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# PROGRESSING TOWARDS OUTCOMES- FOCUSED FAMILY-CENTRED PRACTICE

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*An Operational Framework*

WRITTEN BY

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## List of Abbreviations

AoN: Assessment of Need  
 CAMHS: Child and Adolescent Mental Health Service  
 CDNM: Children’s Disability Network Manager  
 CDNT: Children’s Disability Network Team  
 CDNTIMS: National Children’s Disability Network Team Information Management System (that Ocff Implementation Subgroup reports into)  
 CHO: Community Healthcare Organisation  
 EI: Early Intervention  
 FCP: Family-Centred Practice  
 IFSP: Individual Family Service Plan  
 KPI: Key Performance Indicator  
 MPOC: Measure of Processes of Care  
 NASS: National Ability Support System  
 NTDP: National Team Development Programme  
 Ocff: Outcomes for Children and Families Framework  
 PDS: National Progressing Disability Services for Children and Young People programme  
 SMART: Specific, Measurable, Achievable, Realistic, Time-bound  
 SOP: Standard Operating Procedure  
 Tusla: Child and Family Agency



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## Executive Summary

*Progressing Disability Services for Children and Young People* (PDS) seeks to develop equitable and integrative children's disability services guided by 12 core principles and values, one of which is Family-Centred Practice (FCP). FCP is the accepted model of the PDS programme but this phenomenon needs to be defined further for it to be operationalised meaningfully. Although interpretations vary, outcomes-focused FCP is conceptualised in this document, as per Dunst (2005), as a collection of care processes (e.g. clinical inputs, practices, supports, resources and experiences) with corresponding or consequent outcomes (e.g. the positive consequences of these processes to children and their families).

Informed by the academic literature and learning from an empirical project completed in CHO 3 on collaborative goal setting, this document presents an operational framework<sup>1</sup> or guide for how Children's Disability Network Teams (CDNTs) can work to progress outcomes-focused FCP. Hence, respective chapters consider the CDNT actions required to deliver outcomes-focused FCP; and thereafter measures required to sustain such change. Largely to be implemented by Children's Disability Network Managers (CDNMs), the concluding chapter details a suite of recommendations for CDNTs to realise outcomes-focused FCP, along with supporting regional and national level measures, and a consideration of training needs and future directions in research.

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<sup>1</sup> An operational framework is a guide that can include a service's policies, goals, standards, procedures, and training; or how it provides a service.

# Chapter 1: The Journey towards Outcomes-Focused Family-Centred Practice

## 1.1 Introduction

In Ireland, a child and family-centred ethos was introduced formally to child disability services with the advent of *Progressing Disability Services for Children and Young People* (PDS) in 2010. Family-centred practice (FCP)<sup>2</sup> is firmly recognised as a standard model of child<sup>3</sup> disability and health care internationally (Espe-Sherwindt, 2008). The theoretical foundation of FCP is robust (Dunst, 2002; Rosenbaum, King, Law, King & Evans, 1998) with positive outcomes cited in the literature for both children with disabilities and their families (Dempsey & Keen, 2008). Authors however declare difficulties implementing this philosophy of care from policy to practice (Ingólfssdóttir, Egilson & Traustadóttir, 2017), with some critics asserting the need for further empirical support in relation to the definition, operationalisation and measurement of FCP (Shields, 2015). To date, PDS is in the process of being rolled out nationally. Informed by the existing academic literature, practice-based evidence, HSE policy and key pieces of legislation, this current document therefore seeks to provide a preliminary practice framework to help support the transition of child disability services towards outcomes-focused FCP.

## 1.2 Progressing Disability Services for Children and Young People

PDS has been established as a reformatory programme for the provision of disability services in Ireland to children from birth to 18 years and their families. Historically disability services in Ireland have developed in an ad hoc manner. Significantly, services have been provided by both the HSE and voluntary bodies with varying philosophies of care (Carroll, Murphy & Sixsmith, 2013). The development of varied disability services has led to inconsistent service provision both across and between different Community Healthcare Organisations (CHOs) nationwide and the development of pockets of specialised services. The varied evolution of services led to inequitable service provision to children and families across geographical regions with significant discrepancies noted in relation to access to assessment, intervention, and school-based supports, amongst others (Carroll et al., 2013). In response to these issues, PDS has laid out the roadmap for a standardised and integrative disability service which responds to the needs of the child and family, rather than based on diagnosis. PDS is in the process of being rolled out nationally by the HSE in partnership with its funded voluntary organisations. Key objectives of this programme are to:

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<sup>2</sup> It is acknowledged that both the terms FCP and family-centred care are used interchangeably in the literature to describe this phenomenon. However, for the purpose of this document, the term FCP will be used.

<sup>3</sup> The word “child” is used throughout to refer to “children and young people.”

- Provide a clear pathway and fairer access to services for all children with disabilities.
- Make the best use of available resources for the benefit of children and their families.
- Ensure effective teams work in partnership with families and with education staff to support children with disabilities to reach their full potential.

PDS requires pooling together all resources, including staff, facilities, and equipment, from the HSE and various voluntary agencies, to set up Children’s Disability Network Teams (CDNTs). A CDNT comprises a team of Health and Social Care Professionals who will provide services for a specific geographical area for all children with complex needs aged 0-18-years-old. Once all CDNTs are in place, there will be full national cover and the CDNTs will all be working to the same service delivery model.

**1.2.1 Principles of Progressing Disability Services.** Twelve principles inform the service delivery model for CDNTs. These were identified and developed based on national and international evidence, PDS national and local implementation groups and following consultation with staff and parents (HSE, 2011). These principles underpin all policies and procedures for CDNTs and are described in detail in the Policy Framework for Children’s Disability Network Teams (HSE, 2020).

- |  |                                    |
|--|------------------------------------|
| 1. Accessibility                                   | 7. Equity of Access                |
| 2. Accountability                                  | 8. Evaluation of outcomes          |
| 3. Bio-psychosocial model                          | 9. Family-centred practice         |
| 4. Clinical governance and evidence-based practice | 10. Inclusion                      |
| 5. Cultural competence                             | 11. Interdisciplinary team working |
| 6. Early detection and referral                    | 12. Staff are valued and respected |

**1.3 Outcomes for Children and their Families Framework**

In 2012 the Department of Health tasked the *National Co-ordinating Group of the PDS programme* to develop a performance reporting and accountability system for CDNTs, focused on outcomes for children with disabilities and their families. The *Outcomes for Children and their Families Framework (OCFF)* was subsequently developed (HSE, 2013). This framework proposed the transition from outputs to outcomes-focused services whereby the benefits or added value of services to children and families is measured. The OCFF is grounded in the following concepts:

1. Families and services listen to the child, considering the child’s age and maturity, and strive to achieve the best possible outcomes for that child.

2. Families are, in the main, fully capable of making informed choices and acting on their choices. Parent/carers have the ultimate responsibility for the care of their children and for all decisions made about them.
3. Services exist to support children and families to attain the best possible outcomes.
4. Interventions are appropriate to the needs of the child and family, and emphasise capacity-building, strengthening existing skill sets, promoting the acquisition of new skills, medical care, and other supports; and
5. Children, families, and service providers all benefit most when services are based on true collaborative partnerships between families and professionals.

The OCFF presents 11 outcome statements which pertain to children and their families. The selection of outcomes was based on an extensive national consultation process with children, families and team members and was externally reviewed by internationally regarded researchers in the area (HSE, 2013). The OCFF is intended to replace some of the current output-based statistics gathered by unidisciplinary team members therefore moving towards a more meaningful outcomes-based approach.

The six outcome statements for children are:

1. Children and young people have a voice in matters which affect them, and their views will be given due weight in accordance with their age and maturity.
2. Children and young people enjoy the best possible health.
3. Children and young people are safe.
4. Children and young people have friends and get on well with other people in their lives.
5. Children and young people learn skills to help them to be independent.
6. Children and young people take part in home life, school life and community life.

The five outcomes statements for families are:

1. Families understand their child or young person's needs, what they can do well and what they find difficult as they are growing up.
2. Families look after, take care of, and support their child or young person.
3. Families are supported to ensure that their rights and the rights of their child or young person are respected.
4. Families take part in community services and supports.
5. Families feel supported by family, friends, and neighbours in their local community.

The OCFF report and the outcomes provide a fundamental starting point in the operationalisation and quality control of child and family-centred services in Ireland. As part of this, an HSE working group has been formed to progress the

implementation of the OCFF accountability and performance management framework. This group will develop and trial a suite of lower level service process and outcome indicators to measure the performance of CDNTs [e.g. Self-audit Tool for CDNTs in the *Policy Framework for Service Delivery of Children's Disability Network Teams* (HSE, 2020)] amongst other actions.

#### **1.4 Family-Centred Practice and Progressing Disability Services**

FCP is one of the 12 foundational principles of PDS. This phenomenon in addition to the principles of evaluation of outcomes and interdisciplinary team working are linked particularly closely with the OCFF report (HSE, 2013). FCP recognises families as experts on the needs of their child and family and that the well-being of the child is largely dependent on the well-being of the family unit. This approach empowers children with disabilities and their families to participate in and lead the services they receive. This model of service therefore heralds a cultural shift in the HSE from a “care” to a “support” model. Traditional professional or expert-led models of service which focus on children's deficits are no longer deemed to serve the needs of children and families in Ireland. As part of PDS, outcomes-focused FCP will focus, not on outputs or the number of therapeutic inputs delivered to children and families, but instead the quality and impact of services. CDNT professionals bring specific knowledge, skills, and experience. Together, the family and the CDNT can focus on what is uniquely important to the child and their family, and work to achieve the goals they have chosen. FCP is therefore a vehicle for services to better support child and family outcomes. From the first contact, service professionals, researchers, planners, and policy makers must recognise and strengthen the primacy of the family. As FCP is a principled approach to child disability care delivery rather than a standardised assessment or intervention process or procedure, CDNTs will need to incorporate existing assessment and intervention models [e.g. Assessment of Need (AON), positive behavioural support] into their work, as necessary.

The development and implementation of the OCFF will support the accountability and evaluation of services delivered. However, in CDNTs already reconfigured, the robustness of FCP is arguably, upon scrutiny, found to be insufficient, and the current accountability structures do not support or drive the changes required. As mentioned in the introduction, translating FCP from theory to practice has proven difficult, and guidance on how to approach changing from historical practice to outcomes-focused FCP is lacking. In response to these difficulties, a change management project was commissioned in CHO 3 on collaborative goal setting as part of the Individualised Family Service Plan (IFSP) process. This research sought to translate outcomes-focused FCP into everyday work practices as part of CDNT service delivery and sought to develop a framework for other CDNTs to use to guide their own journey towards outcomes-focused FCP.

## 1.5 Document Aims

It is important that the restructuring of children's disability services in Ireland as part of PDS is guided by clear operational guidelines with specific recommendations for CDNTs regarding the delivery of clearly defined child and family-centred care processes that correspond to specific and measurable outcomes. In building on the draft *OCFF Implementation Project, Project Initiation Document* (Ryan, 2016), this document seeks to promote FCP, an element of which is Individual Family Service Plans (IFSPs), which over time will assist CDNTs in progressing towards the realisation of desired OCFF child and family outcomes (see Figure 1.1).

The integration of outcomes-focused FCP into disability service provision will be achieved through the application of learning from the literature and empirical findings. Specific aims are outlined:

1. Clearly define outcomes-focused FCP as it is described in the academic and empirical literature and delineate how this ethos relates to working in an outcomes-focused manner.
2. Provide examples of family-centred work practices to children and families with disabilities based on a research project on collaborative goal setting conducted in CHO 3.
3. Introduce outcomes-focused family-centred processes, as informed by the evidence-based literature and practice, and relevant HSE policy documents.
4. Outline CDNT actions that support outcomes-focused FCP; and
5. Make recommendations regarding the implementation of a change management programme to support CDNTs to transition towards outcomes-focused FCP.

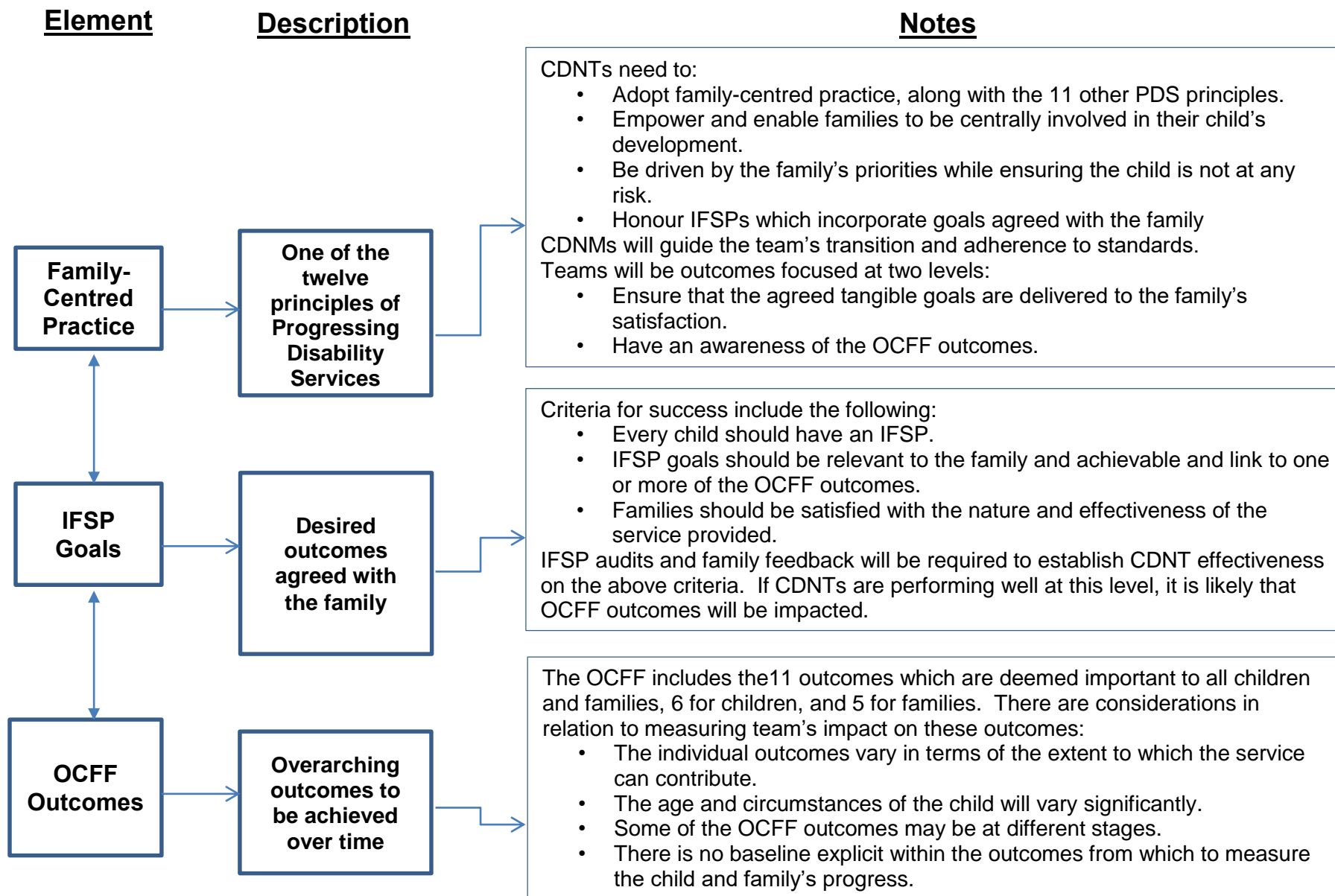


Figure 1.1: The relationship between FCP, IFSPs and the OCFF.



## Chapter 2: Family-Centred Practice

### 2.1 What is Family-Centred Practice?

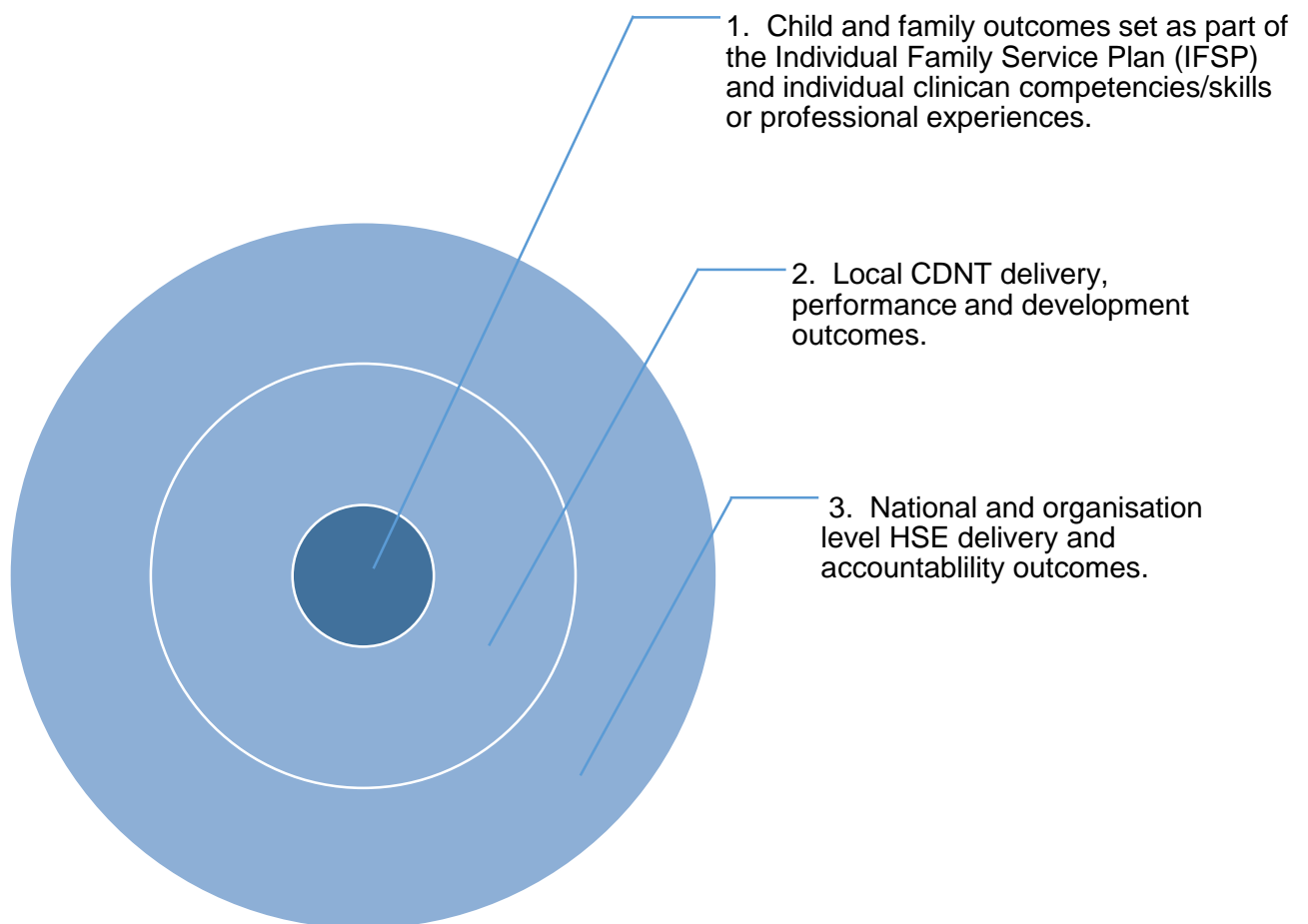
FCP in essence is a model of child disability and health care which prioritises and promotes the strengths and abilities of the family unit through recognising the family as both unique and central in the delivery of services (Dunst, 2002; MacKean, Thurston & Scott 2005). As part of this model, a partnership or collaborative approach to service delivery is emphasised with a move away from expert-led care (Dunst, 2002). The adoption of a formal child and family-centred ethos has been key to the development of the PDS programme in Ireland. Key components of FCP as outlined by Rosenbaum and colleagues (1998) are presented in Table 2.1.

*Table 2.1: Premises, Principles and Elements of Family-Centred Services adapted from Rosenbaum et al. (1998)*

<b>Premises (basic assumptions)</b>		
<ul style="list-style-type: none"> <li>• Parents know their children best and therefore can best determine their child's needs.</li> </ul>	<ul style="list-style-type: none"> <li>• Families are different and unique.</li> </ul>	<ul style="list-style-type: none"> <li>• Optimal child functioning happens within a supportive family and community context.</li> </ul>
<b>Guiding Principles ("should" statements)</b>		
<ul style="list-style-type: none"> <li>• Families should have the opportunity to decide the level of involvement they wish to have in decision making for the child.</li> <li>• Parents should have ultimate responsibility for the care of the child.</li> </ul>	<ul style="list-style-type: none"> <li>• Each family member should be treated with respect (as individuals).</li> </ul>	<ul style="list-style-type: none"> <li>• The needs of all family members should be considered.</li> <li>• The involvement of all family members should be supported and encouraged.</li> </ul>
<b>Elements (service provider behaviours)</b>		
<ul style="list-style-type: none"> <li>• Encourage parent decision making.</li> <li>• Assist in identifying strengths.</li> <li>• Provide information.</li> <li>• Assist in identifying needs.</li> <li>• Collaborate with parents.</li> <li>• Provide accessible services.</li> <li>• Share information about the child.</li> </ul>	<ul style="list-style-type: none"> <li>• Respect families.</li> <li>• Support families.</li> <li>• Listen.</li> <li>• Provide an individualised service.</li> <li>• Accept diversity.</li> <li>• Believe and trust parents.</li> <li>• Communicate clearly.</li> </ul>	<ul style="list-style-type: none"> <li>• Consider psychosocial needs of all family members.</li> <li>• Encourage participation of all family members.</li> <li>• Respect coping styles.</li> <li>• Encourage use of community supports.</li> <li>• Build on strengths.</li> </ul>

Significantly, FCP can be understood, not as a set of standardised interventions and practices, but as a philosophy of care which is defined by the outlined assumptions, principles and behaviours whereby the process or "how" care is delivered is as valuable to the achievement of positive child and family outcomes

as the characteristics or “what” is delivered (Espe-Sherwint, 2008; Henneman & Cardin, 2002). Informed by the work of Dunst (2005), family-centred processes can be defined generally as clinical inputs, practices, supports, resources, and experiences; and family-centred outcomes can be conceptualised as the positive effects of these processes. It is asserted that the reform of services from outputs-focused to outcomes-focused working is achieved intrinsically through the medium of FCP. In examining the definition of child and family-centred outcomes as part of PDS, it is asserted that outcomes can be identified and measured at three distinct ecological levels (see Figure 2.1). The practicalities or “how to” of delivering some family-centred processes and measuring corresponding outcomes will be explored in subsequent chapters of this document.



*Figure 2.1: Levels of Outcome Measurement as part of PDS*

## **2.2 Origins of Family-Centred Practice**

FCP has been described as having its theoretical foundations in family systems theory (Trivette & Dunst, 2000), empowerment (Zimmerman, 2000) and help-giving (Brickman et al., 1982) literature bases, in addition to client-centred therapy (Bamm & Rosenbaum, 2008). Contemporary formulations of FCP for children with disabilities and their families have been informed by social systems theory and ecological models of FCP (Dunst & Trivette, 2009; King, Curran & McPherson, 2013). FCP emerged in the 1950’s in the UK and US as an antidote to the

paternalistic and expert-led paediatric disability and hospital care of the time (Espe-Sherwindt, 2008). Inspired by academic contributions (Jolley & Shields, 2009; Shields, 2015) and key government reports on the well-being of children in hospital (Jolley & Shields, 2009), the advent of parent advocacy, and the formation of government bodies (Rosenbaum et al., 1998), the humanisation of paediatric health care prompted an ideological movement towards a social model of disability care (Rouse, 2012). Contemporary children’s disability care has developed to incorporate both medical and social perspectives via an interdisciplinary biopsychosocial model (George & Engel, 1980). This model was formally adopted by the World Health Organisation in the *International Classification of Functioning, Disability and Health* document (WHO, 2001). In detailing the evolution of family orientated work, Dunst et al. (1991) present disability practice as falling along a continuum from professionally-centred to family-centred paradigms. Four distinct professional models are presented in Table 2.2.

*Table 2.2: Continuum of Family-Centred Models in Disability Care (Dunst et al., 1991) adapted from Espe-Sherwindt (2008)*

Professionally-Centred	Family-Allied	Family-Focused	Family-Centred
<ul style="list-style-type: none"> <li>Professional the expert in determining child’s and family’s needs.</li> <li>Professional guides intervention and is the key decision maker.</li> </ul>	<ul style="list-style-type: none"> <li>Professional determines the needs of the child and family and directs clinical intervention.</li> <li>The family is a partner in implementing intervention.</li> </ul>	<ul style="list-style-type: none"> <li>Family is viewed as a consumer who can make informed decisions regarding intervention and care practices, with clinical guidance.</li> </ul>	<ul style="list-style-type: none"> <li>Professional and family are equal stakeholders.</li> <li>Intervention is flexible and responsive to the family’s needs.</li> <li>Intervention is strengths-based and focuses on positive family outcomes.</li> <li>Families are the key decision makers.</li> </ul>



Significantly the models of practice on this continuum vary based on (i) work activities such as differing professional/family roles; (ii) the perceived capabilities of families; and (iii) who ultimately has authority over decision making. It can therefore be argued that the operationalisation of FCP is dependent in part on service and professional fidelity to the aforementioned premises, principles and elements as outlined by Rosenbaum and colleagues (1998) and the abandonment of outdated expert-led ways of working. This certainly poses a challenge for the implementation of the PDS programme in Ireland as the cultural and organisational shift towards FCP has been somewhat protracted to date with a clear need identified for operational guidelines. The current document therefore seeks to provide a

supportive framework to support the successful transition towards outcomes-focused FCP.

### **2.3 Empirical Evidence for Family-Centred Practice**

In progressing towards outcomes-focused FCP, it is essential that CDNT members understand how FCP is conceptualised theoretically, empirically and in their day to day work. To better understand this phenomenon, it is important to critically examine the evidence for FCP and how FCP has been explored in research to date. Despite FCP's establishment as the standard model of child disability practice internationally, authors have posited that rigorous empirical support for FCP has not been fully demonstrated (Dempsey & Keen, 2008; Shields, 2015). Key reviews have examined the fidelity of paediatric healthcare services to FCP principles under the cause and effect lens of intervention research via a review of both randomised control trial (Shields, Zhou, Pratt et al., 2012) and quasi-experimental research (Shields et al., 2012), with limited support for positive child and family outcomes indicated due to a dearth of available research. Critically both of these reviews examined the fidelity of services delivered to FCP principles and did not conceptualise FCP as a collection of varied care processes and outcomes as per Dunst (2005) or as per King, Rosenbaum and King (1995) in their standardised measure the Measure of Processes of Care (MPOC). Interestingly, a corresponding review of qualitative research provided some support for the efficacy of FCP by concluding that despite the challenges of this model, families are motivated to participate in the care process and carry out parenting roles (Watts et al., 2014).

Broadening the scope of FCP to what is termed processes and outcomes; a body of quasi-experimental and qualitative research provides promising and applied results. Firm support has been garnered that family-centred care processes have positive consequences for both the child and family, with improved service satisfaction indicated and parent self-efficacy typically listed (Dempsey & Keen, 2008; King, Teplicky, King, & Rosenbaum, 2004; Law et al., 2003). FCP has been demonstrated to have benefits for a wide variety of paediatric populations such as children with intellectual disabilities (Wade, Mildon, & Matthews, 2007), mental health conditions (MacKean et al., 2012) and special health-care needs (Kuhlthau et al., 2011). The efficacy for FCP has also been revealed for children/young people of different ages and from a variety of cultural backgrounds (Dunst & Espe-Sherwindt, 2016). Interestingly, FCP has also been established to have benefits for the clinician/health service in addition to those who receive care, with professional satisfaction, reduced clinical costs and better use of clinical resources cited (Neff, Eichner, Hardy & Klein, 2003).

In reviewing the aforementioned literature, it is evident that how FCP is conceptualised (i.e. a universal model/standardised practice vs. collection of family-centred processes and outcomes) and the methodologies employed by researchers in exploring this phenomenon have clear consequences on the perceived efficacy of FCP and recommendations for practice. Shields (2015) presents difficulties in

evaluating FCP, notably the non-standardised nature of healthcare, and the high costs and logistic issues of running high quality research studies, which render the execution of controlled research on FCP exceedingly difficult. In consideration of the outlined methodological difficulties of examining FCP rigorously and the nature of FCP as both a theoretical and clinical phenomenon, it is proposed that the development of universal or standardised model of FCP is somewhat challenging, with no such framework for practice currently in existence. The current document therefore seeks to provide a practice framework for outcomes-focused FCP within appropriate and realistic parameters for the evaluation of and execution of FCP as part of the PDS programme. In the absence of a formal or standardised model of FCP it is important that children's disability services in Ireland are guided by evidence-based models of FCP in operationalising these dynamic work practices and outcomes.

**2.3.1 Evidence-based models of family-centred practice.** Despite the lack of a universal model of FCP, key authors have attempted to formulate evidence-based frameworks of FCP for children with disabilities and their families. Informed by a *Practice-Based Theory of Family-Centred Help-Giving* (Dunst, Trivette & Hamby, 2006), Dunst, Trivette and Hamby (2007) completed a meta-analysis to examine the link between FCP and child and family outcomes with this model presented in Figure 2.2. Specifically, this model presents FCP as consisting of two components, relational help-giving and participatory help-giving. The direct and indirect effects of FCP are demonstrated on both self-efficacy beliefs and positive child, family, and programme outcomes, with greater effects observed for proximal outcomes (i.e. self-efficacy beliefs, service satisfaction and programme resources and supports) followed by the more distal outcomes.

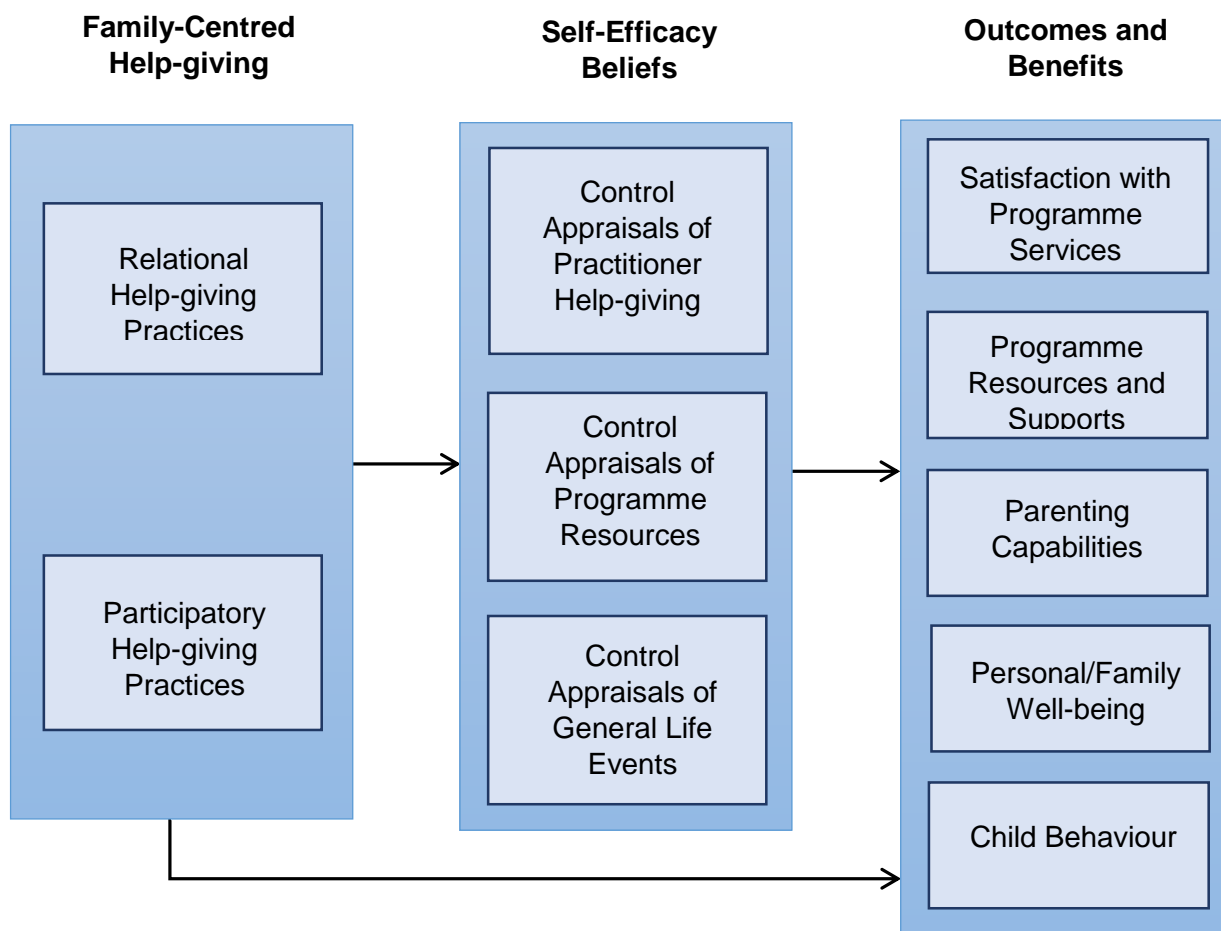
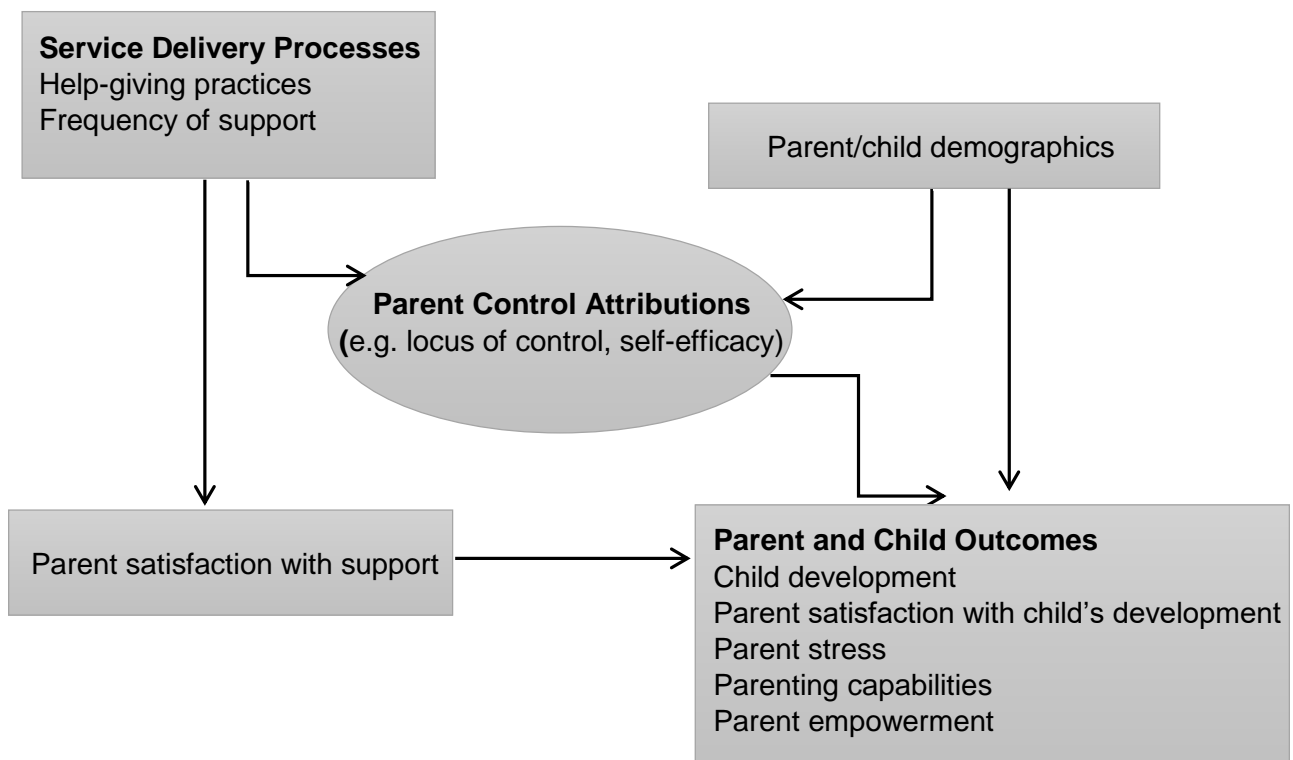


Figure 2.2: Practice Based Theory of Family-Centred Help-giving adapted from Dunst and colleagues (2006; 2007)

To examine FCP through the lens of processes and outcomes as per Dunst (2005), Dempsey and Keen (2008) completed a systematic review exploring the processes, outcomes, and mediating variables of FCP delivered to children with disabilities and their families. In doing this, Dempsey, and Keen categorised and collated independent, mediating, and dependent variables across studies, in response to differences observed on the roles of variables across studies. This resulted in the development of a visual summary of this data (see Figure 2.3). Critically the authors found an indirect relationship between family-centred service inputs and child/family outcomes, namely parent satisfaction and parent control attributions. The characteristics of children and families were a notable confounding variable with these factors directly impacting their outcomes.



*Figure 2.3: A Model of Processes, Outcomes and Mediating Variables in Family-Centred Practice with Families with a Child with a Disability, adapted from Dempsey and Keen (2008)*

In summarising the evidence-based models presented common factors can be extracted from both, care/help-giving processes are delivered by professionals; these processes are mediated by self-efficacy beliefs of families in addition to other factors; and a number of favourable outcomes are listed for both the child and family. Although informative, it is noted that these models serve as research summaries rather than clinical practice guidelines and fail to account fully for the symbiotic nature of FCP between child, parent, professional and the wider service/organisation. In an effort to ameliorate this, McCarthy (2019) presents the results of a multi-method research project on FCP in early intervention (EI) in the form of two expedient models (i) outlining the processes and outcomes of Family-Centred Care (FCC) in EI and (ii) an ecological framework of FCC which contextualises this FCP at individual, team/community and organisational/national level. Broad categories of FCP processes and outcomes, and a sample of the many factors which influence FCP, are presented in Table 2.3.

Table 2.3: Processes and Outcomes of FCP in EI adapted from McCarthy (2019).

Processes	Outcomes	Sample of Influencing Factors
<ul style="list-style-type: none"> <li>• Participatory caregiving</li> <li>• Relational caregiving</li> <li>• Child-focused activities</li> <li>• Operational practices</li> <li>• Emotional support</li> <li>• Other processes</li> </ul>	<ul style="list-style-type: none"> <li>• Child and family outcomes</li> <li>• Professional outcomes</li> <li>• Service operation outcomes</li> <li>• Social and community outcomes</li> <li>• Other outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Service operations and resources</li> <li>• Professional characteristics</li> <li>• Family engagement</li> <li>• Outcomes of FCP</li> <li>• External supports</li> <li>• Child and family characteristics</li> <li>• Culture of “expertism”</li> <li>• Parent well-being</li> </ul>

## 2.4 Family-Centred Practice in Action

A key challenge in the implementation of FCP is the translation of academic theory into operational guidelines and clinical behaviours. Dunst and Espe-Sherwint (2016) caution against the oversimplification of FCP by healthcare professionals as merely “being nice to” or prioritising families. This arguably all too common understanding of FCP fails to account for the multifaceted nature of this phenomenon and the premises, principles, and elements of FCP which must be understood and complied with. In Ireland, research has indicated that many EI professionals had a relatively superficial understanding of FCP while the corresponding knowledge of parents who received EI services for their children was sparse or largely not evidenced at all (McCarthy, 2019). In fully integrating outcomes-focused FCP it is essential that professionals understand FCP as both a theoretical concept and a model of practice to execute, measure and evaluate it effectively. Furthermore, in moving away from paternalistic disability care it is asserted that it is crucial that parents/families are informed about the model of service they are receiving in order to be active and collaborative agents in the services delivered to their child and family.

**2.4.1 The role of the CDNT member in family-centred practice.** FCP can be conceptualised as a “transactional process” between the professional, family and child (Schenker, Parush, Rosenbaum, Rigbi, & Yochman, 2016). Significantly, the professional is as active a participant in the dynamic process of FCP as the beneficiaries of this care and a vital agent in implementing FCP effectively. In examining the previously discussed research summaries presented, help-giving practices are identified as inherent in the delivery of FCP, namely participatory and relational practices (Dunst et al., 2006; 2007). Specifically, relational clinical input is defined by what is typically described as “good” clinical skills (i.e. skills such as active listening, empathy, showing respect and being non-critical and impartial) and professionals’ attitudes towards families’ abilities and skills (Dunst & Trivette, 1996). Participatory help-giving methods are more dynamic in nature and represent responsive and adaptive practices which emerge in response to families’ needs and help to engage families during the process (i.e. collaboration, flexibility, joint decision making and family action) (Dunst & Trivette, 1996). Critically it is the



complementary and simultaneous delivery of both practices which is unique to the phenomenon of FCP (Dunst et al., 2007). The European Association for Early Childhood Intervention (EURYAID) *Recommended Practices in Early Childhood Intervention: A Guidebook for Professionals* (2019) expand on this further by also citing technical quality (i.e. professionals' knowledge, skill set, experience, and specialisation) as an essential factor in the delivery of effective care provision as per Dunst, 1998 (see Figure 2.4). Professional training and skills development will be discussed in further detail in Chapter 4.

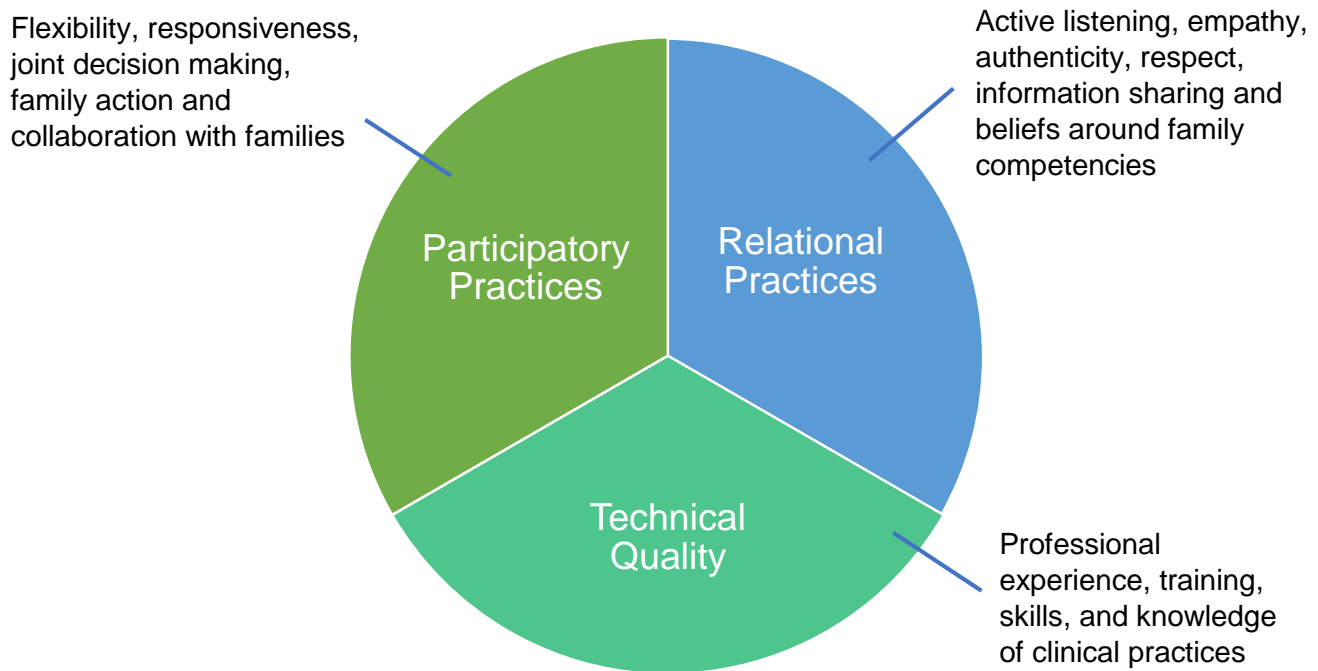


Figure 2.4: Three Components of Effective Help-Giving Practices adapted from Dunst (1998) as referenced in EURYAID (2019)

**2.4.2 The delivery of family-centred practice.** In exploring the phenomenon of FCP it can be argued that the transition of academic theory and empirical research to the changing and non-standardised context of professional practice can be met with several challenges. Informed by an extensive body of research and experience in clinical practice, Dunst and Trivette (2009) proposed a *Family Systems Assessment and Intervention Practice Model* to support the implementation of family-centred early intervention (EI). This model outlines four principles which are both conceptual and operational in nature to provide a practice framework for the delivery of early services to young infants/children with disabilities and their families (see Figure 2.5). This framework presents the symbiotic process of FCP whereby different elements are prioritised and emphasised based on unique family and professional characteristics and specified needs. In addition to the four outlined operational principles, Dunst and Trivette (2009) present corresponding assessment and intervention goals (see Table 2.4)

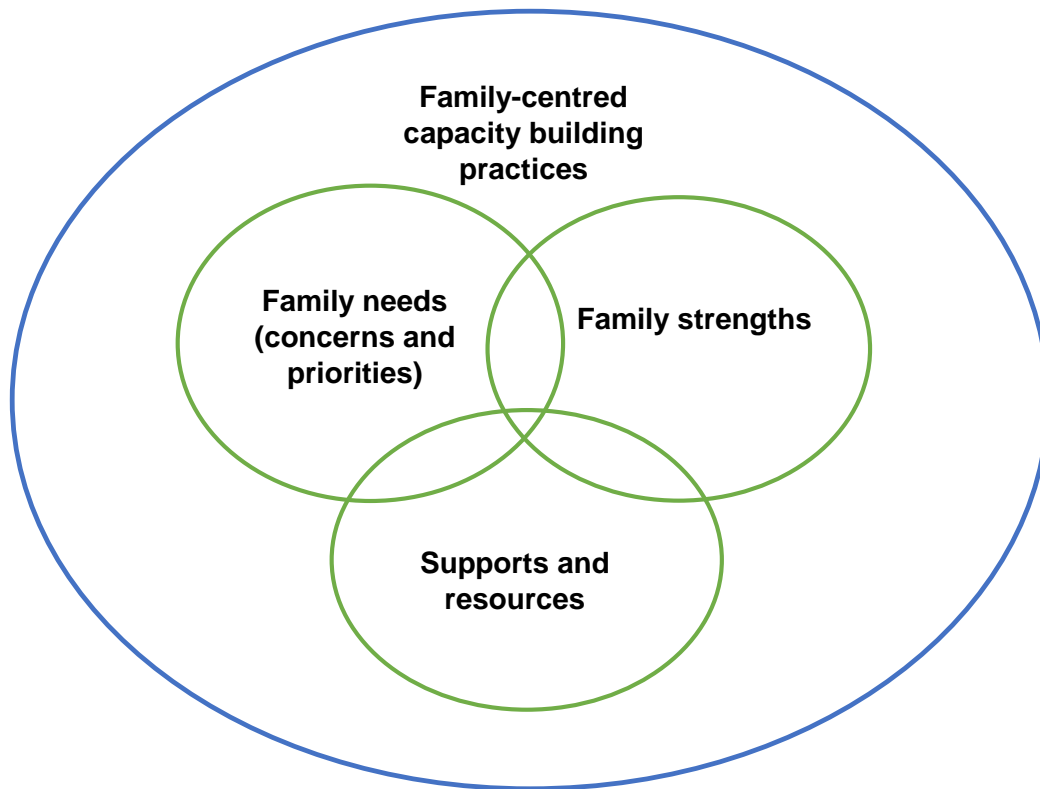


Figure 2.5: Family Systems Assessment and Intervention Practice Model adapted from Dunst and Trivette (2009)

Table 2.4: Family Systems Assessment and Intervention Practice Model, Operational Principles and Corresponding Assessment and Intervention Goals adapted from Dunst and Trivette (2009)

Operational Principles	Assessment and Intervention Goals
(i) To enhance child, parent and family functioning interventions must be grounded on family concerns, needs, goals and priorities.	(i) To identify relevant concerns, needs, goals and priorities, appropriate assessment tools and methods must be employed.
(ii) To help facilitate resources to meet the family's needs, help strengthen the family's social network, and promote information sources and additional support sources.	(ii) Identify family strengths and capacities by first outlining the family's existing capabilities and then identifying strengths that will help facilitate the family in utilising available resources to meet needs.
(iii) To enhance the efficacy of the intervention, employ the family's functioning style (strengths & capabilities) to help facilitate the utilisation and development of resources.	(iii) "Map" the family's personal social network to identify existing supports and resources, and potential supports which have not yet been utilised.

(iv) To promote the family’s capacity to become more self-sufficient through the development and utilisation of skills which help them source and employ relevant resources and supports, to meet identified needs.

(iv) Occupy several help-giving roles to help empower the family to become more confident and skilled at utilising resource and supports to help meet their needs and accomplish their goals.

In examining the impact of the *Family Systems and Intervention Practice Model* on child and family outcomes, Trivette, Dunst and Hamby (2010) report that capacity-building care practices and family-systems interventions had a clear effect on parent self-efficacy and well-being. Indirect influences of practices reported included the influence on parent-child relations and child development in this process, with these outcomes dependent on self-efficacy beliefs and parent well-being. Again, FCP cannot be summarised in simplistic cause and effect framework, as this process is both complex and multifaceted. In consideration of the reviewed theoretical definitions of FCP and the available empirical and operational models of FCP, it is difficult to neatly incorporate FCP into existing disability policy and practices in the absence of a robust and evolving operational framework.

## **2.5 Family-Centred Practice and Working in an Outcomes-Focused Way**

Ascribing to a family-centred set of principles promotes CDNTs to progress towards working in an outcomes-focused way where prescribed goals and process indicators guide service delivery. Critical protocols and procedures listed in this document, such as the IFSP<sup>4</sup> process and the support of a support coordinator,<sup>5</sup> outline clear elements of FCP. Specifically, this chapter sought to outline FCP (theoretically, empirically, and practically) to support disability professionals to understand this complex phenomenon better. It is therefore hoped that this will subsequently improve the family-centredness of interventions delivered and help facilitate parents/families understanding of the model of service they receive. FCP can be understood as a mix of capacity building relational and participatory caregiving practices. This model is still in its adolescence without a universal practice framework. However, progressing the transition towards outcomes-focused FCP will be explored in subsequent chapters through action research with implications for professional development and clinical practice discussed.

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<sup>4</sup> Co-produced with a CDNT, an IFSP is a “dynamic, rolling plan, with continuous progress and updating of strength-based goals relevant to a child and their family” (*Children’s Disability Services Procedures and Process*; HSE, 2018a, p.3). IFSPs are how families access services and supports under a family-centred framework and are therefore an integral part of service efficiency.

<sup>5</sup> The *Children’s Disability Services Procedures and Process* (HSE, 2018a; see Appendix A) proposed assigning a nominated CDNT member to also provide a generic “case coordinating” function for identified children and their families. Other terms used to describe a similar function include “key working” and “link working.” Mindful of the cultural shift from care to empowerment, the proposed new descriptor “support coordinator function is used in this document.

## Chapter 3: CHO 3 Pilot Project: Barriers and Facilitators of Collaborative Goal Setting with Families.

### 3.1 CHO 3 Pilot Project: Barriers and Facilitators of Collaborative Goal Setting with Families

Having explored what FCP is and its importance, this chapter considers FCP and the development of IFSPs through collaborative goal setting with families in Irish CDNTs. Specifically, it explores the experience and reflections of CDNTs in the Mid-West (CHO 3), during their ongoing transition towards providing services in a family-centred manner, through interdisciplinary working. CDNTs within CHO 3 provide services to children with complex developmental difficulties and their families residing in Clare, Limerick, and North Tipperary. Each CDNT has a CDNMs.<sup>6</sup> CHO 3 is a mix of rural and urban populations (Table 3.1). Additionally, each CDNT uses the HSE-owned Children’s Disability Management Information System (MIS).<sup>7</sup>

*Table 3.1: Breakdown of CHO 3 Services and Locations*

	CDNT	Lead Agency
1.	North Tipperary CDNT, Nenagh, Co. Tipperary	Enable Ireland
2.	Treehouse CDNT, Dooradoyle, Limerick	Saint Gabriel’s
3.	Blackberry Park CDNT, Ballykeeffe, Limerick	Enable Ireland
4.	West Limerick CDNT, Newcastle West, Limerick	Brothers of Charity
5.	East Limerick CDNT, Ballysimon, Limerick	Daughters of Charity
6.	Clare CDNT, Ennis, Co. Clare	HSE

The CHO 3 project focused on utilising action plans to support teams to develop processes surrounding collaborative goal setting. An overview of the methods utilised during this time alongside findings and future directions is presented below.

<sup>6</sup> CHO 3 Children’s Disability Service Managers are noted here as Children’s Disability Network Managers (CDNMs). Panelled individuals are in the process of taking up these newly created CDNMs posts for all 91 CDNTs.

<sup>7</sup> To support CDNT working, the HSE is in the process of procuring a National Children’s Disability Network Team Information Management System (CDNTIMS). This will include enhancing the functionality of the existing MIS; providing a comprehensive training programme; and rolling this CDNTIMS out to all CDNTs. As well as linking with the National Ability Support System (NASS), the CDNTIMS will also return both IFSP-related data and family feedback on both the nature of service provided and service effectiveness (see Appendix B).

## Objectives

The overall aim of this research was to look at the potential use of action plans to support teams to develop processes that would facilitate the use of collaborative goal setting.

The research questions explored were:

- What are the barriers and facilitators to family-centred decision-making practices within teams?
- Does the development of action plans affect the development and quality of goal setting within teams?

## Data Collection

Data were collected via focus groups. Each of the focus groups was hosted in the local service by a member(s) of the research team. Focus groups varied in length but were a maximum of two hours.

The initial focus group covered the following questions:

- When it comes to goal setting currently, how do you do this?
- What affects your current goal setting practice in relation to the following:
  - a) Setting team goals
  - b) Setting unidisciplinary goals
  - c) Collaborative goal setting with parents
- What do you think might support this process referring to a, b, and c above?

## Future Directions

Members of the research team were approached by the HSE in late 2018 to present the project findings and were provided with funding for staff reallocation to a change facilitation team to continue the project with CHO 3 collectively. This expansion was not a direct extension of the initial pilot project.

Additional staff were recruited to the change facilitation team to support the principal investigator from the original pilot project. The wider implementation was focused on supporting all CHO 3 CDNTs to move towards a service delivery model that utilised collaborative goal setting with families.

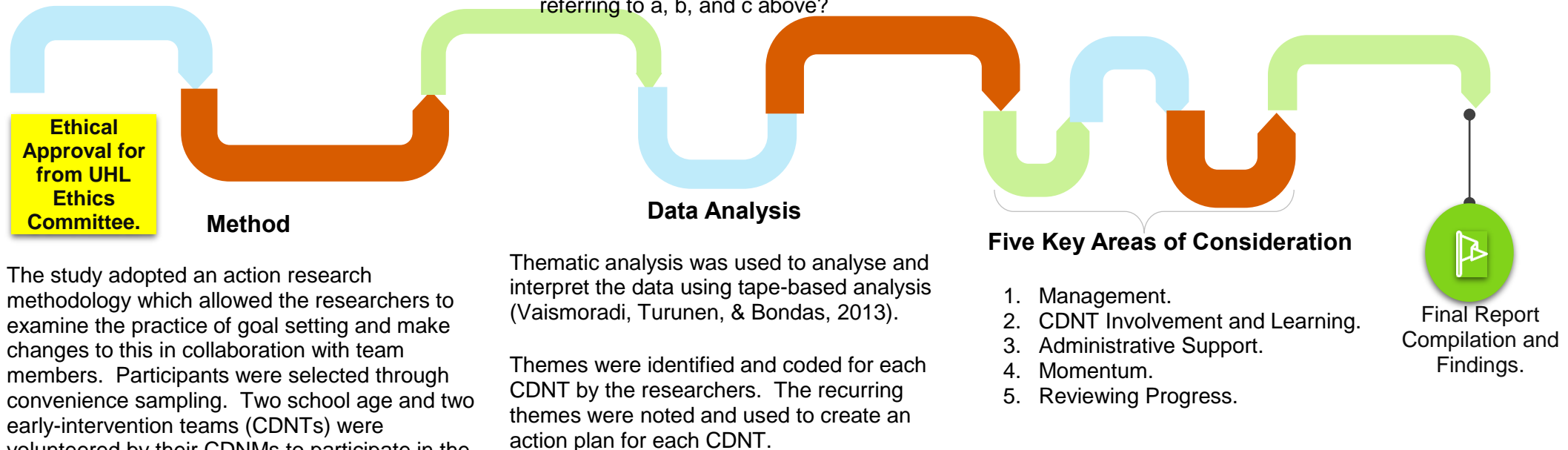


Figure 3.1: Outline of CHO 3 Collaborative Goal Setting project and findings.

**3.1.1 Results.** Through reflection on the action plans generated by the change facilitation team based on the content of the focus groups, CDNTs were able to identify five key areas as building blocks to advancing collaborative goal setting with families within their services. These were: management, team involvement and team learning, administrative support, momentum and reviewing progress.

**3.1.1.1 Management.** Participants reported that CDNMs needed to be the driving force behind CDNTs engaging in collaborative goal setting with families. Given the nature of the change, and the potential perception of risk on behalf of the CDNT members in relation to moving away from traditional unidisciplinary practices to more collaborative work, CDNMs need to champion the change. Specifically, CDNT members reported feelings of anxiety about who would be held accountable in a situation where their clinical judgement and family priorities did not align.

Indeed, some CDNMs noted the importance of “*holding the risk*” throughout this process to ensure their CDNTs could focus on developing their skills without concerns of repercussions. For example, one CDNMs noted the importance of absorbing any risks of the process to ensure its success (e.g. moving from professionally driven services to family-allied services where the family has an increased role in service delivery experiences, increased awareness of reasoning behind waiting times for support, and increased transparency around service delivery errors when they occurred).

**3.1.1.2 CDNT involvement and CDNT learning.** On reflection, when the participating CDNTs were discussing how to work through their action plan, the need to focus on collaborative and supportive working practices in an interdisciplinary way arose as a concern. The creation of service/CDNT-specific action plans allowed each CDNT to focus their efforts on where they could make the most impactful changes to the delivery of services to support moving towards increased collaborative goal setting with families. One CDNT member stated, “*We all have a certain level of trans-disciplinary knowledge....and it does depend on clinician’s knowing where their boundaries and limits are, that’s really important*”. For one to know these boundaries, it is important to draw on the experiences of their colleagues to collectively move forward.

**3.1.1.3 Administrative support.** Participants reported that having a supportive way of documenting information could be a facilitator to change. Specifically, given the nature of collaborative goal setting and the need to be adaptive to changing family needs, having a concrete method or system of maintaining and tracking this information is important. CHO 3 was piloting an information management system called MIS that allowed for CDNTs to manage documentation in a way that centralised the family’s goals and the processes required to support the achievement of same within the system. The system was integral to ensuring that CDNTs focused on family’s goals when planning interventions. “*If we can’t capture those kinds of things (family support) in the document then we’re missing the hugest part of the school age service.*”

**3.1.1.4 Momentum.** During the implementation phase of the action plans, whilst embedding new practices, ensuring momentum was critical. CDNT members expressed concerns that it could be intensive for them and for families at the start of the collaborative goal setting process to explore implications of this change and reflect on experiences. This was partly due to the amount of information CDNTs needed to understand about the family (e.g. current situation, priorities, and supports structures). It was also acknowledged that the process was challenging due to workload management. CDNTs that had their action plans embedded in a more substantive way by the end of the *CHO 3 CDNT Collaborative Goal Setting pilot project* reported that the process of building increased collaborative goal setting opportunities with families had become more efficient. This was partially due to the development of interdisciplinary skills and therefore, facilitating an effective use of expertise across disciplines in a shorter space of time than individual appointments might have allowed. Given the level of work involved (inclusive of the opportunity to reflect on one's practice), it was important that when progress was made, staff used their successes to spur others on and to support other CDNT members.

**3.1.1.5 Reviewing progress.** Participant CDNTs welcomed the opportunity to review their progress with the research teams. Although initially the purpose of the focus groups was to gather data and reflect on changes related to CDNTs trialling their action plans, these meetings became an opportunity for CDNTs to discuss interservice collaboration and learning from others. This then facilitated a progression in terms of service delivery related to collaborative goal setting with families.

### 3.2 Expanded Project: Supporting Collaborative goal setting practises within all CHO 3 CDNTs

Following the pilot project, an expanded project (still under the umbrella of the *CHO 3 CDNT Collaborative Goal Setting Project*) was proposed and funded through the HSE led by a team of three “change facilitators” (including a funded Research Assistant). This expanded project focused on supporting all CDNTs in CHO 3 to develop and refine the skills necessary to increase collaborative goal setting practises.

Table 3.2: CHO 3 CDNT Collaborative Goal Setting Project.

Pilot Project Goals (June 2018 – Jan 2019)	Expanded Project Goals (January 2019 – May 2020)
<ul style="list-style-type: none"> <li>• Focused on collaborative goal setting with selected CDNTs in CHO 3.</li> <li>• Aimed to understand barriers and facilitators to collaborative goal setting within these CDNTs as a starting point for the progression towards the move to outcomes-focused FCP.</li> <li>• Focused on understanding a specific research aim and a lessened focus on daily operations and practical aspects of FCP deliverance.</li> <li>• Did not consult with parents or external stakeholders.</li> </ul>	<ul style="list-style-type: none"> <li>• Focused on CDNM driving change within their own team, with support from change facilitators.</li> <li>• Focused on IFSP and SMART goal writing with <b>all</b> CDNTs in CHO 3 as the vehicle towards collaborative goal setting and a steppingstone to outcomes-focused FCP.</li> <li>• Spent more time with CDNTs to discussing ongoing difficulties with collaborative goal setting with families.</li> <li>• Developed a “Framework for Change” for teams establishing IFSPs for service users, based on FCP model of care, and collated information garnered regarding the family experience and perspective of this process.</li> <li>• Included research with parents on the in-development FOQuS and FOQuS-YP (parent and young person surveys about the OCFF outcomes).</li> <li>• Included consultation with other external stakeholders (e.g. primary care).</li> </ul>
<b>Shared Goals (Both Projects)</b>	
<ul style="list-style-type: none"> <li>• Expand awareness and commitment towards implementing PDS with outcomes-focused FCP as the service delivery approach.</li> </ul>	

Process indicators a CDNT are measured against in relation to embedding outcomes-focused FCP can be measured through the evaluation of completed IFSPs. Therefore, further investigation took place to explore the use of collaborative goal setting to guide IFSP completion. Likewise, the expanded project sought to refine how an Irish iteration of FCP might take shape. This refinement was predicated upon the continued interaction with CDNTs in CHO 3 to investigate the



practices that would support a sustained move towards collaborative goal setting with families.

This would then support teams to write high quality IFSPs and included assisting teams with developing their SMART goal writing skills. Regular meetings with teams provided useful insights into the nature of how CDNTs functioned in the early stages of implementing FCP through the writing of IFSPs with families. This included insights into the establishment of protected time slots for CDNTs to discuss IFSPs in an interdisciplinary context, how CDNTs were managing their waiting list and deciding how IFSPs would be allocated to team caseloads, as well as the implementation of other practices included throughout this report. This was supplemented by expanding the focal point of the work further afield to include other stakeholders, in this case, parents. Specifically, parents were asked to provide feedback based on their individual experiences of their respective service in relation to the OCFE outcomes.<sup>8</sup> Based on the *CHO 3 CDNT Collaborative Goal Setting Project* all CDNTs believed they engaged with families at a level that already included family-centred elements but in practice they moved between points on the continuum discussed in Chapter 2 (Dunst et al., 1991) and illustrated below (Figure 3.2).

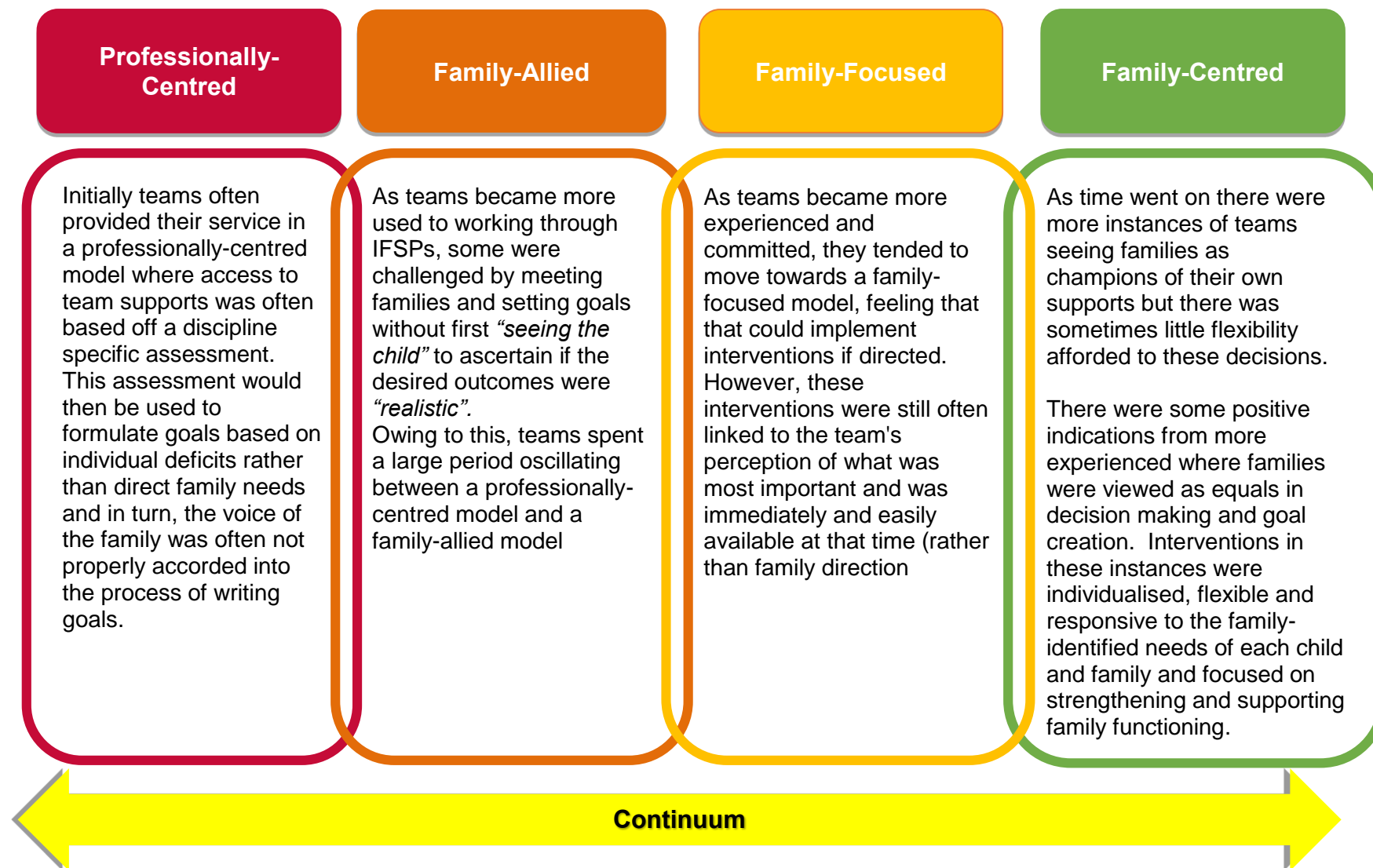


Figure 3.2: Team experiences in CHO 3 of moving to a more family-centred model of service delivery using the Dunst et al. (1991) categories (as adapted from Espe-Sherwindt, 2008).

## Chapter 4: Operational Framework for CDNMs with their CDNTs for Progressing Towards Outcomes-Focused Family-Centred Practice

### 4.1 Introduction

The research completed in CHO 3 on collaborative goal setting sought to begin the process of translating outcomes-focused FCP into everyday work practices as part of CDNT service delivery and to develop a framework for other CDNTs to use to guide their own journey towards outcomes-focused FCP. As described in Chapter 2, FCP can be understood as a mix of capacity building relational and participatory caregiving practices.

With understanding the components of FCP and the findings of the pilot research project in relation to the five key areas of consideration (i.e. Management; Team involvement and learning; Administrative Support; Momentum; and Reviewing Progress), this chapter considers how outcomes-focused FCP can be translated into practice. Within the key areas identified by the participant CHO 3 CDNTs, management was identified as the most significant contributor as to whether a CDNT progresses towards a consistent approach of collaborative goal setting with families. Therefore, there is an emphasis in this chapter on the role of the CDNMs.

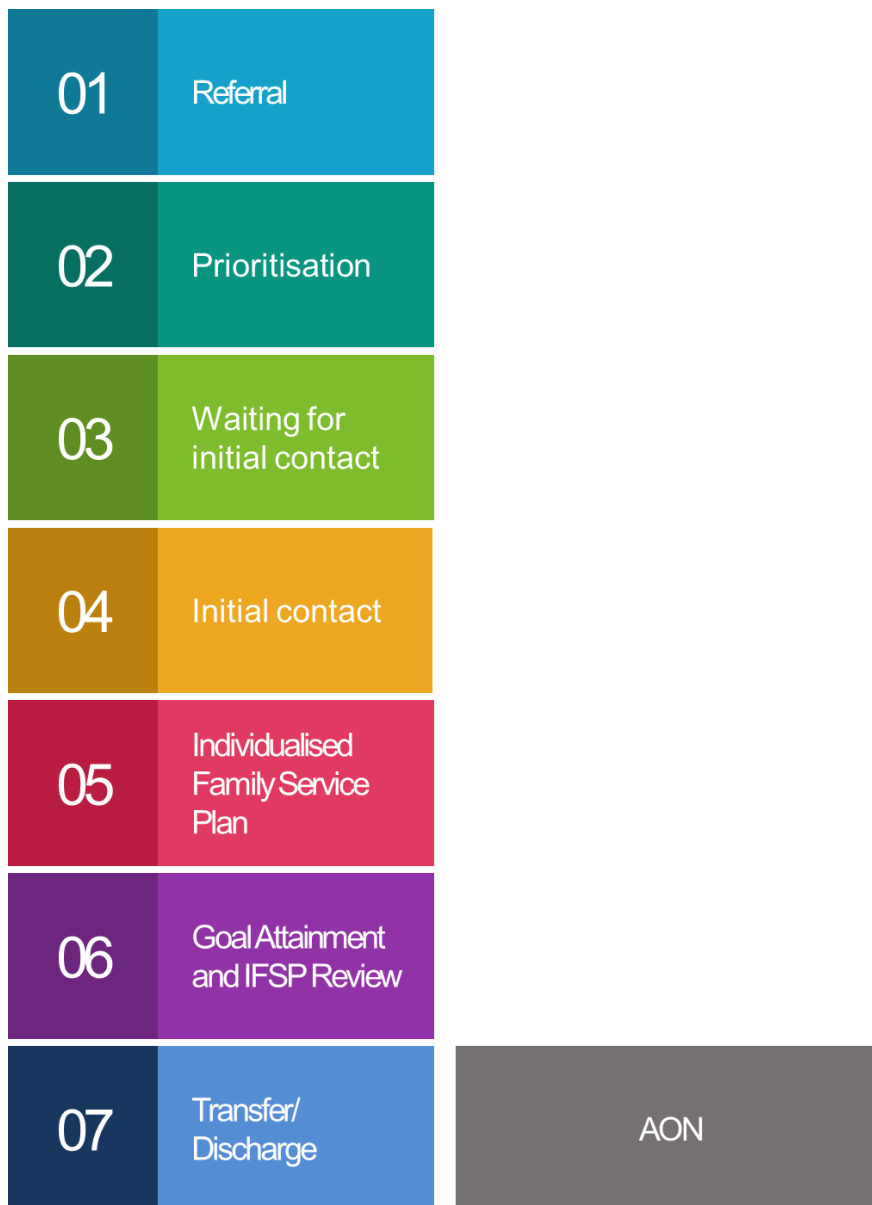
### 4.2 Critical CDNT Work Processes

As informed by the academic literature, the HSE's (2018a) *Children's Disability Services Procedures and Process*,<sup>8</sup> the HSE's (2019) *National Team Development Programme (NTDP)*, and the findings of the CHO 3 Collaborative Goal Setting project, this chapter presents recommendations to deliver outcomes-focused FCP. These recommendations are presented according to each critical CDNT work process element (and other elements such as AoN) as shown in Figure 4.1, followed by learning from employing these in the CHO 3. Outlined at the end of each work process, these CDNT actions are intended to support all existing and reconfiguring CDNTs as part of the national implementation of PDS.<sup>9</sup> Similarly, a summarisation of key operational framework points can be found in Figure 4.2.

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<sup>8</sup> Signed off by the (National) Children's Services Team in 2018, this document details the work processes that all CDNTs will use (see Appendix B).

<sup>9</sup> Each CDNMs will manage their CDNT in implementing these actions.



*Figure 4.1: CDNT Critical Work Processes (adapted from Children’s Disability Services Procedures and Process, HSE, 2018a)<sup>14</sup>*

Figure 4.2 is based on the work processes detailed in Figure 4.1; it represents a summary overview of the key actions outlined throughout Chapter 4 for progressing towards outcomes-focused working. It will not serve as a replacement for total and focused engagement with Chapter 4 but as tool to use for revision or reflection purposes.

# Work Process

# Key Actions








<p><b>REFERRAL</b> (4.2.1)</p> 	<ul style="list-style-type: none"> <li>• Implement the <i>National Policy on Access to Services for Children &amp; Young People with Disability &amp; Developmental Delay</i> (HSE, 2019).</li> <li>• Provide information for referrers on model of service, FCP and outcomes focus.</li> <li>• Have a defined procedure for managing referrals with flow charts.</li> <li>• Use the referral information for a team discussion on the child's and the family's strengths and needs.</li> <li>• Provide information on the service for families in a variety of media – leaflets, website.</li> <li>• CDNTs will send an acknowledgement of acceptance into the service to the family and will clarify what happens next.</li> </ul>
<p><b>PRIORITISATION</b> (4.2.2)</p> 	<ul style="list-style-type: none"> <li>• Implement the <i>National Policy on Access to Services for Children &amp; Young People with Disability &amp; Developmental Delay</i> on prioritization of referrals (HSE, 2019).</li> <li>• CDNTs will communicate regularly with families on the waiting list and keep them informed of their current level of prioritization.</li> </ul>
<p><b>WAITING LIST MANAGEMENT</b> (4.2.3)</p> 	<ul style="list-style-type: none"> <li>• Provide transparent information for families on the waiting list policy and procedure</li> <li>• Introduce families to the model of service using a variety of means (e.g. meetings, leaflets).</li> <li>• Offer universal low intensity waitlist initiatives (e.g. general information on available community supports).</li> </ul>
<p><b>INITIAL CONTACT</b> (4.2.4)</p> 	<ul style="list-style-type: none"> <li>• Provide orientation to the IFSP Process.</li> <li>• Profile family priorities for their child/family based on family priorities and CDNT observations, develop agreed initial goals.</li> <li>• Provide guidance on strategies specific to the agreed initial goals that families can use immediately.</li> <li>• CDNTs will document the role of the support-coordinator and can communicate what the role is clearly to families.</li> <li>• Assign a key worker/support co-ordinator to the family.</li> <li>• Facilitate development of the initial goals and IFSP within six weeks of initial contact.</li> </ul>
<p><b>INDIVIDUAL FAMILY SERVICE PLAN (IFSP)</b> (4.2.5)</p> 	<ul style="list-style-type: none"> <li>• Use one of the national IFSP templates.</li> <li>• Have in place procedures for the management of IFSPs, including the role of the key worker/support co-ordinator.</li> <li>• Conduct IFSPs with the mindset that the family/child's priorities are central to planning service delivery.</li> <li>• Guide families/children in setting goals that are specific, measurable, achievable, realistic, and time-bound.</li> <li>• Have a system to audit IFSPs on a regular basis by the CDN and CDNT.</li> <li>• Have a clear plan to work towards having current IFSPs for 100% of the children attending the service.</li> </ul>
<p><b>GOAL ATTAINMENT AND IFSP REVIEW</b> (4.2.6)</p> 	<ul style="list-style-type: none"> <li>• Treat each IFSP as a dynamic, flexible document which changes depending on current family priorities.</li> <li>• The IFSP is the focus of every contact between the CDNT and the family.</li> <li>• Provide supervision and support for CDNT members on how to set goals in collaboration with families.</li> <li>• Ensure goals relate to the family priorities as set out in the IFSP.</li> <li>• Have in place a system to regularly audit goals and goal attainment by the CDN and CDNT.</li> </ul>
<p><b>TRANSFER/ DISCHARGE</b> (4.2.7)</p> 	<ul style="list-style-type: none"> <li>• Implement the <i>National Policy on Discharge and Transfer from CDNTs</i>.</li> <li>• Have an interdisciplinary transfer form to detail the child's strengths and needs and the current family priorities and goals.</li> </ul>

Figure 4.2: Operational Framework for Progressing Outcomes-Focused Family-Centred Practice.

## 4.2.1 Referral

**4.2.1.1 Existing Practices in CHO 3.** The CDNTs in CHO 3 used a regional referral form that led referrers and families to identify individual discipline-specific support requirements for the referred child, through labelling existing deficits. This form did not offer explicit opportunities to explore the child or families' needs and priorities. Please see Tables 4.1 to 4.4 for specific information in relation to the learnings in CHO 3 in relation to referrals, and considerations for all CDNTs.

*Table 4.1: Learning from CHO 3 CDNTs related to discussing referrals.*

<p><b>Consideration:</b> When discussing referrals, CDNT members expressed difficulties with translating the information from the unidisciplinary needs cited in the referral form to a more CDNT-based discussion about the referred child. CDNTs subsequently found it difficult to identify the most relevant people to complete an IFSP meeting with the family.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> CDNT members began to look at referrals in an interdisciplinary way. The specific deficits that were identified through the referral form were discussed more broadly in terms of their functional and participatory impact.</p>
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*Table 4.2: Learning from CHO 3 CDNTs related to external stakeholder complexities.*

<p><b>Consideration:</b> CDNT members noted that external stakeholders including referrers (e.g. GPs, Area Medical Officers, Primary Care therapists) were not aware of the progression towards increased family-centred practices in service delivery within CDNTs and tended to continue to request services based on a unidisciplinary, block-based therapy model of service delivery. This was further complicated by the continued use of a deficit-based referral form.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> A presentation was prepared by the change facilitation team and trialled with two clinical groups in primary care in two regions of CHO 3. This presentation focused on the move by CDNTs towards service provision using more family-centred practices. The presentation was well received but requires more extensive discussion with a wider range of groups, including external services, within and outside of health service providers.</p>
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*Table 4.3: Learning from CHO 3 CDNTs related to appreciating diverse family needs.*

<p><b>Consideration:</b> CDNT members reflected on the challenges of appreciating the diverse needs of families. A "one size fits all" approach was deemed not appropriate. Rather, CDNTs wanted to offer a variety of services. Services also saw the need to focus on building strong relationships with families and acknowledging their strengths. CDNTs identified needing a plan to involve families at all stages of the service delivery process and support joint decision making.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> CDNTs appreciated the diverse needs of families in relation to the provision of information in a variety of formats (e.g. throughout all stages of service delivery including referral). While it needs further review, the change facilitation team had begun producing an information leaflet on CDNTs' model of service delivery.</p>
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Table 4.4: Considerations for all CDNTs with the oversight of CDNMs in managing the referral process.

**Actions required to progress outcomes-focused FCP:**

- CDNTs will implement the *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* (HSE, 2019) across all stages of referrals.
- CDNTs will provide information to referrers on PDS including outcomes-focused FCP to support consistent messaging to families/young people.
- CDNTs will have a process in place relating to management of referrals for example the use of flow charts.
- CDNTs will discuss all referrals and potential needs, including team supports, that may be required rather than considering same based on diagnosis. Given the interdisciplinary focus, the referral forms from the *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* (HSE, 2019)<sup>10</sup> will facilitate this process.
- CDNTs will engage in interdisciplinary discussion of referrals based on the information provided. This will allow CDNTs to better plan how to proceed with referrals from an IFSP planning and resource allocation perspective. This discussion may also include other children within the same family that may be availing of supports both within CDNTs but also from other healthcare service providers.
- CDNTs will discuss the family/child's needs related to their strengths and how the service will further build on these strengths. This discussion will be central to the referral conversation. This will be supplemented by the referral form.
- CDNTs will establish the family/young person's preferences for communication as well as their accessibility requirements at the time of referral and will use this information to guide all communication with them (e.g. the requirement of language interpreters, considerations related to the scheduling of appointments and arrangements for transportation).
- CDNTs will communicate with families/young people following the receipt of referral with an acknowledgement of acceptance into the service and will clarify what happens next.
- All CDNT members' communications will be offered in an inclusive, clear, and concise way using leaflets, information on a website and will also provide access to a support coordinator for further clarification as required. Information will also be provided respecting cultural beliefs and practices.
- CDNT members will understand and be able to explain to families, referrers, and all external stakeholders what outcomes-focused family-centred practice is and the core elements that make up their service delivery model. This can be supplemented through the provision of materials.

<sup>10</sup> This policy requires the completion of a (generic) "Children's Services Referral Form"; and 1 of 5 age-appropriate "Additional Information Forms".



## 4.2.2 Prioritisation

**4.2.2.1 Existing Practices in CHO 3.** Each CDNT in CHO 3 had their own prioritisation criteria and mechanisms. Children waiting for their initial contact were deemed as “standard” or “urgent” depending on these criteria. See Table 4.5 for the learnings from CHO 3 CDNTs and Table 4.6 for national considerations.

*Table 4.5: Learning from CHO 3 CDNTs related to competing service priorities.*

<p><b>Consideration:</b> CDNTs were grappling with the competing priorities of AoN referrals and the “standard” list of referrals. CDNTs reported that the AoN process was contradictory to working in an outcomes-focused FCP manner. Congruently, working through the IFSPs and AoNs led to challenges with working two opposing processes and managing the required prioritisation of AoN referrals.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> It was acknowledged that families need to be made aware from the start of their relationships with CDNTs that there will be conflicting demands on service providers and that service continuation may be challenged by the statutory obligations of AoN to which services are bound. This information can be included within the “introductory meeting” (see section 4.2.3.1) and through any other means decided upon, literature etc.</p>
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*Table 4.6: Considerations for all CDNTs with oversight from CDNMs for managing the prioritisation across service.*

<p><b>Actions required to progress outcomes-focused FCP:</b></p> <ul style="list-style-type: none"><li>• CDNTs will implement the <i>National Policy on Prioritisation of Referrals to Children’s Disability Network Teams</i> (HSE, 2015).</li><li>• CDNTs will communicate in an open manner with families/children about how their referral has been prioritised (e.g. in the context of competing demands on the CDNT).</li><li>• CDNTs will create and maintain a culture of consistency in how they identify the child/family needs of each referral and consistency in how the referral is “managed” from a service’s procedural framework.</li></ul>
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## 4.2.3 Waiting for Initial Contact

**4.2.3.1 Existing Practices in CHO 3.** Each CDNT in CHO 3 had different procedures and ways of deciding how children and families received information or services whilst they were waiting for initial contact (i.e. the first IFSP-related contact). Initial contact refers to the first meeting between the CDNT and the family. Some CHO 3 CDNTs provided “introductory meetings” for groups of newly referred families (see table 4.8 below and Appendix C). Some CHO 3 CDNTs also offered waiting list initiatives, including generic supports (e.g. “*Sleep Tight*” parent training). Please see Table 4.7 for CHO 3 learnings in relation to supporting children and families waiting for their initial contact and Table 4.8 for national considerations.



*Table 4.7: Learning from CHO 3 CDNTs related to families waiting for their initial contact.*

<p><b>Consideration:</b> CDNTs reported that in the initial contact (i.e. the first IFSP-related contact), they were spending significant amounts of time introducing families to the service delivery model. They expressed that if parents received this information prior to this contact as well as strength-based goal setting training, they would be more confident and empowered for the initial contact/IFSP contact.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> The “introductory meeting” was updated to reflect the changing nature of service delivery to one that incorporated interdisciplinary team working using an outcome-focused FCP approach. All teams agreed to adopt the “introductory meeting”. The possibility of running a peer-facilitated parent training course around strength-based goal setting within CHO 3 was a “next step” in terms of empowering families to take ownership of their IFSP. Please refer to Chapter 6 for further information on this.</p>
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*Table 4.8: Considerations for all CDNTs with oversight from CDNMs for managing waiting for initial contact.*

<p><b>Actions required to progress outcomes-focused FCP:</b></p> <ul style="list-style-type: none"> <li>• CDNTs will communicate regularly with families on the waiting list and keep them informed of their status.</li> <li>• CDNTs will offer generic waitlist initiative groups/information sessions to families prior to their initial contact where possible and relevant (e.g. general information on available community supports).</li> <li>• Where it is considered useful, CDNT members may periodically provide an “introductory meeting” to groups of families. These meetings aim to:             <ul style="list-style-type: none"> <li>○ Introduce families to the nature of the service.</li> <li>○ Introducing outcomes-based and family-centred language.</li> <li>○ Reduce the amount of time CDNTs spend in the initial contact orientating the family to the service and allow time for focusing on initiating IFSP development.</li> </ul> </li> <li>• CDNTs will offer support to families where the focus is on developing and building on goal setting skills for themselves in preparation for their initial contact with the CDNT and IFSP development.             <ul style="list-style-type: none"> <li>○ This could be presented through group sessions with families where the focus is on skill building for collaborative goal setting with their CDNT from a strength-based approach.</li> <li>○ At the end of these sessions each family will be confident on what a goal is, how to write one and how to use supports and information provided by their CDNT to achieve the goal.</li> </ul> </li> </ul>
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#### 4.2.4 Initial Contact

As per the CDNT Critical Work Processes, the aim of the initial contact is to begin to develop the IFSP including discussing priorities, developing some initial goals, and providing some initial strategies<sup>11</sup>. The IFSP can then be completed over several weeks. Another function of this stage of the process is to allocate a support coordinator. Other terms used to describe a similar function include “key worker”

<sup>11</sup> Strategies are actions that parents will undertake to support the achievement of their family’s goals.

and “link worker.” Mindful of the cultural shift from care to empowerment, the proposed new descriptor “support coordinating” (as mentioned above) is used here.

**4.2.4.1 Existing Practices in CHO 3.** There was large variance between CDNTs in CHO 3 as to how children and families became active or had an initial contact with CDNT members. Some teams offered an initial contact/pre-screening appointment where the IFSP process started. Other CDNTs saw families for a team assessment prior to IFSP development whilst others saw families individually for discipline-specific assessments prior to their IFSP. See Table 4.9 for experiences from CHO 3 in relation to the role of support coordinator and see Table 4.10 for considerations for all CDNTs nationally.

*Table 4.9: Learning from CHO 3 CDNTs related to the role of support coordinator<sup>5</sup>.*

<p><b>Consideration:</b> The assigning of a “key worker” is part of the initial contact as defined by national guidance.<sup>5</sup> The role of a “key worker” was discussed with CDNTs. Some CDNT members believed key workers were central to the rollout of FCP while others viewed the role as resource intensive, and given the already stretched nature of the service, were not in favour of it. There was a varied understanding between and within CDNT members as to the role of the “key worker”.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> CDNTs within CHO 3 varied on their process in terms of use of “key workers”. One CDNT member generally acted as a “link worker”. However, the CDNT member in this role was likely to change based on the current family priorities to ensure the “link worker” was the most appropriate CDNT member to respond to the needs of the family for that specific priority where feasible.</p>
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*Table 4.10: Considerations for all CDNTs with oversight from CDNMs s for initial contact.*

<p><b>Actions required to progress outcomes-focused FCP</b></p> <ul style="list-style-type: none"> <li>• CDNTs will document the role of the support coordinator and will be familiar with this role and able to communicate this clearly to families.</li> <li>• CDNTs will allocate a support coordinator to each child/their family.</li> <li>• All CDNT members will ensure that each family is provided with an initial contact meeting that will             <ul style="list-style-type: none"> <li>○ Provide an orientation to the service.</li> <li>○ Profile parental priorities for their child/family.</li> <li>○ Achieve a better understanding of a child’s needs.</li> <li>○ Based on parental priorities and informed by observations, develop some agreed initial goals.</li> <li>○ Provide guidance on strategies specific to the agreed initial goals that parents can use immediately.</li> <li>○ Facilitate completion of initial IFSP within six weeks. During this period, the CDNT may contribute to a shared understanding of a child’s needs via, for example, informal observation in natural environments; administration of screening procedures and discussion with the child and their family.</li> </ul> </li> </ul>
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## 4.2.5 IFSP

**4.2.5.1 Existing Practices in CHO 3.** As it was not possible to initially provide IFSPs to the large volume of children who required them (many of whom had been active with the CDNT and receiving services for a number of years), each CHO 3 CDNT had their own protocol regarding which families first received IFSPs. The decision was dependent on resources and other demands on services. Each CDNT also completed IFSPs differently. Some involved the entire CDNT at the initial meeting while others had one/two/three CDNT member(s) complete the IFSPs with the family. In completing the IFSP document some CDNTs finalised goals on the day with the family, while others completed draft goals with the family and then had a CDNT discussion to finalise these and ascertain the relevant team support requirements. Tables 4.11 and 4.12 present research findings in relation to collaborative and participatory goal setting in CHO 3.

*Table 4.11: Learning from CHO 3 CDNTs related to setting collaborative goals.*

<p><b>Consideration:</b> A concern for some CDNT members was how to set collaborative but realistic goals if they had not assessed the child prior to the IFSP. Some CDNT members reported that it was important to acknowledge the family's goals first prior to assessing the child.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> It was agreed that in some cases it may be useful to have further information or contact with a family prior to their IFSP if it helps the collaborative process. However, discussions took place around the challenges of a CDNT member having a deficit-based awareness of a child following an assessment when entering an IFSP meeting with a family. The process of writing a plan is collaborative and all parties are viewed as equal. This may mean sitting with a family to write a plan where the team members have not met the child but are taking at face value the family's concerns/expectations and being able to express what is important to them.</p>
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*Table 4.12: Learning from CHO 3 CDNTs related to writing participatory goals.*

<p><b>Consideration:</b> CDNT members noted that families require support in writing goals in a participatory way. This was a new experience for both CDNTs and families. Previously goals tended to be based on broad skills like supporting behavioural challenges or working on fine motor skills as opposed to participatory goals. CDNTs also expressed concern about how to support families with this without taking over and reverting to leading as opposed to partnering in goal setting. This became clear when CDNTs engaged the change facilitation team, where</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> This remained a very pressing concern for CHO 3 CDNT members. They emphasised that preparation was crucial. The "introductory meeting" at the referral stage aimed to introduce families to the nature of the service from their first contact with the CDNT. This meeting highlighted that CDNT supports would be offered in a broader, participation-based goal actualisation manner provided by an interdisciplinary CDNT rather than an expert-led unidisciplinary model. Preparation documents</p>
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plans were reviewed, and family priorities discussed.

were sent to families prior to the IFSP meeting encouraging families to attend the meeting with their desired outcomes already identified. CDNTs also highlighted the need to “front-load” supports with families when introducing the IFSP. This was necessary to “action the plan” and provide some strategies at the time of the initial IFSP.

Following the identification of priorities with families, team members expressed concerns around determining the degree of importance that families placed on each of their priorities. Also writing goals that were SMART and managing the assignment of resources from the team in relation to team supports in IFSPs were highlighted as other considerations in the IFSP process. The learnings in relation to these are outlined in Tables 4.13 to 4.15, respectively.

*Table 4.13: Learning from CHO 3 CDNTs related to managing family priorities.*

**Consideration:** CDNTs found it difficult when the family priorities were not in line with what the CDNT believed was clinically necessary at that time. Being able to follow the family’s lead was new to many, even though they may have described themselves as working in a family-centred manner previously. Being able to support families when there were critical areas of concern (e.g. equipment reviews or child protection concerns) that needed to be addressed was also discussed. This was especially relevant if CDNT members were concerned about the impact on a child/young person’s development if they did not receive certain interventions.

**Process adopted to progress outcomes-focused FCP:** CDNTs had an agreed opinion on this that was quite aptly summarised by one team member’s statement: “*we need to meet them where they are at*”. This is an important adage at the heart of the family-centred process, ensuring children and families are approached and engaged at the level they feel comfortable with. This was also discussed in the context of families referred with very young babies with complex needs where parents may not be aware of the developmental trajectory and there might be a conflict between parental aspirations for their baby and a professional’s reasoning around a path of intervention.

*Table 4.14: Learning from CHO 3 CDNTs related to SMART goals.*

**Consideration:** Some CDNT members were concerned that they were not setting SMART goals. Initially, many of the discussed goals were not SMART (when assessed versus a SMART goal checker). There were challenges with making goals measurable so that the goal was explicit enough to ensure both family and CDNT members knew when the goal was achieved. The ease at which one was able to set SMART goals tended to relate to how knowledgeable a professional was in a certain area and their ability

**Process adopted to progress outcomes-focused FCP:** To allow for improvements in setting goals and providing strategies to families, up-skilling was suggested by CDNT members in generic areas like behaviour management, toileting, and sleep. Some CDNTs members attended parent training presented by their colleagues to improve their related competencies. Some CDNTs found using the 6 F’s (Rosenbaum & Garter 2011) helpful in formatting universal goals and explaining ideas to families. CDNT

to collect the necessary information from the family. All CDNT members also needed to be comfortable with writing universal goals and identifying universal strategies to support achievement of goals.

members discussed the use of a tool like the “Goal Attainment Scale” to make goals more measurable. However, some CDNT members found that this tool was more suited to a unidisciplinary way of working and that having the SMART analogy was more usable in the context of interdisciplinary working.

*Table 4.15: Learning from CHO 3 CDNTs related to resource consideration.*

**Consideration:** Resources need to be a consideration when CDNT members are committing to “team supports”<sup>12</sup> within the IFSP. CDNTs need to be transparent with families and encourage tapping into available community supports. In an ideal world IFSPs can facilitate parents to be aspirational and the team supports follow to actualise this. Competing demands for limited resources currently in CHO 3 do not allow for this.

**Process adopted to progress outcomes-focused FCP:** CHO 3 CDNTs are not homogenous in relation to resources, location, demographics of population served, and availability of community supports. Therefore, each CDNT needs to reflect their resource needs in a different way. Some CDNTs need different resources than others to support their population of families for examples some CDNTs had access to greater numbers of community supports if a large proportion of their families lived in socially disadvantaged areas. CDNTs could link with these services and support families to access these supports in their local areas. This required increased networking and advocacy roles for CDNT members. CDNTs noted this with HSE management on a regular basis.

IFSPs form the bedrock of how teams, supported and guided by their managers deliver their services and allocate resources to families. When completing these plans with families, teams have many factors to consider and some of these are mentioned above. These are further summarised in Table 4.16 below.

*Table 4.16: Considerations for all CDNTs with oversight from CDNTMs for IFSP process<sup>4</sup>*

**Actions required to progress outcomes-focused FCP:**

- CDNTs will utilise one of the *National IFSP Templates* when completing IFSPs with families.
- CDNTs and CDNTMs will have an action plan developed where all children and families have an IFSP.
- CDNT members will be familiar with their service IFSP management policy. This can be a regional policy developed throughout the CHO to ensure consistency of communication to families. This can include:
  - How families are prioritised for IFSPs.

<sup>12</sup> “Team supports” are a CDNT’s role in supporting the achievement of a child’s and family’s goal (as detailed in their IFSP).

- How these discussions are scheduled, either in person with team members or by phone or video link.
- What information is sent to the family prior to the IFSP and allocating responsibility to a team member to have these returned by the family prior to the IFSP taking place.
- The role of the support coordinator in the IFSP.
- How team members are allocated to completing IFSPs with families/young people.
- And how the team will audit IFSPs on a regular basis.
- CDNTs will ensure that families/children are aware that they can discuss the possibility of bringing an advocate or other support person to any IFSP-related discussion (e.g. face-to-face meeting; telehealth discussion). The CDNT will have a clear protocol on this and families, upon request, will receive a copy of this protocol.
- CDNTs will send the required information to the family to prepare for any IFSP-related discussion. This will include a strengths-based checklist where families/young people can list their strengths in relation to what they bring to the relationship with CDNTs.
- CDNTs will familiarise themselves with the completed referral form and any other related information on the families/young person's concerns surrounding their expectation of the service prior to the initial contact and/or first IFSP-related discussion.
- CDNTs will enter and conduct any IFSP-related discussion with the mind-set that the family/child's priorities are central to planning service delivery and the CDNT will not be biased based on previously completed assessments or information.
- CDNTs will support children and families to be aware that their IFSP is the only route to services. CDNTs will consistently communicate this message (e.g. through CDNT discussions).
- CDNTs will be competent in setting strength-based goals that are written in a collaborative manner with families. Doing so will support the accessibility of goals for families.
- CDNTs will use empowering language when engaging with families and children around the IFSP process. Team supports will not be identified until the family/child's own capacity and strengths are acknowledged as supportive to goal achievement. Once this has been established with families, team supports can be identified and tailored appropriately.
- CDNTs will guide families/children in setting goals that are specific, targeted, realistic and measurable.
- When setting goals with families, CDNTs will use tools (e.g. SAFER [Chiu et al. 2001] and RBI [McWilliam, Casey, and Sims, 2009]) that are based on routine daily activities that the family engage in so that existing opportunities families have can be used to build skills and help define areas where team supports may be required.
- CDNTs will problem solve when family priorities and goals are not in line with CDNT priorities. A solution-focused discussion is critical in these circumstances.
- CDNTs will ensure that the IFSP document reflects the decisions made during the IFSP process. A regular audit of random completed IFSPs can facilitate ongoing quality assurance of this.
- CDNTs will not alter IFSPs without consulting with families. Team supports may need to be altered due to resource allocation reasons, but this will be discussed with the family.
- CDNTs will ensure that during all stages of the IFSP process, all partners are clear on what will happen next.
- CDNTs will reflect on their practices throughout their experiences with families at all stages of the IFSP process. The shift from being the "expert" and director of service delivery to being a collaborator requires an awareness that everyone comes engaged in the IFSP process as equals and that finding potential solutions only comes after exploring strengths and challenges through egalitarian discussion with families.



## 4.2.6 IFSP Review and Goal Attainment

**4.2.6.1 Existing Practices in CHO 3.** Families who had an IFSP in CHO 3 received services based on this IFSP and the team supports agreed within. There was a variation in terms of the reviewing of IFSPs within CHO 3 teams. Some CDNTs regularly reviewed their IFSPs whilst others advised parents to contact the service when their IFSP needed to be reviewed. Table 4.17 presents research learnings relating to reviewing and adhering to IFSPs and Table 4.18 outlines how the IFSP was identified as the primary method of service planning.

*Table 4.17: Learning from CHO 3 CDNTs related to reviewing the plan and adhering to the IFSP.*

<p><b>Consideration:</b> CDNTs found reviewing the plan on a session by session basis challenging. Likewise, respecting the updated IFSP document as the “go to” for all CDNT members to plan interventions was difficult. This consideration adds to the overall requirement for consistency.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> There was no consistent approach to reviewing IFSPs in CHO 3. CDNTs were encouraged to value the IFSP and review it with families on each occasion they were in contact with them. CDNTs were encouraged to support their Teams around family-centred practices.</p>
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*Table 4.18: Learning from CHO 3 CDNTs related to acknowledging the IFSP as the only way to plan services.*

<p><b>Consideration:</b> Acknowledging that the IFSP was the only way to plan services with and for families was a significant challenge as it required CDNT members to review the plan when any communication was initiated by or with families. There was also discussion about the importance of moving away from discipline-specific supports and more towards the CDNT as the access to supports for different functional concerns. This can help build on “team actions”<sup>13</sup> and supports for the team or individuals within the CDNT.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> All contacts with families including face-to-face meetings, groups and phone calls need to be related to the IFSP and clearly identified as such for the plan to be valued by the family and by the CDNT. Remembering at every step of writing the plan that this was the only way of communicating with families on their intervention was consistently re-iterated within teams and by the change facilitation team. CDNT members also need to value the IFSP. Routine review appointments should not be offered unless they are a part of the IFSP. Also, if there are no ongoing requirements for a CDNT member’s input within the IFSP the child/family will not be on that CDNT member’s workload. This can be challenging if assessment results and the professionals’ own experience tells them that this</p>
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<sup>13</sup> “Team actions” is the mechanism used to break the “team supports” the CDNT has agreed to provide down into specific, executable actions that in turn can be converted into appointments. They are tasks rather than appointments. For example, they may include contacting specific people on the family’s behalf, creating resources, researching equipment etc.

	family continues to need their support, but the family has not explicitly stated that as a goal currently.
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It was the experience of teams in CHO 3 where group interventions were offered to families as part of their service delivery model. The offering of groups tended to be based on diagnosis in part, and in some instances on need for example sleep advice groups or preparing of visuals sessions. Table 4.19 is related to the learning on this and then Table 4.20 will summarise the national considerations for IFSP Review and Goal Attainment.

*Table 4.19: Learning from CHO 3 CDNTs related to offering group interventions.*

<p><b>Consideration:</b> CHO 3 CDNTs/CDNT members differed when offering intervention and specifically group intervention. Some CDNT members within the same CDNT offered groups to everyone regardless of family priorities, while other CDNT members only offered groups if the family expressed an interest in being supported in that area.</p>	<p><b>Process adopted to increase outcomes-focused FCP:</b> CDNTs were encouraged to increase the awareness of families as to why they were being invited to a group or intervention (i.e. to support goal achievement as part of the IFSP). In line with this, CDNTs began to ensure that they invited families to groups where the group would explicitly support achievement of an IFSP goal. When teams actively did this, they reported that attendance at groups increased and “dropouts” reduced for the duration of the group.</p>
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*Table 4.20: Consideration for all CDNTs with oversight from CDNMs for IFSP Review and Goal Attainment.*

<p><b>Actions required to progress outcomes-focused FCP:</b></p> <ul style="list-style-type: none"> <li>• CDNTs will treat each IFSP as a dynamic, flexible document which changes depending on the evolving needs and priorities of the family/young person.</li> <li>• CDNTs will always ensure that goals set in the IFSP always relate back to priorities set by the family.</li> <li>• CDNTs, at every contact with families/young people, will refer to the IFSP and alter the content in consultation with the family as and when required related to goal achievement, changes in priorities and updated strategies and team supports.</li> <li>• CDNTs will respect the IFSP as the only route to services for families, thus ensuring the IFSP is kept current and relevant.</li> <li>• CDNTs together with families will agree on how each goal is measured so that everyone involved is clear on when and how the goal will be achieved. This is supported by writing goals in a SMART manner with families.</li> <li>• CDNTs will have a system in place to regularly audit goals and goal attainments, examples to support this would be IFSP audit tools or SMART goal checkers.</li> <li>• CDNTs with the support of their CDNMs will seek support and engage in ongoing reflection on goal writing. This may include receiving external training and supervision on same.</li> </ul>
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## 4.2.7 Transfer/Discharge.

**4.2.7.1 Existing Practices in CHO 3.** Service user transfers between CDNTs in CHO 3 were most often scheduled at predefined intervals (e.g. when moving from early intervention to school age services). These transitions will reduce when *the National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* (HSE, 2019) is implemented in CHO 3. However, there will always be instances of transfers between CDNT for a variety of reasons for example if families change addresses and move into another CDNTs catchment area. Learnings from CHO 3 CDNTs in relation to transfer forms is presented in Table 4.21 and national considerations in relation to transfer/discharge for all CDNTs.

*Table 4.21: Learning from CHO 3 CDNTs related to transfer forms.*

<p><b>Consideration:</b> Transfer forms (which were completed when children were transferring from one CDNT to another) recorded information that encouraged CDNT members to focus on the discipline-specific areas of difficulty.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> The CHO 3 transfer form was updated to allow CDNTs to record priorities for the child/family at the time of the transfer, as well as current strategies and team supports that had been offered. This encouraged a family-centred approach to the transfer.</p>
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*Table 4.22: Considerations for all CDNTs with oversight from CDNMs for transfer/discharge.*

<p><b>Actions required to progress outcomes-focused FCP:</b></p> <ul style="list-style-type: none"> <li>• CDNTs will implement the <i>National Policy on Discharge/Closure and Transfer from Children’s Disability Network Team</i> (HSE, 2017).</li> <li>• CDNTs will communicate with families in a manner that is clear and concise regarding the timing of discharge or transfer between CDNTs.</li> <li>• CDNTs and CDNMs will have an interdisciplinary transfer form which details the child’s strengths and needs and the current family priorities and goals.</li> <li>• CDNTs will review IFSPs and ongoing needs identified prior to transfer/discharge and forward up-to-date information onto the receiving service or original referrer or both as relevant.</li> <li>• CDNTs will include strategies and resources to support the achievement of any current IFSP goals whilst the child and family wait for future supports/services as or if required.</li> <li>• CDNTs will provide families with the information they require to make choices and decisions about their options into the future.</li> </ul>
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## 4.2.8 AoN

**4.2.8.1 Existing Practices in CHO 3.** Within CHO 3, CDNTs were completing AoNs under the old Standard Operating Procedures (SOP) which involved a full diagnostic assessment for the AoN to be completed. Some CDNTs had started to discuss the IFSP as the next step in service delivery and had highlighted this as a required process within the service statement. Information on how CHO 3 CDNTs related to AoN referrals is outlined in Table 4.23.

*Table 4.23: Learning from CHO 3 CDNTs related to AoN referrals.*

<p><b>Consideration:</b> Families that had been referred through the AoN process often required increased support with IFSP development and actualisation. The AoN process highlighted deficits and encouraged an “expert led” model of service. It could sometimes be difficult for families to move from this model, where they had been advised what their child’s “health needs” were and what services they “required”, to then be asked what their priorities were, sometimes after a lengthy wait.</p>	<p><b>Process adopted to progress outcomes-focused FCP:</b> Teams had started to list services required in generic terms as allowed by the form e.g. “ASD Service” and reference the IFSP within the AoN documentation. This allowed CDNTs to move away, in as much as was practical, from discipline-specific, deficit-based language within the AoN reports. The “introductory meeting” also served to inform families that came through the AoN system about the service delivery model.</p>
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## 4.3 Role of CDNMs in Ensuring CDNT Accountability by Leading CDNTs in Outcomes-Focused FCP

There was specific learning in relation to what CDNMs must consider leading their CDNT in the transition towards outcomes-focused FCP. This includes the need for the CDNMs to be a “change-champion”, measuring and maintaining progress, monitoring challenges, supporting CDNT member roles amongst other managerial actions. Tables 4.24 and 4.25 relate to championing FCP in service delivery and supporting team members to own their own role in implementing this change.

*Table 4.24: Learning from CHO 3 CDNTs related to the need for the CDNMs to champion the change towards outcomes-focused FCP.*

<p><b>Consideration:</b> Some CDNT members were engaging in elements of outcomes-focused FCP and embraced and championed the change within their team. Other CDNT members required additional support to engage in the change.</p>	<p><b>Process recommended to progress to outcomes-focused FCP:</b> CDNMs need to be the primary change champions prioritising and embracing the change towards outcomes-focused FCP and bringing their teams along with them. In time CDNMs can identify and support team members to become change champions themselves. The concept of change champions will be further discussed in Chapter 5.</p>
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*Table 4.25: Learning from CHO 3 CDNTs related to the need for the CDNMs to support CDNTs to engage in family-centred behaviours.*

<p><b>Consideration:</b> Most CDNT members were engaging in family-centred practices to some extent but required support to reflect on their practice and begin to engage in family-centred practices in all their interactions with families. They needed support to understand that engaging in outcomes-focused FCP required a change in the team’s ethos as well as a change in behaviours.</p>	<p><b>Process recommended to progress outcomes-focused FCP:</b> CDNMs need to ensure that they and their CDNT members engage in relational help giving practices (i.e. skills such as active listening, empathy, showing respect and being non-critical and impartial) and participatory help-giving practices (e.g. collaboration, flexibility, joint decision making and family action) throughout their interactions with families. CDNMs need to monitor the ongoing use of these practices and seek additional training if this is an area of development for CDNT members.</p>
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Table 4.26 and 4.27 note the learning in relation to the need for reflection within teams led by CDNMs. Moving towards outcomes-focused family-centred service delivery will be a complex and non-linear process and the need to reflect regularly and review the need for additional resources and training supports will be important.

*Table 4.26: Learning from CHO 3 CDNTs related to the need for the CDNMs to support CDNTs to measure and maintain progress in working in an outcomes-focused family-centred way.*

<p><b>Consideration:</b> CDNTs struggled to monitor their progress and were sometimes unsure if they were making progress in their ongoing transition towards outcomes-focused FCP. The number of IFSPs CDNTs were involved in increased but CDNT members often expressed uncertainty as to how to maintain momentum in the face of competing demands on their time (e.g. AoN).</p>	<p><b>Process recommended to progress to outcomes-focused FCP:</b> CDNMs can provide flexible ways for CDNTs to maintain and measure progress in the face of conflicting demands. This will facilitate CDNTs to work in a systematic way and will allow them to move up and down a given “pathway” depending on resource challenges. The self-audit tool contained within the <i>Policy Framework for Children’s Disability Network Teams</i> (HSE, 2020) and mentioned in Chapter 1 is a tool that can support this.</p>
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*Table 4.27: Learning from CHO 3 CDNTs related to the need for the CDNMs to monitor and identify challenges for CDNTs progressing towards outcomes-focused FCP.*

<p><b>Consideration:</b> CDNTs found it difficult to identify the specific challenges they were experiencing in working in an outcomes-focused family-centred manner. CDNTs expressed generic challenges (e.g. competing priorities, lack of resources or</p>	<p><b>Process recommended to progress to outcomes-focused FCP:</b> CDNMs will identify where challenges are in relation to progressing towards outcomes-focused FCP and whether they are at an operational level (e.g. following</p>
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<p>time constraints) but also acknowledged that some intervention was still occurring and therefore there were opportunities to engage in outcomes-focused FCP that were not being utilised.</p>	<p>policies/guidance documents) or at a resource level and plan accordingly. In the case of operational challenges, CDNMs can seek external support for the CDNT as a whole or individual CDNT members as required.</p>
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Tables 4.28 and 4.29 note the learning in relation to the need for CDNMs to hold their CDNTs to account and ensure that all team members are fulfilling the roles expected of them in relation to outcome-focused FCP. Findings to support the role of the CDNMs related to this are evidenced above in Chapter 3 following the research completed in CHO 3.

*Table 4.28: Learning from CHO 3 CDNTs related to the need for the CDNMs to ensure CDNT members fulfil their roles in transitioning towards outcomes-focused FCP.*

<p><b>Consideration:</b> Some CDNT members embraced their new roles in adopting outcomes-focused FCP whilst others found it difficult to move away from more unidisciplinary expert-led roles. Some CDNT members cited difficulties in terms of understanding expectations in this new way of working. This was compounded by continued requests for output-based stats being sought from external sources.</p>	<p><b>Process recommended to progress to outcomes-focused FCP:</b> CDNMs will ensure that all CDNT members embrace and fulfil their roles in adopting these new practices and ensure accountability at all levels. CDNMs also need to support their CDNTs to move away from an output-based data management system (e.g. throughput metrics) to an outcome-focused data management system (e.g. positive outcomes achieved). Currently, until the lower level operational metrics are put in place, the CDNMs could use the Self-Audit Tool for CDNTs. This can provide CDNTs with a means to promote continuous improvement and identify and prioritise further developments under the framework of the 12 principles of PDS.</p>
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*Table 4.29: Learning from CHO 3 CDNTs related to the need for the CDNMs to instil within their CDNT the importance of the IFSP document to service planning and delivery.*

<p><b>Consideration:</b> CDNT members did not consistently place value on the IFSP as the access route for families to team support and as a mechanism for planning.</p> <p>There was also inconsistent knowledge of and engagement in the expected practices and agreed work processes within CDNTs.</p>	<p><b>Process recommended to progress to outcomes-focused FCP:</b> CDNMs will instil within their CDNT the importance of using the IFSP to guide the service planning and delivery requirement of outcome-focused working. CDNMs will ensure CDNTs implement the agreed work processes and engage in the desired CDNT actions within these work processes (see section 4.2).</p>
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This chapter provides a preliminary Operational Framework to support CDNMs with their CDNTs to progress towards outcomes-focused FCP. The aim of sharing this information is to provide guidance to CDNMs and CDNTs regarding considerations which may be relevant to their progression towards outcomes-focused FCP as well as some processes which may support them in this endeavour. It is hoped that this framework can also be used as a stepping stone from which CDNMs build their own processes based on their own CDNTs unique make-up and experiences whilst keeping focus at all times on the 12 PDS principles and also the ongoing developments in terms of the OCFF. The framework is based around the experiences of six CDNTs within a single CHO and it is envisaged that this framework will evolve over time as more CDNTs reconfigure and build on the experiences detailed above.

## Chapter 5: Considerations for Implementing and Sustaining Outcomes-Focused FCP

While the HSE's (2018b) *People's Needs Defining Change – Health Services Change Guide* is a comprehensive guide for implementing change, this chapter details actions specific to supporting CDNMs to implement outcomes-focused FCP.

### 5.1 Parental/Familial and Child Engagement

Supporting families and young people availing of CDNT services to develop their own skills to successfully collaborate with services needs to be considered. Within a family-centred approach, the emphasis is focused on ensuring that families are listened to and supported to achieve their goals. This involves a significant shift for services and families to an approach where both families and CDNT members work together to develop IFSPs that are tailored to meet the identified needs and priorities of each family. Much of the related research suggests that services can play a major role in supporting parents in their advocacy role by engaging in higher levels of parent-professional collaboration (Boshoff et al., 2016; Casagrande & Ingersoll, 2017a; O'Connor, 2020; Rehm et al., 2013; Ryan & Cole, 2009; Timberlake et al., 2014 and Wang et al., 2004).

As part of PDS, CDNTs are asking families to become partners in developing IFSPs for their children and their family, whereas in the past this may not have been their experience. It is hoped that supporting families to enter this collaborative, participatory process prepared and informed will enhance their engagement. It is also anticipated that working with parents and carers who are informed, confident champions for their child will also help CDNT members realise the level of collaboration needed to achieve a meaningful service for the families. The development of a peer-facilitated co-designed programme is recommended to enable families to set a positive vision for their future, supporting them to develop practical tools to engage in outcome-focused FCP, seeking optimum outcomes for families to strengthen parent-professional collaborations, growing family empowerment and promoting wellbeing practices.

### 5.2 Informing Referrers and External Service Providers

Supporting external referrers and service providers with information on outcomes-focused FCP adopted by CDNTs is critical. The development of an education pack that could be delivered as an online training to referrers and could be completed in line with the nationwide rollout of the *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay* (HSE, 2019) would be beneficial.

### 5.3 Change Champion Exploration

As mentioned in Chapter 4 the potential for change champion introduction could be explored by CDNMs. While managers will be the primary change champions within their own CDNTs in terms of facilitating progression towards outcomes-focused FCP,

they will also encourage their CDNT members to be change champions. This holds the potential as a viable and practical solution to self-sustainment and service evolution of outcomes- focused family-centred practices within CDNTs. Change champions as a concept have clear benefits as per the literature but this idea needs to be extensively explored prior to introduction. There will be a requirement for CDNTMs to value the additional time and responsibility this adds to a CDNT member's current role. Also, regional CHO and national HSE oversight support will be required to ensure all practices remain aligned with ongoing research and national operational guidelines.

#### **5.4 CDNT Training**

In consideration of how to promote outcomes-focused FCP in CDNTs, it is useful to consider Schein's (2004) identification of three distinct levels in organisational cultures:

1. Artefacts and behaviours that include any tangible, overt or verbally identifiable elements in any organisation.
2. Espoused values or the organisation's stated values and rules of behaviour; and
3. Assumptions or shared basic assumptions are the deeply embedded, taken-for-granted behaviours that are usually unconscious, but constitute the essence of culture.

As per Figure 5.1 below, these 3 levels of cultural phenomena can variously be fostered by training (e.g. providing information and practice-based workshops); providing supervision; and evaluating practice (to establish if a minimum competency threshold is demonstrated). However, even with appropriately structured conceptual and operational training, the desired behaviour may only become a reflex over time (i.e. training alone will not produce the desired behaviour). Therefore, for example, one-off training modules, even if supported by supervision and practice evaluation, are unlikely to promote immediate behaviour change such as working in an outcome-focused manner. So, further to initial training, it is likely that both supervision and practice evaluation will be required on an ongoing basis before behavioural change may become evident.



## \*How to change behaviour?

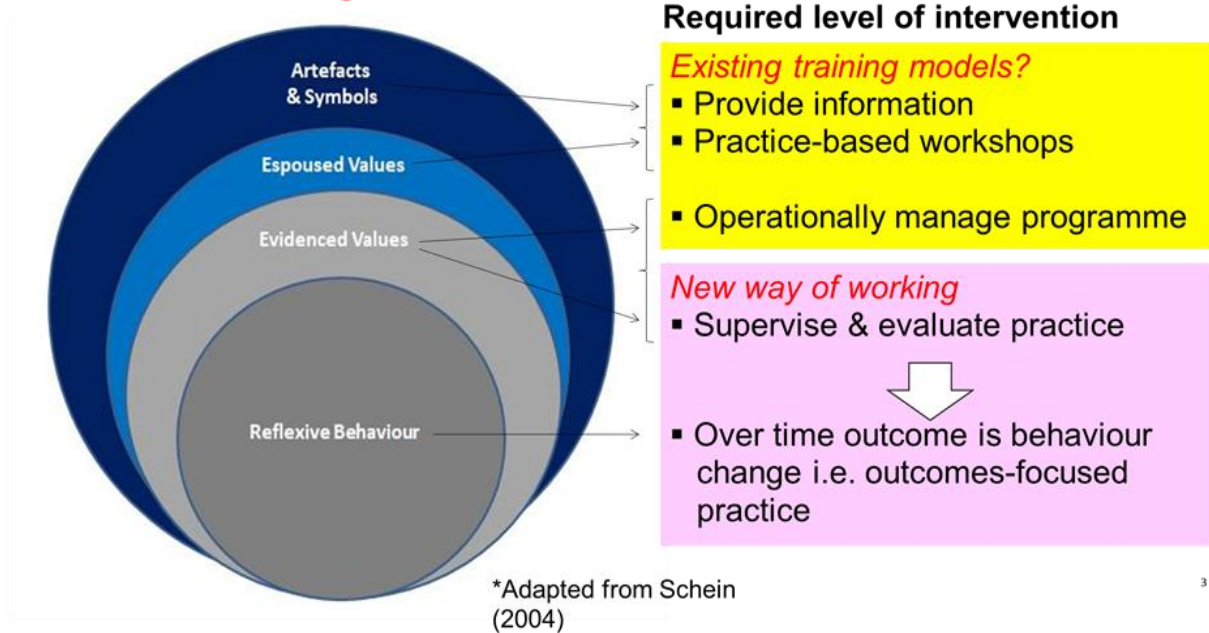


Figure 5.1: How to achieve CDNT member behavioural change.

### 5.5 Suggested Framework of Supports to Develop and Sustain CDNT Member Behavioural Change

Training requirements for CDNT members to support working in an outcomes-focused manner using FCP has been challenging to define as seen in the literature and from the experience of the authors. This is due in large part to the uncertainty surrounding the implementation of outcomes-focused FCP. One observation from Johnston and colleagues (2017) is that for professionals to work in a collaborative and partnership-based manner with families they must have the skills and disposition necessary to excel, but likewise the service “system” must enable this. In doing so, a robust and detailed framework for training is necessary to underpin one’s individual skills and disposition while enabling their advancement. In turn, training needs to be provided at four levels (see Figure 5.2).



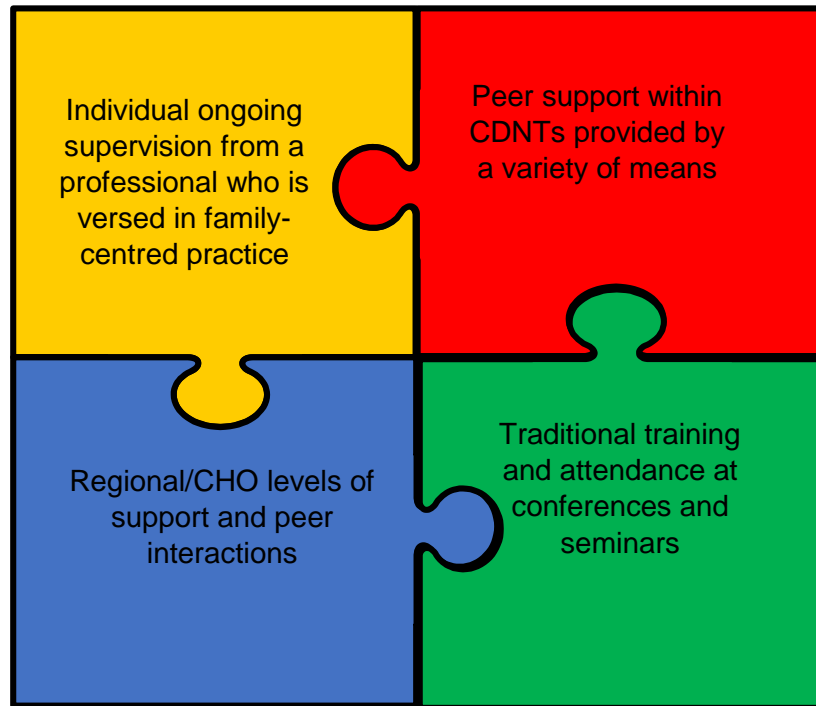


Figure 5.2: Examples of suggested levels of supports for CDNTs (Johnson et al., 2017).

**5.5.1 CDNT Induction Training.** Currently within each employer of CDNT members there is little standardisation with respect to provision of information on outcomes-focused working using FCP. The NTDP (2019) includes training for CDNMs and CDNTs who will be reconfiguring soon. As per the NTDP, this information must be made available on an ongoing basis to new CDNT members. CDNMs have a responsibility to ensure this training is completed by all existing and incoming CDNT members. The authors of this document recommend that any induction will include relevant policy documentation including the HSE guidance documents, and up-to-date research and implementation processes relating to FCP within CDNTs. This documentation must also include supportive information for those transitioning to working in an interdisciplinary and collaborative manner with families and their children. Given the limited congruency between educative practices in universities and members coming into CDNTs from other services, a clear path to outcomes-focused working using family-centred practices would help to fill this gap. This induction training could be available regionally or nationally depending on recruitment practices. See the NTDP for further information on the proposed programme.

**5.5.2 Individual level supervision.** One-to-one supervision is a standard method of practice to support growth and to ensure progression (Ray & Altekruise, 2000). It has been shown to be an effective means of individual engagement. Through supervision, individuals may identify “critical incidences” or areas of focus to work on in the interim between supervision sessions. Within the context of needing our CDNTs to work in an outcomes-focused FCP manner, we cannot assume that

CDNT members will receive supervision from those versed in this philosophy of service delivery. Indeed, it is the authors' experience that this is often not available to CDNT members as supervision continues to be offered in a discipline-specific manner from those senior or deemed to have more clinical experience than the supervisee.

**5.5.3 Peer support within CDNTs.** Peer support can take the form of informal one-to-one meetings to discuss family IFSPs; supporting colleagues during the IFSP process; or providing secondary support when meeting with families such as universal strategy advice. Another method, potentially bolstered by a service induction day, is meeting with new CDNT members, or sitting in on their early interactions with families. CDNTs also need to create systems of support for their CDNTs such as ensuring there is protected time for IFSP review meetings (outside of operational meetings). These meetings could provide a safe space for sharing views and acknowledging individual clinical boundaries facilitating a more effective progression to working in a family-centred manner.

**5.5.4 Regional CHO networking.** The concept of the “learning forum” is potentially a useful tool for supporting staff in the initial stages of implementing outcomes-focused FCP and, at later stages, to shape reflective processes. Within CHO 3 these forums provided a setting for regional CDNT members to interact and share ideas. These forums are an example of regional learning and can benefit the progression of outcomes-focused FCP to support CDNTs who may be finding the process challenging. Given the potentially diverse needs within each CDNT, it is likely that operational models of FCP may be different for each depending on, for example, their resources and the profile of their caseloads. These regional learning opportunities also allowed for a clear camaraderie to be established as CDNTs realise that the struggles they may be experiencing with implementing outcomes-focused FCP are commensurate with other services. Suggestions of collaborative learning opportunities across regional CDNT support networks include:

- To guard against potential misunderstanding of and ambivalence towards outcomes-focused FCP, there is a benefit to thoroughly discuss this concept with all CDNT members across a CHO. This is an opportunity for shared learning and likewise, supports training team members in potentially effective practices other services may be undertaking.
- Supporting a shared understanding of what a universal strategy is and building a regional bank of strategies may reduce the need for individual teams to gather resources other teams in their CHO may already have available. Having a “regional team day” for sharing universal strategies that are potentially applicable in many scenarios to many families is a potentially useful experience for all.

- Standardising language and acronyms across services nationwide (e.g. support coordinator) to ensure congruency between client experiences in CDNTs and external service providers.
- Tracking the key themes of goals over time to understand patterns and to assist with development of a goal bank.

Simultaneously, CHO 3 had also begun to develop a regional electronic shared folder (that could inform a national CDNT shared folder). This will include resources for CDNTs to utilise in their IFSPs with families, groups and other intervention supports, all of which will be aligned to national guidelines. The regional learning forums can also be used to discuss shared resources, and future direction of such a folder.

#### **5.5.5 Traditional training and attendance at conferences and seminars.**

CDNT members will continue to engage in ongoing professional development. Such development may be divergent from, but must add value to, implementing family-centred practices (e.g. Motivational Interviewing and solution-focused approaches). Likewise, given the occurrence of many national conferences on diverse topics related to service user experiences (e.g. the biennial PDS programme conference), CDNT members have opportunities to avail of Irish-based experiential presentations related to disseminating family-centred research.

**5.5.6 Practice evaluation.** CDNMs will regularly evaluate whether their CDNT members, both individually and collectively, are providing outcomes-focused FCP. Where CDNMs find that their CDNT members are not engaging in outcomes-focused FCP, (e.g. as informed by family feedback on CDNT service delivery), the CDNMs can work with relevant staff to support them in developing and engaging in the necessary skills/actions to do so. This includes reviewing whether CDNT members are adhering to the nationally agreed CDNT work processes (HSE, 2018a; see below section) and the relevant recommendations in this document. One potential measure, the MPOC family and clinician forms (King, King & Rosenbaum, 2004; Woodside, Rosenbaum, King & King, 1998), can be used for evaluation of CDNT members' family-centred practices. CDNMs can also use it with their CDNTs to better understand how their practices are evolving towards FCP.

The Self-Audit Tool for CDNTs (2020) is intended to be completed on an annual basis collectively by a CDNT. It can be used to provide an indication of progress towards FCP as one of the 12 PDS principles. It can highlight both CDNT achievements, and what is not working well and what needs to be addressed by the specific team as long as the information included by the CDNT is specific and detailed enough to show concerns and progress. Further to trialling over a 12-month period in CHO 3 using the Management Information System (MIS), seven indicators were also approved for inclusion in the (national) CDNTIMS by the (national) Children's Services Team (see Appendix B). Five of these relate to IFSPs. The sixth and seventh indicators are family feedback on both the nature of the service

provided (e.g. feeling understood; supports offered) and service effectiveness (e.g. how families support their children). These two indicators are currently being trialled in selected CDNTs in the form of the 13-item Family Experiences Survey. A summary of the various training elements, areas and methods can be seen in Figure 5.3 (p. 56). It can be noted that practice evaluation is separate from outcome evaluation, which is discussed below.

## 5.6 Oversight

For change to be embraced and sustained there is a requirement for those involved in the change to have a will to change and a belief that it is worthwhile. There is also an ongoing need for governance in relation to operational and clinical service delivery (HSE, 2020).

**5.6.1 National PDS Implementation Steering Group.** This document recommends that the HSE Heads of Disability Services in each CHO (or their nominees) report to the HSE Chief Officer-led *National PDS Implementation Steering Group* on the progress of their CDNTs in transitioning to outcome-focused FCP. At local level, the Head of Disability Services in each CHO (or their nominees) will work with relevant CDNMs to monitor whether each team is progressing towards outcomes-focused FCP. The Head of Disability Service will report overall progress to the *HSE National PDS Implementation Steering Group*.

**5.6.2 Monitoring Child and Family Outcomes using the OCFF.** Continuing to solely measure CDNT members' work in an output-based manner will not promote their transitioning to working in an outcomes-focused manner. In line with services being measured on outcomes, services will be evaluated and held accountable at a national level using the OCFF (HSE, 2013). CDNMs with their CDNTs will be expected to frame service delivery in a way that honours the importance of the 11 outcome statements. The *HSE National PDS Implementation Steering Group* will be interested in the extent to which a family feel the team have supported them to meet a given outcome as well as the overall extent to which the family feels that the 11 outcomes within the OCFF are met. The team's impact on these outcomes will be measured through IFSP goal attainment and a still in development family feedback survey based on the 11 outcome statements for e.g. the FOQuS and FOQuS-YP. Team members and the families they support will require information on the OCFF outcome statements and how these will impact their service delivery/experience. How the OCFF will be used to monitor child and family outcomes is at an early stage of development. This will require ongoing review and reflection as the implementation progresses.



Figure 5.3: Elements, Areas and Methods of Training.

# Chapter 6: Recommendations for Implementing the Operational Framework for Outcomes-Focused FCP

## 6.1 Document Overview

This document sought to articulate an operational framework to support CDNTs in progressing towards working outcomes-focused FCP, including setting defined IFSP goals for each child and their family based on the child's and family's current priorities. Working in an outcomes-focused FCP way will facilitate implementation of the PDS programme. This chapter briefly profiles the content of this operational framework and details recommendations that will support CDNTs to fully integrate outcomes-focused FCP.

This framework had the following broad aims:

1. Clearly define FCP as it is described in the academic and empirical literature and delineate how this ethos relates to working in an outcomes-focused manner.
2. Provide examples of family-centred work practices to children and families with disabilities from the *CHO 3 CDNT Collaborative Goal Setting Project*.
3. Introduce outcomes-focused family-centred processes, as informed by the evidence-based literature and practice, and relevant HSE policy documents.
4. Outline CDNT actions that support outcomes-focused FCP; and
5. Make recommendations regarding the implementation of a change management programme to support CDNTs to transition towards outcomes-focused FCP.

In summary, this document sought to meet the outlined aims in the following chapters which are detailed below:

- **Chapter 1:** introduces the aims of the current operational framework and details the legislative and organisational journey towards the establishment of PDS and outcomes-focused working.
- **Chapter 2:** defines the phenomenon of FCP as it is described in the theoretical, empirical, and clinical literature and outlines how FCP relates to working in an outcomes-focused way.
- **Chapter 3:** describes a research project on collaborative goal setting conducted in CHO 3 and outlines an overview of findings.
- **Chapter 4:** details the proposed operational framework as largely defined by the CDNT work processes that will support CDNT members to progress towards outcomes-focused FCP; and the learning from the *CHO 3 CDNT Collaborative Goal Setting Project* regarding implementing some of these.
- **Chapter 5:** outlines a change management approach to support the implementation of outcomes-focused FCP.

As noted in the introduction of this document, it is the position of the authors that the standardisation of children's disability services in Ireland as part of the PDS programme must be guided by clear operational guidelines. Specific recommendations for CDNMs and CDNTs at regional and national level pertaining to children and their families, CDNT members and management are proposed. It is strongly recommended that before implementing the outlined recommendations, this document is read in full to fully grasp and contextualise the rationale behind the presented operational framework. Recommendations are outlined as follows:

## **6.2 Recommendations**

Informed by the academic literature and the learning from the *CHO 3 CDNT Collaborative Goal Setting Project* recommendations are presented across seven sections which outline the operational framework for outcomes-focused FCP. Recommendations apply to both long-established and newly reconfigured CDNTs given that it cannot be assumed that the former are more progressed in outcomes-focused FCP. It is acknowledged that different CDNTs, dependent on the mix of available staff competencies, may also progress towards outcomes-focused FCP in different ways.

### **6.2.1 CDNMs Recommendations.**

1. CDNMs will be the primary change champions for this new way of working prioritising and embracing the change with their teams. This will include including identifying and supporting team members to become change champions themselves.
2. Regardless of whether CDNTs are long-established or newly reconfigured, CDNMs will manage the transition of their CDNTs towards outcomes-focused FCP. This will include:
  - i. Identifying CDNT change management needs, including having in place both clear structures (e.g. action plans and flow charts related to referral management; management of IFSP processes, including meetings; monitoring appointments not attended); and supports that CDNT members can avail of when transitioning to outcomes-focused working.
  - ii. Facilitating CDNT member's outcomes-focused FCP training (see section 6.2.4)
  - iii. Regularly evaluating whether their CDNT members, both individually and collectively, are providing outcomes-focused FCP, and, where required, working with these staff to develop and engage in the necessary skills to do so (e.g. reviewing family feedback on service delivery; see Chapter 4)<sup>14</sup>;
  - iv. Ensuring that their CDNT progress towards 100% of children and families receiving services having an IFSP; and

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<sup>14</sup> To be returned by the CDNTIMS, data for these metrics could also be returned manually.

- v. Managing resources in an effective manner to ensure a smooth and timely transition to outcomes-focused FCP.
3. CDNMs will ensure that their CDNT is working in a way that is outcomes-focused and family-centred by ensuring that they and their CDNT members engage in relational help-giving practices (i.e. skills such as active listening, empathy, showing respect and being non-critical and impartial) and participatory help-giving practices (e.g. collaboration, flexibility, joint decision making and family action) throughout their interactions with families.
  4. CDNMs will ensure that nationally agreed work processes are implemented in their CDNT (as detailed in the *Children's Disability Services Procedures and Process*, HSE, 2018a; see Appendix C; and in the *Policy Framework for CDNTs*, HSE, 2020).
  5. CDNMs will ensure that all CDNT members embrace and fulfil their roles in adopting these work practices and ensure accountability at all levels.
  6. CDNMs will allocate protected time for CDNTs when transitioning to outcomes-focused FCP. This can include up-skilling CDNT members in universal strategies; helping to clarify their roles in IFSP service delivery; and supporting team members with writing and refining family prioritised SMART goals (see section 4.2.5 IFSP).
  7. To protect against children and their families receiving conflicting information from external stakeholders (e.g. referrers, teachers, etc.) about the model of service delivery, CDNMs will disseminate information (that aligns with national guidance) about the transition to more outcomes-focused FCP.
  8. Where appropriate, CDNMs will assign nominated CDNT members to provide a "support coordinator" function for children and their families that will include providing a clear route of access to CDNT members; facilitating continuity of care; and addressing individual concerns.
  9. CDNMs will support their CDNTs to move towards an outcome-focused data management system (e.g. positive outcomes achieved).

### **6.2.2 Regional Recommendations.**

1. The HSE Head of Disability Services in each CHO (or his/her nominee) will ensure that CDNMs avail of a variety of CDNMs supports including
  - i. An agreed transition strategy considering existing CDNT caseload and AoN workloads.
  - ii. Appropriate outcomes-focused FCP training; and
  - iii. Using a suite of (nationally formulated) low level outcome-focused metrics as a means of operational feedback on areas requiring CDNMs attention (see section 4.2).
2. The HSE Head of Disability Services in each CHO (or his/her nominee) will work with their CDNMs of each CDNT to monitor whether each CDNT is progressing towards outcomes-focused FCP, including regular reviews with CDNMs focusing on IFSP compliance rates; feedback from reviews of randomly selected IFSPs; and speed of transition etc.



3. The HSE Head of Disability Services in each CHO (or his/her nominee) will nominate change champions (e.g. CDNMs, CDNT members) to be part of a regional CHO change champion group that will provide on-site support to sustain the transition to outcomes-focused working overtime. This will include coordinating the ongoing sharing of information resources that are aligned with national guidelines (e.g. conducting IFSPs; groups and other intervention supports; see section 6.7.4) across CDNTs, as supported by the creation of CHO-wide resources.<sup>15</sup> These champions will document evolving process changes as they emerge (i.e. as CDNTs transition to outcomes-focused practice); and report same to the *National PDS Implementation Group*.

### **6.2.3 National Recommendations.**

1. A newly appointed National Project Manager will lead on rolling-out outcome-focused FCP across all CHOs.
2. This lead will report into the *HSE National PDS Implementation Steering Group* on the progress of each CHO's CDNTs in fully integrating outcomes-focused FCP.
3. Guided by the *KPI – Activity Design and Optimisation Group for Disability Services* working group, the HSE heads of disability services in each CHO will work with the *National PDS Implementation Steering Group* to get agreement on ceasing the practice of CDNTs (and discipline-specific line managers) having to input into Compstats.

**6.2.4 Training.** FCP in essence consists of relational help-giving processes often described as “good” clinical skills (i.e. skills such as active listening, empathy, showing respect and being non-critical and impartial) and participatory processes which are flexible and dynamic practices (i.e. collaboration, flexibility, joint decision making and family action; see Chapter 2). It is fundamental that CDNT members develop each skill set in operationalising FCP effectively.

1. Using multiple platforms (e.g. online, workshops), CDNMs will ensure that all newly recruited CDNT members receive training on how CDNTs use outcomes-focused FCP. This could include an introduction to FCP practices (e.g. support coordinator function; use of IFSPs as a service delivery driver and how to write SMART goals that are appropriate to families' needs); an overview of how to work in an interdisciplinary CDNT; and guidance on “how to” engage with families (e.g. use of collaborative/participatory language; providing all family members with information and training opportunities).
2. CDNMs will review existing CDNT member training needs related to how to work in an outcomes-focused FCP manner; and together with each CDNT member, jointly develop a training plan.

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<sup>15</sup> For example, CHO 3 is building an electronic shared folder that includes multiple resources.

3. CDNMs will facilitate a mix of training provision at various levels (see section 6.7.5):
  - i. Provide regular one-to-one FCP team working supervision to each CDNT member (e.g. how to embed family prioritised IFSP goals yet accommodate discipline-specific guidance in CDNT-based interventions).
  - ii. Facilitate peer support within CDNTs (e.g. encourage support coordinators to discuss with CDNT colleagues IFSP goals and clarify recommendations; foster SMART goal writing skills).
  - iii. Oversee regional/CHO levels of supports and peer interactions (e.g. learning forums with members from different CDNTs to share the learned benefits of how their CDNT is working in an outcomes-focused manner).
  - iv. Facilitate attendance at relevant conferences and seminars that address working in an outcomes-focused manner; or that focus on skills that can be applied during FCP theory implementation (see section 6.7.5); and
  - v. Promote opportunities to share evidence-based knowledge (e.g. journal clubs; small scale practice-based research projects).

#### **6.2.5 Recommendations for Family Inclusion.**

1. The voice of all stakeholders including families and young people will be acknowledged in implementing this framework. Children and their families and young people will be integrated into the decision-making process at a service and national level through representation on appropriate groups. This could include children and their families creating training materials for CDNT members on how to communicate with service users; co-designing materials on how family-centred practices can be described to newly referred children and their families; or through feedback from family forums.
2. Supporting children and their families to enter this collaborative process and be well-prepared and informed will enhance their engagement and enable the development of meaningful collaboration to identify their priority goals. For example, this could be facilitated through the co-production of a training programme for children and their families based on a strength-based approach to goal setting (see section 6.2).
3. Children and their families will be provided with opportunities to provide feedback on their experiences of their CDNT. While the option to complete the “Your Service Your Say” records will continue, they will also be asked on a regular basis to provide feedback on their experience of whether their CDNT provides an outcomes-focused service using FCP. Satisfaction could also be gauged before and after interventions.

#### **6.2.6 Recommendations for Family-Centred Processes**

1. CDNTs will communicate with families regularly at all stages from referral to discharge. All communication with and information provided to children and families will be clear and consistent. Information provision will be timely and accessible to families; in line with *National Adult Literacy Agency* (NALA)

guidelines; and will be made available in a variety of formats where relevant (e.g. in different languages, easy reads etc.; see section 4.21).

2. CDNTs will offer generic waitlist initiatives to families who are waiting on their initial contact. These initiatives relate to generic themes (e.g. behaviour management; post diagnosis support; preparing for school; sleep; toileting). They could also be invited to group-based information sessions; and/or, when appropriate, to sessions on strengths-based goal setting in preparation for their “initial contact.” The purpose and function of these waitlist initiatives will be clearly explained to families.
3. When conducting the initial contact with families, where possible, a minimum of two CDNT members, preferably from different disciplines, will attend (see section 4.24).
4. The IFSP will be a dynamic, rolling plan, with continuous progress and updating of priorities and of goals (HSE, 2018a, p.3).
5. Goals within the IFSP will be strength-based written collaboratively with family’s participation in focus.
6. Once an IFSP is in place, supports will only be offered if their content relates to a child and their family achieving self-identified goals.
7. CDNT members will regularly reflect both individually and as a team, on the IFSPs they have been involved in and whether goals have been attained based on supports and strategies listed within the IFSP.
8. To facilitate the continuity of care of children and their families when transferring between different services (e.g. CDNTs; Primary Care; CHOs), their identified goals or priorities will be maintained unless they have directed otherwise (see section 4.2.7).

**6.2.7 Research/Evaluation Implications.** It is critical to progress a research appreciative culture in our disability services whereby research is prioritised and used to drive service developments such as the integration of outcomes-focused FCP. While conducting research can be a complex process that involves multiple steps and a range of competencies, CDNTs will ensure that their CDNT members can access, if required, appropriate supports to evaluate whether their CDNTs are engaging in FCP and outcomes-focused working.

#### *Family-Centred Practice*

1. Once FCP has been embedded across a variety of CDNTs, a review of this and its impact on the service provided by CDNTs to children and their families can be completed. This could include consideration of family feedback, as well as the impact on CDNTs in terms of resource requirements per child, staffing levels, discipline mix, waiting lists, ease of induction, CDNT member satisfaction, waiting times etc.

2. Research can also be completed to identify what CDNT actions increase the involvement of parents in the process of FCP; and under what CDNT conditions can the effects of these actions be maximised.
3. Further to FCP training (e.g. theoretical components of, empirical and operational), teams can evaluate whether they provide more family-centred services; whether these practices improve child and family satisfaction; and how the medium of delivery affects such outcomes.
4. Evaluate what CDNT member-family relationship variables and CDNT level factors (e.g. “introductory meeting”; initial contact; IFSP formulation; support coordination) can be controlled to maximise how children and parents influence decision making; and how is it best to proceed if a professional disagrees with a family’s goals.

*Outcomes-Focused Working:*

1. To support CDNMs in understanding whether their CDNTs services are experienced by children and families as providing outcomes-focused FCP:
  - i. Further trial and ultimately provide as a support to CDNMs the “Family Experiences Survey” suite of lower level or operational outcomes-focused metrics that profile families’ experiences of the nature and effectiveness of CDNTs (see section 5.5.6 and Appendix B);<sup>16</sup> and
  - ii. Examine how children and families understand, observe, and/or determine the achievement of positive outcomes because of receiving family-centred services from their CDNT. This includes discrepancies and commonalities between their and CDNT members’ understanding of what these outcomes are and the achievement of same.

### **6.3 Conclusion and Future Considerations**

The current report offers a preliminary operational framework for implementing outcomes-focused FCP based on the theoretical, empirical and practice literature, and the experiences of CDNTs in CHO 3. Recommendations are based on the information available to the authors at the time of writing this report. It is therefore acknowledged that the current report was unable to explore some aspects of outcome-focused FCP in detail (e.g. the role of “support coordinator”). FCP is a model of practice still in its adolescence with the absence of a universal model of care. The operational guidelines detailed in this report therefore are subject to ongoing revision as CDNTs develop and progress in Ireland towards integrating outcomes-focused FCP, with future recommendations informed by the developing academic literature and practice-based evidence.

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<sup>16</sup> As per section 5.6.6, these are distinct from the OCFE.

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## Appendices

### Appendix A: Children’s Disability Services Procedures and Process (HSE, 2018a)

	Aspect	Commentary
1.	Referral	As per, the <i>National Policy on Access to Services for Children and Young People with Disability and Developmental Delay</i> (HSE, 2019) children will be referred to CDNTs using the “Children’s Services Referral Form” and 1 of 5 age-appropriate “Additional Information Forms”. If accepted for children’s disability services, the child and family will be prioritised and wait-listed for an initial contact.
2.	Prioritisation	As per, the <i>National Policy on Prioritisation of Referrals to Children’s Disability Network Teams</i> (HSE, 2015), referrals will be organised into two categories, “urgent” and “non-urgent”.
3.	Waiting for Initial Contact	CDNTs have a duty of care to children on their waiting list to ensure that the waiting list is monitored and validated; and all wait-listed referrals are offered universal low-intensity waitlist initiatives.
4.	Initial Contact	Families will be offered an initial contact where the CDNT will <ul style="list-style-type: none"> <li>○ Provide an orientation to the service.</li> <li>○ Profile parental priorities for their child/family.</li> <li>○ Achieve a better understanding of a child’s needs</li> <li>○ Based on parental priorities and informed by child disability team observations, develop some agreed initial goals.</li> <li>○ Provide guidance on strategies specific to the agreed initial goals that parents can use immediately.</li> <li>○ Assign a support co-ordinator to the family; and</li> <li>○ Facilitate development of first IFSP within six weeks.</li> </ul> During this period the CDNT may contribute to a shared understanding of a child’s needs via, for example, informal observation in the child’s natural environment; play-based observations; administration of formal and informal screening tools; and discussion with the child and their family.
5.	IFSP	All children and their families will have a co-produced IFSP that will be a dynamic, rolling plan, with continuous progress and updating of goals.
6.	Goal attainment and IFSP Review	Goal attainment will be consistently monitored.
7.	AoN	The pathway for AoN referrals will differ slightly; and will involve conducting a Preliminary Team Assessment.

**Appendix B: Some CDNT indicators of FCP practice to be used in the (National) Children’s Disability Network Team Information Management System (CDNTIMS)<sup>17</sup>**

	<b>Indicator</b>	<b>Rationale and Calculation Basis</b>
1.	Percentage of children with IFSPs	<ul style="list-style-type: none"> <li>• Referrals of new children and their families coming into CDNTs will have an IFSP from the outset while their existing caseload will have IFSPs built up progressively over time. In relation to the “point in the journey,” IFSPs will be dynamic i.e. they will potentially change with any interaction with the child and their family. Even using one valid goal as the yardstick will be of benefit in tracking the progress of the CDNT and identifying where there may be areas that need to be addressed.</li> <li>• This indicator calculates the number of children with an IFSP, having at least one goal, as a percentage of the total number of children on the active caseload.</li> <li>• To be returned by the CDNTIMS, this indicator can be calculated and returned manually.</li> </ul>
2.	Goal attainment rate	<ul style="list-style-type: none"> <li>• This indicator and indicators #3 and #4 below are aspects of the IFSPs that are measured from the data. It is acknowledged that goal setting will be a critical part of the process in terms of its balance and relevance to the underlying circumstances. These measures will be useful in identifying outliers and areas requiring CDNTMs’ attention. There is no norm in this regard, and may never be, but large numbers of goals, that are of very long duration, or goals that are seldom attained may require scrutiny to ensure that they help inform, and adhere to, policy.</li> <li>• As each goal is completed, it will be categorised in terms of the progress the child has made towards achieving that goal. The progress can be categorised across five categories (i.e. regression; no change; partially achieved; achieved; surpassed) with each category having an equivalent score in the background. The goal attainment rate will be the average score across the goals completed.</li> <li>• To be returned by the CDNTIMS, this indicator can be calculated and returned manually.</li> </ul>
3.	Average duration of goals	<ul style="list-style-type: none"> <li>• The lifespan of each goal is defined by the dates of its creation and completion. That period will be expressed as an average number of weeks. As noted above, there may never be a norm in this regard but the average duration will help to identify outliers in order to pick up goals that are overly simple or overly complex and as such may undermine the family involvement in the process. It will identify situations that may require management attention.</li> </ul>

<sup>17</sup> Further to trialling over a 12-month period of the CHO 3 HSE-owned Children’s Disability Management Information System (MIS), indicators #1 through #5 were approved for inclusion in the (national) CDNTIMS by the (national) Children’s Services Team, along with indicators #6 and #7 that are deliverables from the nationally approved extended FCP project in CHO 3 whose work is ongoing.

		<ul style="list-style-type: none"> <li>• To be returned by the CDNTIMS, this indicator could be calculated and returned manually.</li> </ul>
4.	Average goals per child	<ul style="list-style-type: none"> <li>• This indicator is the average of the number of current goals per child. Again, it is not a pass or fail situation but will identify outliers that may require management intervention.</li> <li>• To be returned by the CDNTIMS, this indicator can be calculated and returned manually.</li> </ul>
5.	Scoring by category from IFSP audits	<ul style="list-style-type: none"> <li>• Functionality changes to the CHO 3 Management Information System (MIS) assumed a simple audit mechanism that would be managed at the outset by a Research Assistant. A simple audit mechanism will incorporate specified headings under which randomly selected plans will be reviewed and assessed. However, a flexible mechanism such as this, particularly at this early stage, will help to define the elements that should be considered when plans are being developed. It will also identify areas requiring further training or definition and will provide a means of peer comparison across CDNTs.</li> <li>• Each reviewed plan is scored on a 1 to 10 basis across a small number of (yet-to-be-agreed) categories. The average will be used to identify trends or areas where additional support or definition may be required. It is envisaged that this will evolve over time as informed by experience of using this indicator.</li> <li>• To be returned by the CDNTIMS, this indicator can be calculated and returned manually.</li> </ul>
6.	Family feedback on service delivery <sup>18</sup>	<ul style="list-style-type: none"> <li>• This indicator and indicator #7 below assumes that a number of basic questions will be agreed on which will be scored in a simple way in order to provide an aggregated means by which the effectiveness of the CDNT, from the parent's perspective, can be judged. It is assumed that this will be reviewed periodically and modified as appropriate dependent on the usefulness of this feedback. The simple questionnaire will be completed at specific intervals so that the results can be comparable from a point-in-time perspective.</li> <li>• This will be based on several questions. It is envisaged that the questions will be reviewed every couple of months during the pilot phase to continuously improve the calibre and relevance of the information.</li> </ul>
7.	Family feedback on service effectiveness	<ul style="list-style-type: none"> <li>• This indicator will be based on several questions. It is envisaged that the questions will be reviewed every couple of months during the pilot phase to continuously improve the calibre and relevance of the information and to provide input for the wider OCFE feedback discussions.</li> </ul>

<sup>18</sup> Both indicators are currently being trialled in the form of the Family Experiences Survey (see section 5.6.6).

**Appendix C: Comparison of Mid-West (CHO 3) “Introductory Meeting” and “Initial Contact.”**

<b>Introductory Meeting</b>	<b>Initial Contact (as profiled in HSE, 2018a)</b>
<p><b>Occurs when:</b></p> <ul style="list-style-type: none"> <li>• A family has been referred to the CDNT and are on the waiting list (i.e. prior to the IFSP).</li> </ul>	<p><b>Occurs when:</b></p> <ul style="list-style-type: none"> <li>• The child comes off the waitlist and becomes active with the CDNT.</li> </ul>
<p><b>Delivered:</b></p> <ul style="list-style-type: none"> <li>• By CDNM and administrator.</li> <li>• In the clinic.</li> <li>• To a group of families who have been referred to the service.</li> </ul>	<p><b>Delivered:</b></p> <ul style="list-style-type: none"> <li>• By two CDNT members.</li> <li>• In the home or in the clinic.</li> <li>• With one individual family.</li> </ul>
<p><b>Aims to:</b></p> <ul style="list-style-type: none"> <li>• Provide an orientation to the service by: <ul style="list-style-type: none"> <li>○ Introducing families to the nature of the service.</li> <li>○ Introducing outcomes-based and family-centred language.</li> </ul> </li> <li>• Reduce the amount of time CDNT members must spend in the initial contact (see right hand column) orientating the family to the service and allow time for focusing on IFSP development.</li> </ul>	<p><b>Aims to:</b></p> <ul style="list-style-type: none"> <li>• Provide orientation to the service.</li> <li>• Profile parent priorities for their child and family.</li> <li>• Achieve a better understanding of a child’s and family’s needs through, for example: observation, play-based observations.</li> <li>• Begin development of initial goals and an initial IFSP.</li> <li>• Assign nominated support coordinator.</li> </ul>



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