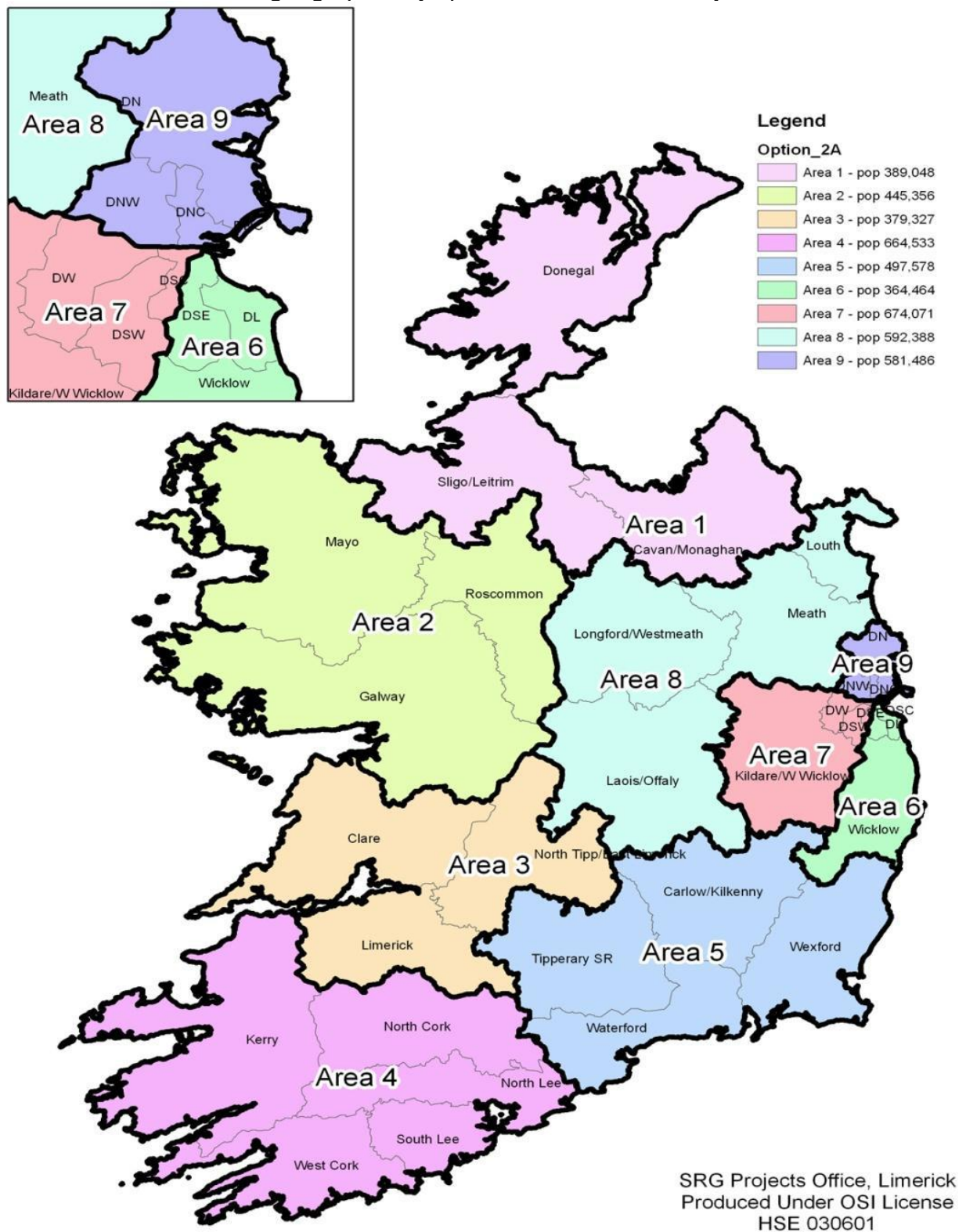


Figure 3. Map of Community Healthcare Organisations.

2.1 Acute Hospital Services

In Ireland, acute hospital services for children are delivered by a range of hospitals within the six hospital groups and Children's Health Ireland (CHI).

Hospital Groups and CHI provide a range of paediatric services at local, regional and national level. These include unscheduled care (unplanned/emergency care), scheduled care (planned care), diagnostic services, specialist services, cancer services, maternity and children's services and the National Ambulance Service (NAS). These services are provided in response to population need, consistent with health policies and objectives including HSE Clinical Care Programmes and Slaintecare. Smaller hospitals manage routine or planned care locally and more complex care is managed in the larger hospitals. Access arrangements and referral pathways for children requiring acute care are delivered in an integrated way to meet the needs of children. This includes close working relationships between Hospital Groups and HSE Community Operations.

The Office of the National Director of Acute Operations, HSE works closely with many stakeholders including Hospital Group CEO's, other HSE Divisions, Department of Health, Child and Family Agency and An Garda Síochána in the delivery of paediatric services and oversight of Children First within acute services.

2.2 HSE Disability Services

HSE Disability Services provide access to a range of specialist services and supports for children with a disability, including those with an intellectual disability, assessed in the moderate, severe or profound range. However, it is recognised that some individuals with mild disabilities may have complex needs that require joint working between different HSE services (i.e. Acute Hospitals; CAMHS; Disability; Primary Care Services) and other agencies, including Tusla, Tusla. A collaborative approach is the key to achieving a positive outcome which meets the needs of the child and family in these instances.

Traditionally children's disability services were delivered by stand-alone disability service providers with their own access criteria for specific cohorts of children with a disability. Under the *Progressing Disability Services for Children and Young People (PDSCYP)* programme (HSE, 2010), many children's disability services have been reconfigured into geographically-based inter-disciplinary Children's Disability Network Teams (CDNTs) that are aligned with Primary Care Networks services in each of the nine CHOs. Providing a service to children aged 0-18-years with complex needs, these CDNTs work in partnership with families and are largely made up of Health and Social Care Professionals. Further to the recruitment of Children's Disability Network Managers, the remaining CDNTs are being established.

There are also a range of other disability services including residential services; respite and home supports; day support services; rehabilitative training; personal assistant services; and technical aids and appliances.

2.3 HSE Mental Health Services

Child and Adolescent Mental Health Services (CAMHS) Community Mental Health Teams (CMHTs) or CAMHS teams are the first line of specialist mental health services for children and young people up to 18 years of age who are directly referred to the CAMHS team from a number of sources. The CAMHS teams accept referrals for moderate-to-severe mental health difficulties of children and adolescents which

cannot be managed within primary care. Referrals to CAMHS also support children and adolescents with a mental illness and intellectual disabilities. Where the child or adolescent presents with a moderate-to-severe mental disorder and autism, CAMHS teams provide appropriate inter-disciplinary mental health assessment and treatment for the mental disorder in partnership with other agencies including HSE Primary Care, CDNTs, and other agencies supporting children and adolescents (Government of Ireland, 2020; p.47).

In the context of ongoing and significant mental health and intellectual disability service gaps across the country, where a child or young person has a moderate-to-severe degree of intellectual disability and co-morbid mental health disorder(s), they should be referred to the relevant Children and Adolescent Mental Health Intellectual Disability (CAMHS-ID) team.

There are also a number of HSE-provided inpatient CAMHS units across the country. These are approved centres under the Mental Health Act 2001. They are not statutory residential special care facilities for children.

2.4 HSE Primary Care Services

Primary Care Services deliver care to service users close to home through a community-based approach. In order that service users can access services at the most appropriate, cost effective service level, a focus on reforming existing and building new capacity in primary care. This will deliver appropriate care in an appropriate setting with a strong emphasis on prevention and public health, in line with *Sláintecare* goals. Capacity building in primary care leads to reductions in Emergency Department visits and inpatient hospitalisations.

A range of multi-disciplinary services are provided by a wide range of staff including GPs, Community Nursing and Health and Social Care Professionals, working with wider community services (e.g., Older People; Disability; CAMHS; Palliative Care) and Acute Hospital services to deliver efficient, effective and sustainable services, meeting the needs of services users.

Primary Care Teams and Community Healthcare Networks are the vehicles through which services will be provided across the system. In general, the following children will have their needs adequately met by their local primary care network:

- Children under the age of 18; and
- Children with a mild physical or intellectual disability if their needs can be met by Primary Care Networks regardless of number of disciplines required.

The Primary Care Team is the main provider of support for children with non-complex difficulties in functional skills/applied skill sets required for activities of daily living, learning new skills and social interactions. This may involve physical, social, emotional, communication and behavioural needs.

Appendix C – Relevant Legislation and Policies

This *Joint Protocol (2020)* reflects and is consistent with the following legislation and policy documents:²⁶

- Department of Health (2001). *Primary Care Strategy, A New Direction*. Dublin: Author.
- Department of Health (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: Author.
- Department of Health and Children (2020). *Sharing the Vision: A Mental Health Policy for Everyone*. Dublin: Author.
- European Commission (2018). *The General Data Protection Regulation*. Luxembourg: Author.
- Government of Ireland (1991). *Child Care Act 1991*. Dublin: Author.
- Government of Ireland (1995). *Child Care (Placement of Children in Residential Care) Regulations*. Dublin: Author.
- Government of Ireland (1995). *Child Care (Placement of Children in Foster Care) Regulations*. Dublin: Author.
- Government of Ireland (1995). *Child Care (Placement of Children with Relatives) Regulations*. Dublin: Author.
- Government of Ireland (2001). *Mental Health Act 2001*. Dublin: Author.
- Government of Ireland (2001). *Children's Act 2001*. Dublin: Author.
- Government of Ireland (2005). *Disability Act 2005*. Dublin: Author.
- Government of Ireland (2005). *Commission to Inquire into Child Abuse (Amendment) Act 2005*. Dublin: Author.
- Government of Ireland (2007). *Health Act 2007*. Dublin: Author.
- Government of Ireland (2007). *Child Care Amendment Act 2007*. Dublin: Author.
- Government of Ireland (2013). *Child and Family Agency Act*. Dublin: Author.
- Government of Ireland (2014). *Freedom of Information Act 2014*. Dublin: Author.
- Government of Ireland (2015). *Child Care Amendment Act 2015*. Dublin: Author.
- Government of Ireland (2015). *Children First Act 2015*. Dublin: Author.
- Government of Ireland (2017). *Sláintecare Report*. Dublin: Author.
- Government of Ireland (2018). *Data Protection Act 2018*. Dublin: Author.
- Health Information and Quality Authority (2012). *National Standards for the Protection and Welfare of Children*. Dublin: Author.
- Health Information and Quality Authority (2015). *National Standards for Children's Residential Centres*. Dublin: Author.
- Health Information and Quality Authority (2015). *National Standards for Special Care Units*. Dublin: Author.
- Health Service Executive (2012). *Value for Money and Policy Review – Disability Services*. Dublin: Author.
- Health Service Executive (2013). *Progressing Disability Services for Children and Young People Programme*. Dublin: Author.
- Health Service Executive (2014). *Safeguarding Vulnerable Persons at Risk of Abuse*. Dublin: Author.
- Health Service Executive (2016). *Home Sharing in Intellectual Disability Services in Ireland – Report of the National Expert Group*. Dublin: Author.
- Health Service Executive (2017). *Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services*. Dublin: Author.

²⁶ This list is not exhaustive and is subject to change.

Health Service Executive (2018). *Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders*. Dublin: Author.

Health Service Executive (2019). *National Policy on Access to Services for Children and Young People with a Disability or Developmental Delay*. Dublin: Author.

Ombudsman for Children (2018). *Molly's Case: How Tusla and the HSE Provided and Coordinated Supports for a Child with a Disability in the Care of the State*. Dublin: Author.

Ombudsman for Children (2020). *Jack's Case: How the HSE and Tusla, Child and Family Agency, Provided for and Managed the Care of a Child with Profound Disabilities*, Dublin: Author.

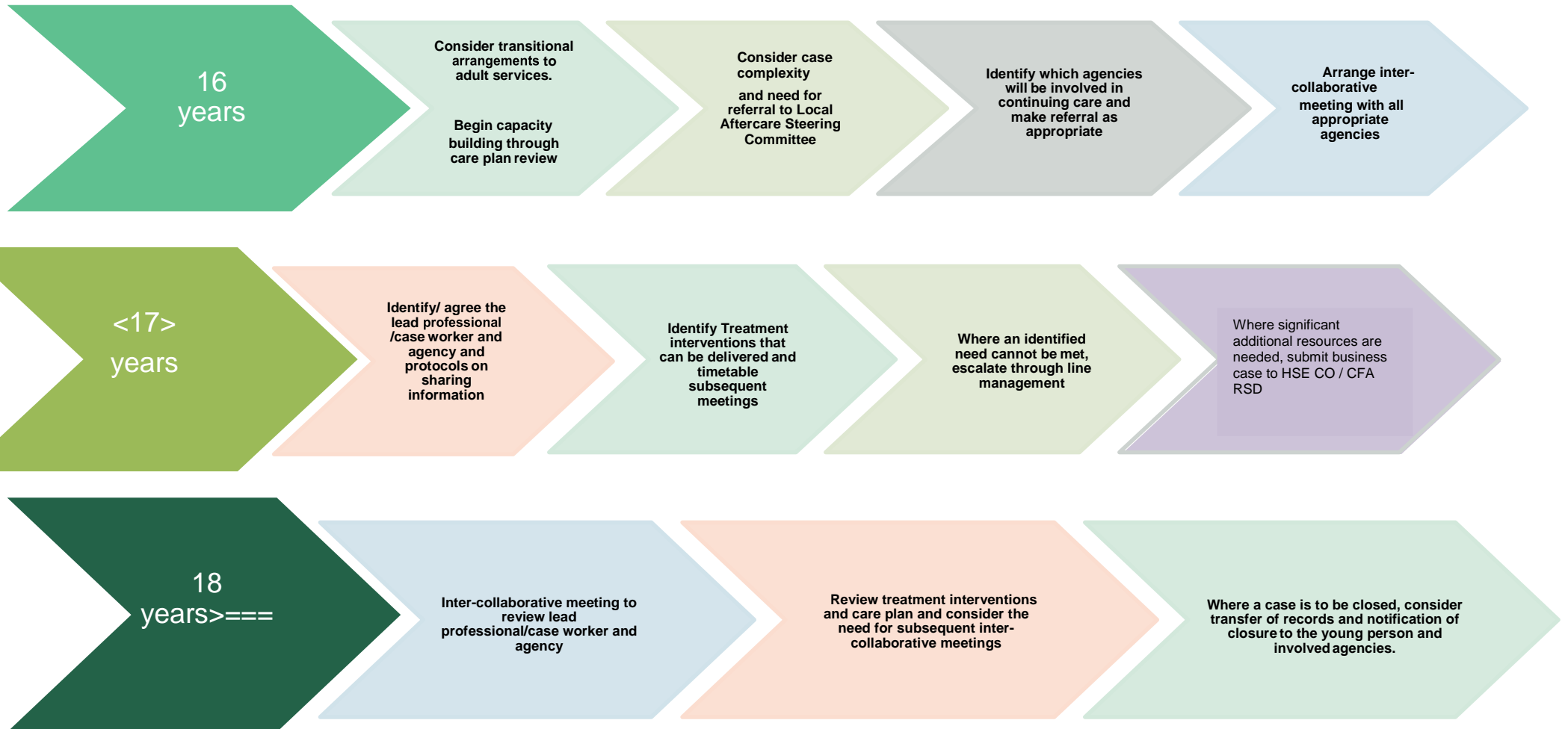
Tusla Child and Family Agency (2013). *Meitheal – A National Practice Model for all Agencies working with Children, Young People and their Families*. Dublin: Author.

Tusla Child and Family Agency (2017). *Children First: National Guidance for the Protection and Welfare of Children*. Dublin: Author.

Tusla Child and Family Agency (2017). *Tusla National Leaving and Aftercare Policy and Implementation Plan (2017)*. Dublin: Author.

Appendix D – Process Map

Process map for consideration in cases concerning the ongoing welfare and support needs of a young person entering adult services.



Appendix E – Summary of Amendments in this *Joint Protocol (2020)*

This *Joint Protocol (2020)* includes a number of significant edits to the *Joint Protocol (2017)*. These include:

1. Consideration of the role of the Acute Hospitals that is now integrated into this *Joint Protocol (2020)*;
2. Summary of relevant policies; integration of related structures; and a requirement for all HSE services to fully engage as appropriate with presenting cases;
3. Requirement that all Tusla services engage in this *Joint Protocol (2020)* in respect of all children with complex disabilities and complex health care needs;
4. In 2017 Tusla and the HSE re-affirmed their commitment to use the (statutory) Child in Care Review process to review all children in care (including those with a complex disability);
5. Adoption of an agreed definition of disability;
6. Refined operating principles; all HSE and Tusla services are required to refine (as appropriate) their business processes to ensure they comply with this *Joint Protocol (2020)*;
7. Clarification of the *Joint Protocol (2020)* structures (including the different levels at which it needs to be implemented);
8. A focus on strengthening the management and clinical governance arrangements (e.g., how to escalate cases; designating in each CHO a HSE manager to make budgetary decisions);
9. Clarification that Section 38 and 39 Voluntary Organisations are required to adhere to all aspects of implementing this *Joint Protocol (2020)*;
10. A greater focus on transition planning for 16-to-18-year-olds;
11. Clarification around legal issues including:
 - a. Who can take a child into care as a result of Child Protection and Welfare concerns (Child Care Act 1991);
 - b. The requirement for parental consent to accommodate a child in a disability placement (e.g., residential or home share) where there are no child protection issues;
 - c. What may, and may not, constitute ‘abandonment’; and
 - d. The importance of both agencies (HSE and Tusla) working together to provide intervention; and to prevent the need for litigation by adhering to this *Joint Protocol (2020)*;
12. Details of the principles agreed by both the Department of Health and the Department of Children and Youth Affairs (DCYA) in relation to the future responsibilities and funding for children in care or transitioning out of State care.
13. Consideration of the GDPR (e.g., development of a specific data sharing agreement; European Commission, 2018); and
14. Importantly, some case examples that demonstrate how to implement this *Joint Protocol (2020)* when dealing with potentially challenging scenarios.