

Evaluating the Quality of Education, Health and Care Plans for English Primary School Students with Down Syndrome



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QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

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QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Abstract

The regulation of provisions and supports provided to English children and young people with special educational needs and disabilities are described within the statutory document of the Education Health and Care Plan (EHC plan). Within these plans are *outcomes* which are what inform the details of the plan, regulate provisions and provide areas of focus for the students learning and development (Department for Education & Department of Health, 2015). These outcomes should be high-quality, participation-focused and in line with SMART criteria descriptions as stated in the Special Educational Needs and Disability (SEND) Code of Practice 2015. High quality outcomes provide students with special educational needs and disabilities the best opportunities to achieve their learning and development aspirations. This thesis aimed to evaluate the quality of outcomes contained within the EHC plans of English primary students with Down syndrome. 17 EHC Plans were included in the quantitative analysis of this non-experimental descriptive research project which provided 226 outcomes to be examined. These plans came from 6 of the 9 regions of England, belonging to 10 boys and 7 girls ranging in age from 5 to 12 years. The outcomes were rated using McWilliam's Goal Functionality Scale III (2014) with 10% of the outcomes being rated by two independent, trained raters to calculate inter-rater agreement, which was found to be highly reliable ($\alpha=0.985$). Overall, EHC plan outcomes for primary students with Down syndrome were found to be not high-quality, averaging a score of 2.91 out of 7 on the Goal Functionality Scale III (McWilliam, 2014). However, outcome quality varied dramatically across the 7 items of the rating scale, ranging from 0.4% to 96.5% in regards to percentage of outcomes meeting criteria across scale items. Implications drawn from results of this thesis included improving outcome quality through the development of a rating scale created in line with SEND policy and SMART criteria as well as the potential utilization of the ICF in the writing of outcomes. Suggestions were made to research the effectiveness of outcome provision implementation and to improve the training programmes of professionals involved in the outcome writing and intervention process in the future.

Keywords: Special Educational Needs and Disabilities (SEND), Down syndrome (DS), outcome, SMART criteria, Education Health and Care Plan (EHC plan), participation, special education, quality

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Table of Contents

Abstract..... iii

Acknowledgement..... iv

Introduction..... 1

Statement of Problem..... 2

Thesis Rationale, Aim and Research Question 3

Thesis Overview 4

Chapter 1: Empirical and Theoretical Framework..... 6

1.1 Documentation of Special Educational Needs Across the Globe 6

1.1.1 A Brief History 7

1.1.2 Statutory Documents of Special Educational Needs and Disabilities 9

1.1.3 Participation Focused Ideology.....11

1.2 Recent History: Documentation of Special Educational Needs in England 12

1.3 The Education, Health and Care Plan 15

1.4 Defining Quality Outcomes 16

1.5 Related Research..... 18

1.6 Down Syndrome 21

Chapter 2: Methodology..... 24

2.1 Research Design..... 24

2.2 Research Methods 24

2.3 Eligibility Criteria 25

2.4 Recruitment..... 25

2.4.1 Contacting support groups 26

2.4.2 Social Media 27

2.4.2 Data Collection 28

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

2.5 The Final Sample	29
2.6 Scoring the Outcomes	30
2.7 Reliability.....	32
2.7.1 Second Rater	33
2.7.2 Additional Second Rater	34
2.8 Ethics.....	35
Chapter 3: Results.....	37
3.1 Descriptive Statistics.....	37
3.1.1 Frequency of Objectives per EHC Plan	37
3.1.2 Overall Quality of EHC Plan Outcomes	38
3.2 Statistical Analysis	40
3.2.1 Outcome Quality and Key Stage.....	40
3.2.2 Outcome Quality and Region.....	41
Chapter 4: Discussion	43
4.1 Results of Outcome Quality within the Larger Context	43
4.2 Limitations	45
4.2.1 Limitations within the Sample	46
4.2.2 Limitations within the use of McWilliam’s Goal Functionality Scale III (2014)	47
4.3 Future Research and Recommendations	48
Chapter 5: Conclusion	51
References	52
Appendices.....	57

Overview of Tables

Table 1	18
<i>Overview of quality indicators of outcomes for children with SEND and its match to SMART criteria definitions</i>	18
Table 2	30
<i>Frequency of plans and outcomes per region, gender, type of placement and age.</i>	30
Table 3	32
<i>Examples of outcomes and ratings using the Goal Functionality Scale III (McWilliam, 2014) ..</i>	32
Table 4	34
<i>Interrater Reliability between Researcher and Second-Rater Ratings</i>	34
Table 5	35
<i>Interrater Reliability between Researcher and Third-Rater Ratings</i>	35
Table 6	38
<i>Frequency of Outcomes per EHC Plan</i>	38
Table 7	39
<i>Frequencies of Total Outcome Score (N = 226)</i>	39
Table 8	40
<i>Mean quality ratings across all objectives (N = 226)</i>	40
Table 9	41
<i>Outcome Quality and Key Stage</i>	41
Table 10	42
<i>Outcome Quality and Region*</i>	42

Introduction

In England, the needs, provisions, and outcomes for children and young people with Special Educational Needs and Disabilities (SEND) are described, monitored and regulated in the Education, Health and Care Plan (EHC plan) document. Within this document are outcomes which are defined as “the benefit or difference made to an individual as a result of an intervention... it should be personal... something that those involved have control and influence over and... *specific, measurable, achievable, realistic and time-bound* (SMART)” (Department for Education & Department of Health, 2015, p. 163). This thesis delivers the first research to date which provides a systematic evaluation of the quality of education outcomes for primary students with Down syndrome who have an EHC plan. The introduction of this thesis presents components related to the research question such as the statement of problem, aim, rationale and justification for the thesis and clearly outlines the chapters of the thesis to come.

Statement of Problem

Introduced in 2014, the EHC plan is England’s legal document for children and young people with SEND. Mandated by the Children and Families Act 2014, the EHC plan aims to provide a holistic picture of the child’s functioning, needs and related provisions based on collaboration between the student, their family and related service members in the student’s education, health and care settings. Made up of the 11 distinct sections, section E of the EHC plan is mandated to include outcomes which should be high-quality, holistic and participation-focused outcomes in order to best regulate the provisions provided to them (Castro, Grande, & Palikara, 2019; Department for Education, 2014). Aspects of outcome quality defined by the 2014 Act and corresponding 2015 Code of Practice is expressed as fitting the five aspects of SMART outcome criteria: *specific, measurable, achievable, realistic and time-bound* (Department for Education & Department of Health, 2015). Despite the definition of quality within the context of SMART criteria, there has been no development of a tool to assess or develop quality that is specific to assessing these criteria in EHC plan outcomes. The importance of outcomes that are SMART, participation-focused and functional are argued throughout literature for emphasizing effective development of skills across contexts (Snyder et al., 2015) and reflected in the special educational framework on a national and international level (Castro et al., 2019).

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Since the introduction and implementation of the EHC plan in 2014, there has been only one systematic evaluation of the content and quality of the outcomes within them. The study used the 2005 model of McWilliam's Goal Functionality Scale to evaluate outcome quality for children and young people with EHC plans in England. In this evaluation, overall outcome quality for students with SEND of all grade levels were found to be of poor quality, lacking especially in areas regarding specificity, functionality and participation (Castro et al., 2019). In this thesis, students with Down syndrome (DS) were placed into the "other" category in regard to categorization of type of need and no specific insights for this group were gathered (Castro et al., 2019). Although DS is one of the most common causes of intellectual disability (Sherman, 2007), due to large differences in cognitive, behavioral and emotional strengths in functioning among diagnosis and individuals, we cannot make the assumption that the conclusions from research done regarding students with intellectual disabilities will apply to students with DS (de Graaf, van Hove, & Haveman, 2013). With the national and global shift towards student centered, participation focused and functional education provisions and outcomes for students with SEND, the evaluation of the quality of said outcomes within the EHC plan for this specific group is paramount.

Thesis Rationale, Aim and Research Question

Previous research suggests that the outcomes for students with SEND of all grade levels are of low quality, with noticeable differences in aspects of quality existing between more or less affluent local education authorities and between students attending mainstream or special schools (Castro et al., 2019). The current thesis focuses on the outcomes written for primary school students with DS; a subsection of the SEND population that no specific insights have been gathered about in past research. Primary students with DS are more likely than students with other neurodevelopmental disorders and/or intellectual disabilities to attend mainstream schools, and have access to a 1-on-1 support person (Van Herwegen, Ashworth, & Palikara, 2018), however, little research has been done in regards to the population navigating these settings and supports to achieve the best outcomes for their learning and development. As EHC plans are at the center of supporting inclusion and ensuring effective education provisions, the identification of patterns and gaps in quality of outcomes for the primary school population with DS related to participation and SMART criteria, these quality indicators can provide a meaningful point of reference in the implementation of education provisions, effective inclusion, interventions, goal

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

development and supports for students from the early years of education (Will, Fidler, Daunhauer, & Gerlach-Mcdonald, 2017). This can lead to improvements made in outcome development, thus leading to better educational planning, utilization of supports, and education outcomes for the population (Will, Fidler, Daunhauer, & Gerlach-Mcdonald, 2017).

The aim of this thesis was to study the quality of education outcomes for primary school students with DS in England. Outcome quality was rated using McWilliam's Goal Functionality Scale III (2014) in order to evaluate the outcome across seven dimensions of quality including; emphasizing participation in a routine [item 1], being observable and measurable [item 2], developing a necessary and/or useful skill [item 3], having an acquisition criterion [item 4], having a meaningful acquisition criterion [item 5], having a generalization criterion [item 6], and having a timeframe criterion [item 7]. This scale was chosen due to its quality indicators being in line with student participation and its overlap with the 2015 Code of Practice definition of quality being the meeting of SMART criteria (Department for Education & Department of Health, 2015). The overarching research question guiding this non-experimental quantitative thesis was;

“What is the quality of education outcomes for primary students with Down syndrome in England?”.

Follow up secondary research questions related to categorical variables were also investigated such as;

- “Does the quality of the outcomes depend on the age or key stage of the child?”
- “Does the quality of the outcomes depend on the type of school that the child attends?”
- “Does the quality of the outcomes depend on the region of England the child lives in?”

Thesis Overview

This thesis is organized into five main chapters. The first of which, *Empirical and Theoretical Framework*, begins by outlining a brief history, the changes in documentation and ideology related to special needs education across the globe. These same topics are then detailed

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

within the realm and relevancy of England's own education system and followed by particulars related to the EHC plan, what constitutes an outcome of high quality as well as related research relevant to the thesis and the population of students with Down syndrome. The next chapter, *Chapter 2*, details the methodological design and methods of the thesis, the participants who took part in the thesis and scoring of the outcomes. Descriptive statistics and statistical analysis are detailed and presented in the results chapter of *Chapter 3*. A discussion chapter follows the results which explores the implications and limitations of the results, makes comparisons to past research and suggests areas for future research. The discussion chapter is followed by a conclusion which will summarize the previous chapters of the thesis, evaluate the main strengths, weaknesses and implications discovered and proposed in the thesis and make final concluding remarks.

Chapter 1: Empirical and Theoretical Framework

This chapter will provide background, context and essential framework ideology related to the thesis. The history of safe-guarded provisions for children and young people with SEND within documents which includes the major conferences, statements and legislation that have been a part of reaching the current framework will be presented within both the global and English context. This history is crucial in understanding how the EHC plan was developed, the context in which it is being implemented in as well as the national and global lens in which the quality of outcomes are being evaluated in. The structure and purpose of the EHC plan is then followed by the defining of quality outcomes within the context of this thesis which includes a description of the rating tool used in the analysis and its relation to the global and national English framework of special needs education. An overview of related research is proceeded by the final section which presents relevant learning profile information about the population of the thesis, children and young people with DS.

1.1 Documentation of Special Educational Needs Across the Globe

Argued as being one of the most central and important aspects of service provision for children with SEND is the creation and implementation of a statutory document of special educational needs (Castro, Palikara, Gaona, & Eirinaki, 2020). This document should holistically describes the student's needs, aspirations, levels of functioning, outcomes or goals, services and provisions for the long-term and short-term future (Castro et al., 2020; Rowland, Quinn, & Steiner, 2015). These documents exist across the globe in many different countries and take on a variety of titles, including an individualized education plan, habilitation plan or, in the case of England, the Education, Health and Care plan (Castro et al., 2020). The development of these documents and has taken place in tandem with the redefinition of disability, the ideological shift towards inclusive education for all and an increase in participation focused provisions (Castro & Palikara, 2016; Hayes & Bulat, 2017). Through detailing the history of education for learners with SEND and the development of documentation from both a policy and ideological perspective, the international context in which the EHC plan exists within becomes clear. This is crucial in examining the quality of outcomes contained within the plans, as it compares to studies done outside of England and where aspects of quality lay within the global framework of special needs education.

1.1.1 A Brief History

Before the development of an individualized document for children and young people with SEND was to be created, the recognition that this was a population capable and worthy of receiving education was necessary. When examining the history of special needs education on an international level, the first document most frequently mentioned and argued as being highly significant within the field is the *Salamanca Statement and Framework for Action on Special Needs Education* (Ainscow, Slee, & Best, 2019). The Salamanca Statement and Framework was the final report from the 1994 World Conference on Special Needs Education where 92 governments and 25 international organizations met in Salamanca, Spain, to develop the objectives of Education for All and inclusive education (Ainscow, 2019). In point 2 of the opening proclamations, the Statement states that, “every child has a fundamental right to education... [and] those with special educational needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting [their] needs” (UNESCO, 1994). Ideological and pedagogical foundations of holistic and child centered education relevant to the present thesis are also reflected in the statement’s proclamation that “every child has unique characteristics, interests, abilities and learning needs, education systems should be designed and educational programed implemented to take into account the wide diversity of these characteristics and needs” (UNESCO, 1994).

These proclamations were ratified by 92 governments (UNESCO, 1994) and were followed by point 3 which, pertinent to this thesis, highlights education provisions and urges all governments to;...

... establish decentralized and participatory mechanisms for planning, monitoring and evaluating educational provision for children and adults with special educational needs. [And] encourage and facilitate the participation of parents, communities and organizations of persons with disabilities in the planning and decision-making process concerning provision for special educational needs (UNESCO, 1994).

These proclamations align with the aims of individualized documents for students with SEND which describe the students strengths, weaknesses, learning needs, goals, educational placement and provisions developed with school professionals working with the student, the student and their families (Hayes & Bulat, 2017). As the catalyst for global conversation,

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

conferences and policy related to special needs education, inclusion and related documentation of SEND, the Salamanca Statement of 1994 has been followed by several other landmark international policy documents. The need for individualized holistic, student-centered documents which can be used as a tool for the planning, monitoring and evaluation of student progress and achievement is reflected in subsequent convention and policy documents.

Following Salamanca in 2006 and supporting the shift from a disability model of charity to one based on human rights (Soriano, 2017) was the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In Article 24 of the CRPD, countries are asked to ensure that children with disabilities have access to free, accessible and inclusive primary and secondary education and that they not be discriminated against based on their disability (Hayes & Bulat, 2017; UN, 2006). Individualized education for students with SEND was explicitly mentioned in article 24 (2) (e) which stated that “effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion” (UN, 2006). Relevant to the development of individualized documents and learning outcomes for learners with SEND, the CRPD also highlights that schools address *each* students academic, social and life skills, including receiving reasonable accommodations in the classroom and the use of alternative learning methods to address these if needed (Hayes & Bulat, 2017; UN, 2006). The United Kingdom signed the CRPD in 2007 and ratified it in 2009 (Nations, 2016). Comments made by the CRPD Committee since 2006 have clarified and elaborated on points made in the CRPD which are relevant to the present thesis.

Statements regarding reasonable accommodations being provided for students with disabilities based on their individual needs have been clarified by the Committee in their comments in concluding that students with the same type of disability may have very different accommodation needs based on their own individual needs and profile as well as the type of reasonable accommodation being determined in collaboration with the school, parents and student (Hayes & Bulat, 2017; UN, 2016). Approaching education through a ‘whole person approach’ is another Committee point of focus in their 2016 general comments (UN). The ‘whole person approach’ is detailed by the use of adapted teaching and learning methods to differing strengths and needs, focus is placed on the capabilities of the learner, offering a flexible curricula and reasonable supports, provisions and supports that provide a personalized education for the student (UN, 2016). These points are directly in line with a holistic, student centered,

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

collaborative approach seen in the development of individualized education document such as the EHC plan in England.

Perhaps the most relevant comment made by the CRPD Committee in regard to the current thesis is seen in point 33 of the *General comment No. 4* document. Made in regard to the development of some type of individualized education plan this point states (UN, 2016);

The Committee emphasizes the need to provide individualized education plans that can identify the reasonable accommodations and specific support required by individual students... the effectiveness of such plans should be regularly monitored and evaluated with direct involvement of the learner concerned. The nature of the provision must be determined in collaboration with the student, together, where appropriate, with the parents, caregivers or other third parties. The learner must have access to recourse mechanisms if the support is unavailable or inadequate (p. 9).

While no comments specific to learning outcomes or goals associated with the encouraged individualized education plan were found in follow-up CRPD general comment documents, point 74 does highlight the need for methods of monitoring student progress outside of the typical range of standardized tests and achievement scores (UN, 2016). The Committee states that through the use of systems of individualized supports, appropriate teaching methods, accommodations and supports, curriculum can be adapted so that all learners are able to access it (UN, 2016).

1.1.2 Statutory Documents of Special Educational Needs and Disabilities

While there is no one common international document detailing the formatting, scope or levels of needs, provisions and associated outcomes for students with SEND in international policy legislation, many countries have developed some type of said document. Encouraged by the subsequent UN Committee on the CRPD, these documents are argued as being one of the most important facets of education provisions for children with SEND (Castro et al., 2020). While documents might differ in specific regard to context and policy details, they have in common that they aim to describe and detail a holistic picture of the functioning, behavior, needs, strengths and goals for each child with SEND (Castro et al., 2020). These documents are noted as being a useful way of developing, ensuring and organizing both general and individualized support provisions for students with SEND (Fina, 2017).

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

First established in the United States in 1975 through the Education for All Act, the Individual Education Plan (IEP) has become a model for special education strategies and documents for countries world-wide (Hayes & Bulat, 2017). The IEP identifies the individual needs, learning goals, placement and related services of students with disabilities, the proposed teaching strategies and accommodations to be made in the classroom for the student (Hayes & Bulat, 2017). Developed with the support of a team consisting of family or legal guardians and professionals connected to the student including teachers, administrators, support staff and related service providers, the IEP is created collaboratively. The team is required to meet annually to review student progress, proposed outcomes and make any amendments or revisions to the document, thus, the document is not static and changes alongside the student it serves to support. Since the development of the IEP and subsequent modifications, IEP's are legally mandated in many countries such as the United States, Australia, Canada, New Zealand, Costa Rica, Malawi, Turkey, South Africa and Uganda (Hayes & Bulat, 2017). As defined by 34 C.F.R. Part 300, the United States mandates that an IEP must include (a) the present level of function and its effect on the student's progress in the general education curriculum; (b) measurable annual goals with short-term objectives; (c) a description of how and when the student's progress toward meeting annual goals will be measured; (d) a statement of the special education and related services and accommodations to be provided; (e) the extent, if any, to which the student will not participate in regular classroom activities; (f) a statement of any accommodations for alternative assessment and why the student needs them; and (g) the start state, frequency, location, and duration of services (*Assistance to States for the Education of Children with Disabilities*, 2013). The process of preparing, implementing and evaluating an effective IEP, regardless of the country, student or outcomes being addressed usually begins with the meeting and role designations of the IEP team (Aljahtani, 2016). Members of the IEP process should include the student, their parents or guardians and those related to providing education services including but not limited to; the general education teacher, special education teacher, related service members such as therapists (speech, physio, occupational, vision, etc.) other experts related to the child's needs, a member of the evaluation staff and/or a representative of the school system (Aljahtani, 2016). These meeting happen annually with all team members and function to carry out evaluations, determine and discuss the needs of the students, related teaching strategies, targets and goals to provide provisions to the student (Aljahtani, 2016).

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

An IEP that is written to include all components that are required by law is not one that is necessarily of high quality that best meet the needs of the student for their greatest educational achievement (Rowland et al., 2015). The educational benefit or plan in action can be seen in the outcomes within the IEP as these are the goals for the student to learn and develop throughout the year until the next IEP review with the team. However, these goals do not seem to be ones of high quality leading to student success. Ridgley et al. (2020) noted that many of the IEP goals evaluated did not address functional skills, lacked specificity in identifying the targeted skill or behavior and the conditions necessary for it to be elicited to meet criteria of the goal as well as lacking acquisition criteria for knowing when the goal was achieved.

1.1.3 Participation Focused Ideology

As time and policy have evolved, so has mainstream ideology surrounding disability and the focus of provisions to be provided to students with SEND. Inclusive education practices, student centered pedagogy and related special education provisions existing now exemplify the shift from a medical model to a social and biopsychosocial model of disability. Widely used for most of the 20th century, the *medical model* of disability, presumes that a persons' disability exists separate of society and policy (Areheart, 2008). The medical model positions disability as solely a biological trait which causes the disabled person to be incapacitated and entirely dependent on others (Areheart, 2008), which is a model which all but absolves society from making a more accessible world. Opposite the medical model is the *social model* of disability which takes into account aspects of life outside of medical diagnosis in totality such as attitudes and environmental barriers (Hayes & Bulat, 2017). The social model of disability removes the focus from interventions to make the individual with a disability fit the environment around them and instead focusses on the restructuring of the educational environment as a whole so that all students, including those with disabilities can be successful in them (Matthews, 2009). Somewhere in between those two models, used widely across the globe since its introduction in the early 2000's and in this thesis is the *biopsychosocial model* of disability which characterizes disability and functioning as outcomes of interactions between health conditions and contextual factors (WHO, 2002).

The International Classification of Functioning, Disability and Health (ICF) is a framework developed by the World Health Organization and recommended for use in conjunction with recommendations and guidelines set forth by the Convention on the Rights of

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Persons with Disabilities (WHO, 2002). Within it, the World Health Organization categorizes disability as a restriction in *functioning*, where functioning refers to all *body functions, activities* (“the execution of a task or action by an individual”) (2002, p. 10) and *participation* (“involvement in a life situation”) (2002, p.10) (Organization, 2001; WHO, 2002). When applying this model, framework and definitions to special education provisions and goals for development; functioning and participation should be considered as a main objective of these document and provisions (Castro et al., 2019). The ICF describes “disability for its unique characteristics of facilitating in-depth and individualized functioning profiles, which are also holistic, biopsychosocial and independent of diagnosis” (Castro et al., 2020, p. 1624; Stucki, Kostanjsek, & Cieza) which, if used in documents for students with SEND, would provide a standardized language for special education across a variety of contexts and disciplines (Castro et al., 2020). The ICF highlights the shift from mere documents of accountability towards documents that actually inform service providers of a holistic picture of the child or young person’s strengths, needs and functioning through the use of the common language for SEND across contexts (Castro et al., 2020). Recommendations have been made to use the ICF as a method of enhancing the quality of documents and outcomes for students with SEND. The importance of such an evaluation of outcome quality which focus on student participation in routines and environment meaningful and relevant to the student which are the topic of this thesis are reflected in this participation focused ideology.

1.2 Recent History: Documentation of Special Educational Needs in England

The current EHC plan which exists today is a result of changes in policy and ideology surrounding the development of such plans since the introduction of so called ‘Statements of Special Educational Needs’ within the 1981 Education Act. These statements, and subsequent documents of which they have been replaced by, detail the profiles, needs, provisions and practices for students with SEND in England. The EHC plan has gone through three major reforms as reflected in the policies of the 1993 Education Act, 2001 Special Educational Needs and Disability Act and the 2014 Children and Families Act. Each of these reforms have been accompanied by updated Special Educational Needs and Disability Code(s) of Practice which are the statutory guidance documents for those supporting students with SEND. Guidance is outlined for schools and related providers or organizations in regard to advising, assessing and meeting the needs of all children with SEND as related to education legislation.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

The early years of statutory documents for students with special educational needs was first mandated in policy in the 1981 Education Act following the *Warnock Enquiry* and subsequent *Warnock Report* of 1978. The enquiry has been argued as being the most comprehensive review of SEND in the United Kingdom to date and the following report as being a catalyst for inclusion; putting the inquiry's findings into an expansive plan for lifelong inclusion (Lindsay & Wedell, 2020; Webster, 2019). First named *Statements of Special Educational Needs (SEN)*, these documents, which were to be reviewed annually, were quite simple and required to only provide detail regarding the results of assessments of needs for the child and to specify the special educational provisions in order to meet those needs (Department of Education and Science, 1981). These initial statements were critiqued, reformed and developed in following years resulting in major changes in being implemented in 1993 Education Act and its counterpart Code of Practice 1994 which set out procedures in regards to assessment, management, reporting and establishing good practice for schools working with students with special educational needs (May, 2004). The key aspects of reform from the 1994 Code and statements included the need for increased student participation, involvement and promotion in practice. The subsequent 2001 updated Code of Practice attempted to address these issues (May, 2004) through the implementation of the updated Statement of SEN Needs which was mandated to have the following six sections (Skills, 2001)

1. *Introduction*: The child's name and address and date of birth. The child's home language and religion. The name and address (es) of the child's parents.
2. *Special Educational Needs* (learning difficulties): Details of each and every one of the child's special educational needs as identified by the Local Education Authority (LEA) during statutory assessment and of the advice received and attached as appendices to the statement.
3. *Special Educational Provision*: The special educational provision that the LEA consider necessary to meet the child's special educational needs
 - a. The *objectives* that the special educational provision should aim to meet.
 - b. The *special educational provision* which the LEA consider appropriate to meet the needs set out in Part 2 and to meet the objectives.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

- c. The arrangements to be made for monitoring progress in meeting those objectives, particularly for setting short-term targets for the child's progress and for reviewing his or her progress on a regular basis.
4. *Placement*: The type and name of school where the special educational provision set out in Part 3 is to be made or the LEA's arrangements for provision to be made otherwise than in school.
5. *Non-Educational Needs*: All relevant non-educational needs of the child as agreed between the health services, social services or other agencies and the LEA.
6. *Non-Educational Provision*: Details of relevant non-educational provision required to meet the non-educational needs of the child as agreed between the health services and/or social services and the LEA, including the agreed arrangements for its provision. (pp. 100, 101)

While the 2001 Code of Practice was regarded as an improvement to the 1994 Code, it was heavily criticized and ultimately replaced 13 years after its introduction (Robinson, Moore, & Hooley, 2018). The 2001 Statements of SEN were noted as being too focused on diagnosis, exclusionary to parents, segmented in regards to related services across the realms of education, health and social care and little centered around outcomes for the student (Castro-Kemp, Palikara, & Grande, 2019; Ko, 2015). With these critiques, these statements began being transitioned into Education, Health and Care Plans along-side the Children and Families Act 2014 and its related 2015 Code of Practice which sought to rectify the problems from Statements of SEN (Castro et al., 2020).

The 2015 Code of Practice mandated the transition from Statements of SEN to EHC plans and signified a shift from plans that were bound by diagnosis to plans which were focused on student participation and functioning outside of diagnosis (Castro et al., 2020). This shift is one that aligned with international trends in special education ideology from one focused and bound on diagnosis to one which is more holistic with student participation at placed the center of provisions (Castro et al., 2019). The new policy of EHC plans placed emphasis on a holistic assessment of the individual with SEND (now from birth to 25 years old) developed by a multi-agency team with a renewed emphasis on the voice and perspective of the student and their family as essential in the building of the plan (Daniels, Thompson, & Tawell, 2019). In order to investigate the efficacy and supposed improvements in the regulation of SEND provisions,

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

implementations and the impact on student development, studies such as the one that is the topic of this thesis are crucial in guiding further EHC plan development.

1.3 The Education, Health and Care Plan

The most recent Code of Practice which accompanies Section 3 of the English Children and Families Act 2014 is a reform which sought to fill in the gaps of previous statements and create new and improved documents called Education, Health and Care plan's or EHC plans. The new documentation of SEND mandated that the "needs of the individual and young person should sit at the heart of the assessment and planning process" (Department for Education & Department of Health, 2015, p. 147) by stating the student and their families *must* be consulted and involved in the process of assessment and production of the EHC plan. Increased collaboration between agencies and disciplines of Education, Health and Care services provided to the student should be coordinated and included in the EHC plan and their provisions should contribute to specific outcomes. The EHC plan also places focus on the outcomes related to recommendations and provisions provided to the student (Ko, 2015).

The 2015 Code of Practice states that the purpose of the EHC plan is to "make special education provision to meet the special educational needs of the child or young person, to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood (Department for Education & Department of Health, 2015, p. 142). Section 9.5 of the Code of Practice states;

EHC plans should be forward-looking documents that help raise aspirations and outline the provision required to meet assessed needs to support the child or young person in achieving their ambitions. EHC plans should specify how services will be delivered as part of a whole package and explain how best to achieve the outcomes sought across education, health and social care for the child or young person (p. 143).

As the EHC plan aims to be a holistic document related to all relevant aspects of the student's education, health and care, it is made up of multiple sections, each of which cover a specific aspect of the students functioning, needs and aspirations. While no one specific design, form or layout is necessary, the following 11 sections are legally mandated by Regulation 12 of the Special Educational Needs and Disability Regulations to be present in the plan;

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

- **Section A:** The views, interests and aspirations of the child and his or her parents or the young person.
- **Section B:** The child or young person's special educational needs.
- **Section C:** The child or young person's health needs which are related to their SEN.
- **Section D:** The child or young person's social care needs which are related to their SEN.
- **Section E:** The outcomes sought for the child or young person.
- **Section F:** The special educational provision required by the child or young person.
- **Section G:** Any health provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN.
- **Section H1:** Any social care provision which must be made for the child or young person under 18 resulting from section 2 of the Chronically Sick and Disabled Persons Act 1970.
- **Section H2:** Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN.
- **Section I:** Placement
- **Section J:** Personal Budget (including arrangements for direct payments)
- **Section K:** The advice and information gathered during the EHC need assessment must be attached.

The focus of this thesis is on the quality of the outcomes contained within Section E of the EHC plan. Details pertaining to outcomes, their quality and definitions contained within the 2015 Code of Practice are to come in the following section.

1.4 Defining Quality Outcomes

Outcomes, synonymous with 'targets' or 'goals' in international policy and literature on special education and disability, are objectives created for children with SEND which specify a skill or behavior (or set of) for them to accomplish with the support of provisions, accommodations and professionals within a specified time frame (Castro et al., 2020). As stated in section 9.64 of the 2015 Code of Practice, "outcomes should always enable children and young people to move towards the long term-aspirations of employment or higher education, independent living and community participation" (Department for Education & Department of Health). The outcomes contained within an EHC plan are what details student success and guides

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

achievement targets for the duration of the EHC plan. Section 9.66 of the 2015 Code of Practice details an outcome in the EHC plan as;

... the benefit or difference made to an individual as a result of an intervention. It should be personal and not expressed from a service perspective; it should be something that those involved have control and influence over, and while it does not always have to be formal or accredited, it should be specific, measurable, achievable, realistic and time bound (SMART). When an outcome is focused on education or training, it will describe what the expected benefit will be to the individual as a result of the educational or training intervention provided (p. 163).

As stated in the description above, all outcomes should be specific, measurable, achievable, realistic and time bound, therefore fitting the SMART criteria acronym (Department for Education & Department of Health, 2015). The SMART acronym is one used across international literature and policy in education outcomes (Castro et al., 2020) and is a tool used in order to develop outcomes of high quality. While there is no rating scale developed specifically for evaluating how 'SMART' an outcome is, the Goal Functionality Scale III developed by McWilliam in 2014 encompasses multiple dimensions of quality seen in its exhaustive framework and its criteria overlaps with SMART criteria (Castro et al., 2019), making it suitable for evaluating outcomes in line with said criteria. With versions used in previous related research which evaluated outcome quality related to SMART criteria, the Goal Functionality Scale III (GFS III) (McWilliam, 2014) was selected as the tool of quality evaluation for this study. Table 1 presents an overview of the SMART criteria and its relation to rating criteria within McWilliams GFS III. More detail regarding the GFS III and its application in this study is featured in Chapter 3 of this thesis.

Table 1

Overview of quality indicators of outcomes for children with SEND and its match to SMART criteria definitions

SMART criteria	McWilliam Goal Functionality Scale III (2014)
Specific (Jung, 2007; Siegert, 2004)	Emphasize the child’s participation in a routine (i.e., activity) State specifically (in an observable and measurable manner) what the child will do
Measurable (Conzemius, 2013)	There should be an acquisition criterion (when do we know that the child has acquired the behaviour?) There should be a generalization criterion (i.e., to other contexts and situations)
Achievable (Piskurich, 2015)	The acquisition criterion should be meaningful for the child’s participation, i.e., embedded in a routine
Relevant (Jung, 2007; Siegert, 2004)	Address a skill that is either necessary or useful for participation in home, school or community routines Have a meaningful acquisition criterion (i.e., one that shows improvement in functional behavior)
Time-Bound (Conzemius, 2013)	There should be a time frame for the acquisition of the new skill or behavior

Note: Adapted from *Evaluating the quality of outcomes defined for children with Education Health and Care plans in England: A local picture with global implications*, by Castro, S., Grande, C., & Palikara O., p 43. Copyright 2019 Elsevier Ltd.

1.5 Related Research

The evaluation of outcome quality has been a topic of research seen within both EHC plans in England and in statutory individualised education documents for students with SEND across the globe. Using previous research as a framework made clear potential trends in the data, areas of reference and points of discussion.

The research question for this thesis was inspired by a study done by Castro, Grande and Palikara (2019) which analysed the quality of 2813 outcomes from 236 Education, Health and

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Care Plans from English students (aged 4-21) with a special educational diagnosis. This 2019 paper utilized McWilliam's Goal Functionality Scale II (2005) to evaluate the quality of outcomes across seven items of criteria: (a) indication of the routine in which the child will participate, (b) specification of the desired behavior, (c) relevance of the specified behaviour for the child's overall participation, (d) quantification of the acquisition criterion, (e) relevance of the acquisition criterion (included in a daily routine), (f) presence of a generalization criterion, and (g) presence of a timeframe criterion. These seven criteria were then independently rated on a scale from 1 to 4 representing the following meeting of the criteria: *not at all, somewhat, much or very much*. The overall quality of outcomes was of low quality with the majority of the ratings falling into the 'not at all' and 'somewhat' categories meaning that the majority of outcomes evaluated were of low-quality (2019). This study noted higher quality outcomes coming from more affluent local authorities which they hypothesize to be due to higher levels of investment in training and professional development for professionals involved in the EHC plan process and/or that parents coming from a background of higher education may have greater input on the plan than parents from less affluent areas. While outcomes coming from both mainstream and special schools were of overall low quality, results also revealed that the outcomes coming from plans developed by special schools had a higher frequency of higher quality scores in regard to outcomes specifying routines and behaviors relevant for student participation, the presence of acquisition criterion and a time frame for said acquisition criterion. Researchers also concluded that children with multi-sensory impairments had, on average, higher scores across items 1, 2 and 3 which indicate the routine to be participated in, specification of the desired behavior and relevance of the behavior to the child's participation, respectively when compared to children with autism spectrum-disorder. Castro et al., concluded that there is a need for effective training and professional development for all professionals, across all types of schools and economic levels of local authorities, involved in the EHC process in order to increase quality and SMART-ness of outcomes, needed especially in regards to increase the specialization and participation aspects of outcome quality (2019).

A research review done by Hannah Cochrane and Anita Soni in 2020 sought to examine themes related to implementation of EHC plan including: the EHC process experience, reflection on the plan and outcomes of the process. They discovered that, in general, parental involvement and multi-agency collaboration seem to have increased since the implementation of the EHC

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

plan in 2015 but that there are still issues surrounding the involvement of the child or young person in their own plan. EHC plans have been criticized for being reductionist and overly focused on the problems that the students faced because of the student themselves instead of being holistic and supportive of the child's needs (Buck, 2015; Cochrane & Soni, 2020). Similar critiques from parents in regards to the framing of outcomes as being poor and deficit-focused pointed to the need for care to be taken when writing outcomes to be positively framed, aspirational and considerate of wider environmental and societal factors that may be impacting the child or young person with SEND (Cochrane & Soni, 2020; Skipp, 2016).

When looking at research conducted outside of England, similar results pointing to overall low-quality and poor functional outcomes for students with special educational needs have been found in various other countries. Rakap (2015) conducted an analysis of 2235 individualised education programme (IEP) goals and objectives from 100 Turkish pre-school students with a broad spectrum of special educational needs. The IEP document in Turkey has a similar purpose as the EHC plan does in England, serving as the “road maps for individualising services for children with disabilities, specifically through the development of high-quality goals/objectives” (p. 173). Rakap utilized McWilliam's *Goal Functionality Scale II* (2009) to rank the quality of outcomes in addition to the *IEP/Individualised Family Service Plan Goals and Objectives Rating Instruments* developed by Notari-Syversen and Schuster (1995). The overall quality of the goals and objectives were found to be generally poor, with a large number not reflecting functional and practical skills necessary for success on a daily basis (Rakap, 2015).

A similar Portuguese study that evaluated outcomes from 82 public-preschool students with a broad spectrum of special educational needs completed by Aguiar, Boavida, McWilliam, and Pimentel (2010) discovered low quality outcomes from the majority of analysed outcomes utilizing the same rating scales as Rakap. Aguiar et al. (2010), discovered that, overall educational outcomes were “too broad, lacked functionality and measurability, and did not appropriately address skills within the context of natural routines and settings... [and indicated] that measurability was slightly higher the more severe the children's disabilities were and that autonomy (i.e., self-help) goals were somewhat more functional and measurable than were social, language, cognitive and motor goals” (p. 233, 2010).

When looking at the research done regarding the quality of education outcomes for students with SEND both within England and in surrounding countries with similar statutory

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

documents, it is clear that high-quality outcomes are far and few between. Using the World Health Organization definition of disability as a restriction in functioning, which is used as a hypernym for all aspects of participation (2001, 2007) which includes the functioning and participation in activities performed, daily routines and ‘involvement in life situations’ (p. 248) which can thus be extended to a participation-focused ideology within SEND provisions and outcomes as seen in the evaluations of outcomes in the research (Castro et al., 2019). The lack of quality outcomes found in research does not represent these definitions and points of focus within SEND. As student participation levels can play a large role in the explanation of student learning and development, there should be a focus placed on participation within the development of both individual documents for students with SEND and their outcomes (Castro et al., 2019; Pinto et al., 2019). The discrepancies in quality found in previous research has discovered the need for devising outcomes of higher quality in regard to student participation, specificity, measurability, relevance, generalization and time criteria for students with SEND of all ages within EHC plans in England as well as pre-school students outside of England (Boavida et al., 2010; Castro-Kemp et al., 2019; Rakap, 2015). This demonstrates the need for the ideological shift in special education towards participation-focused pedagogy and provisions to be put into practice and implementation; starting with the written outcomes and documents which legally mandate the provisions for these students.

As the aim of this thesis was to evaluate the quality of education outcomes for primary school students with DS in England, the use of previous research as a framework and point of reference for the current state of outcomes and goals in similar document was pertinent. The current thesis seeks to add to existing the body of research through focusing on a population which has previously been ignored or categorized as other. Through gathering results and insights gained from this thesis and comparing them to the conclusions from past research, the development of high-quality outcomes in EHC plans and other individualised education documents alike, can be furthered.

1.6 Down Syndrome

Down syndrome is associated with a range of strengths and weaknesses and because of this they need supports within the profile of their functioning. If the outcomes are that of low quality, then the resulting education will be that of low quality as well. Being the most common genetic cause of intellectual disability (Sherman, 2007), it has been estimated in recent years that

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

12,800 young people under the age of 18 in the UK have DS (DSE, 2021). DS is typically caused by abnormalities in chromosome 21 (Mégarbané et al., 2013). Trisomy 21 or having an extra 21st chromosome accounts for 95% of the cases of DS (Lanfranchi, Jerman, Dal Pont, Alberti, & Vianello, 2010). The IQ scores typical to children with DS range between 30 and 70 (Mégarbané et al., 2013), meaning that some individuals experience much more significant difficulties than others. Children and young people with DS are predisposed to developing common strengths, challenges, characteristics and dispositions in a wide range of developmental domains (Daunhauer et al., 2014). In regards to academic skills relevant to that of primary school which are the population of interest in this thesis, students with DS typically show stronger receptive and comprehension skills than expressive skills in relation to language skills (Almoghyrah, 2021; Daunhauer & Fidler, 2011). This is mirrored in displaying strengths in reading (word recognition) (Bazin-Berryman, 2018) and difficulties in realms related to expressive language skills, motor development and executive function (Lanfranchi et al., 2010). In basic mathematics, primary students with DS typically demonstrate deficits in basic mathematical reasoning in the area of numeracy, specifically in subitizing (Onnivello, Lanfranchi, & Zorzi, 2019). Challenges in goal directed behavior and executive functioning relating to the EHC plan which could be included in outcomes and provisions include working memory, social interaction, safety and cognitive-behavioral task behavior (Daunhauer et al., 2014; Will, Fidler, Daunhauer, & Gerlach - McDonald, 2017). These domains are all relevant to that of the EHC plan that should be supported, developed and included in outcome development.

Children and young people with DS display a number of strengths and learning potential and these strengths can either be developed or hindered dependent on teaching methods and approaches to education. Commonly known as being highly sociable and affectionate individuals (Pochon, Touchet, & Ibernou, 2017), children with DS tend to have success learning in socially oriented learning environments with positive reinforcement (Grieco, Pulsifer, Seligsohn, Skotko, & Schwartz, 2015). Grieco et al., (2015) noted that paradigms of observational learning, including visual learning and associating objects with rewards, all favored more successful outcomes for students with DS when compared to instrumental and verbal learning. Favorable outcomes in regard to observational learning environments go hand-in-hand with patterns found in challenges with language and short-term memory and strength in visuospatial skills which are

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

typical for students with DS (Ranzato, Tolmie, & Van Herwegen, 2021; Van Herwegen et al., 2018).

A cross-syndrome comparison study between DS, Williams Syndrome (WS) and Autism Spectrum Disorder (ASD) which examined parents' views regarding their child's educational provision was done by Van Herwegen, Ashworth and Palikara produced valuable insights into the provisions provided for students with DS in 2018. Through parent survey, researchers examined the effect of challenges relating to the three specific neurodevelopmental disorders on education provisions and supports. Parents of all three groups, 99 having children with WS, 88 with DS and 82 with ASD, emphasized issues in their children receiving support from staff who weren't adequately trained or specialized in their child's disability as well as high rates of turnover in the person providing their child with the 1-1 support (Van Herwegen et al., 2018). Results particular to DS noted primary school students with DS were more likely to attend mainstream settings and receive more 1-to-1 support when compared to students with WS and ASD. This insight is particularly important when looking into the quality of EHC plans and outcome quality for students with DS at mainstream schools and in inclusive education environments. While there is no one way to guarantee effective inclusion, it has been noted that the way in which the classroom teacher organizes and manages an inclusive classroom while working with the 1-to-1 support person is essential (Fox, Farrell, & Davis, 2004). These are all components of discussion that should be included in the process of EHC plan creation and outcome development.

Education outcomes should be functional and SMART in order to give students with DS the best possible quality outcomes. The teaching of academic skills that are meaningful to the student's daily life have been noted to contribute to social inclusion and a sense of belonging at school in inclusive education settings as well as contribute to better participation and orientation in daily and recreational activities (de Graaf et al., 2013). SMART outcomes implemented in child-centered and participation-based methods rooted in evidence-based research could help provide students with DS the greatest opportunities for success. The need for the evaluation of outcome quality for the population of primary students with DS is one that can guide future document, outcome and intervention planning for the population at the early stages leading to potentially better outcomes in future years of schooling.

Chapter 2: Methodology

This chapter will present the methodology used to evaluate the quality of outcomes in EHC plans for primary students with DS in England. It will provide information and insights related to the research design, methods used in the rating process, characteristics of the population sample, tools of advertisement and evaluation, procedures used in order to ensure reliability and validity of the findings, and ethical considerations taken into account during the process of completing the thesis. This thesis was inspired by the previously presented 2019 study completed by Castro, Grande and Palikara which used a previous version of the GFS and examined EHC plan outcomes different and a wider population parameter of students aged 4-21 with any special educational need. This thesis is not a direct nor a conceptual replication of Castro., et al. 2019 study.

2.1 Research Design

This research qualifies as *quantitative non-experimental descriptive* research. While the evaluation of the EHC plans were done qualitatively, the outcomes were analysed quantitatively, fitting the definition of quantitative analysis by Creswell, as quality was measured using a numerical rating scale and analysed using statistical instruments and tools (2009). The evaluation and analysis of outcomes in the EHC plan was a description of phenomena that is completely independent of the manipulation of conditions or a variable that could affect the subject's responses. Radhakrishnan (2012) defines non-experimental descriptive research as research that "investigates [the] current status of something, the way things are or were" (p. 25) which is directly in line with the research question and methodology of this thesis.

2.2 Research Methods

Following the recruitment of participants and the use of McWilliam's GFS III (2014), quantitative research methods and analysis regarding participant descriptives, outcome quality frequencies and other relevant statistical tests were performed using Jamovi version 1.6.23 statistics software. Due to the nature of the thesis, both descriptive and inferential statistical analysis methods were needed in order to model and analyse the association between outcomes, their respective scores and overall score quality. Types of statistical analysis completed were chosen based on the number of EHC plans received, not the total number of outcomes. This was due to high variance and non-equal distribution of the number of outcomes contained in each plan.

2.3 Eligibility Criteria

The participants in the thesis are the primary school students with DS who the EHC plan and outcomes were created for and belong to. In order to be eligible to be included in the project, participants were required to fit the following criteria;

- Age 5-12,
- Attending a Mainstream or Special Primary School in England,
- Diagnosed with Down syndrome (Trisomy 21), and
- Has an EHC plan

2.4 Recruitment

Recruitment of gathering participant EHC plans via their parent or guardian was done entirely digitally using a variety of online platforms. Various recruitment methods for data collection were used throughout the project and this section details the various methods of recruitment including contact with Down syndrome support groups and advertisement through the use of social media platforms and via related Down syndrome organizations. Participants were recruited from January through June of 2021.

2.4.1 Contacting support groups

Recruitment of participants began in January 2021 with the informal emailing of 71 DS support groups from families across all 9 regions of England to first engage with groups and share initial information regarding the thesis including its' research question, aim, purpose, participant eligibility requirements and data handling procedures. Contact information for DS support groups was found via the Down Syndrome Association (DSA) website at <https://www.downs-syndrome.org.uk/about-dsa/our-network/local-support-groups/>.

Groups were contacted in various ways dependent on their information posted; either through an administration email, point of contact or chair-person for the group or a message sent on the support groups contact page found on their webpage. Initial contact sharing information about the thesis project was sent while pending ethical approval from the Norsk Senter for Forskningsdata (NSD). This was then followed up in February with second contacting after receiving ethical approval with the official sharing of project related documents and ethical approval. The 71 organizations were then contacted again with the following documents in the hope of their sharing the information and documents to the contacts and members in their groups (see Appendices A-D for documents sent to support groups);

- Parent information letter (see Appendix A),
- Consent statement (see Appendix B), and
- Project flyer (see Appendix C)

These documents and information sent in correspondence were then shared by the various support groups to their contacts via group monthly news-letters, email contact lists, meeting announcements and posts in social media threads. Follow up emails and website messages to groups were sent in March, April and May resulting in the collection of 11 total EHC plans from email and messaging contact methods.

Feedback and responses to support groups reached a lull in the Spring and in collaboration with supervisors, it was decided to focus on advertising through other platforms, such as social media, in an attempt to reach more potential participants.

2.4.2 Social Media

Various social media platforms were utilized for the advertisement of this project including the creation of a project Facebook page and Twitter account as well as advertising through other related Down syndrome group social media accounts.

2.4.2.1 Facebook. The Facebook page “Quality of EHCP Outcomes for Primary School Students with Down Syndrome” was created on March 23, 2021 as a tool to boost participation in the thesis. Through this page, posts containing links to project documents, steps of participation, recruitment flyers and posts featured on various related sites were published approximately once a week. In order to make the page known to other related social media pages who may take interest, engagement with various Down syndrome groups, pages and networks who appeared in the suggested tabs.

The Facebook page was “liked” by 57 accounts and “followed” by 64 accounts and in a boosted post received over 2,000 views, however, only 4 participants were recruited using the Facebook platform. The parents of the 4 participants shared their child’s EHC plan using the secure Nettskjema link.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

2.4.2.2 Twitter. Created on March 15, the Twitter account Evaluating the Quality of EHCP Outcomes “@DSoutcomesEHCP” was used similarly to the Facebook page. With the 280-character limit on the Twitter platform, the posts were mostly graphics consisting of recruitment flyers (see Appendix C), researcher contact information and quick facts about the project. The 41 tweets received a total of 5,700 views, however, there was no engagement with the account from potential participants and no EHC plans were collected via Twitter.

2.4.2.3 Other Related Group Accounts. Using technology and social media to collaborate with various groups, such as the Down’s Syndrome Association was another tool employed for recruitment. Published on their official website under the “News & Research” section and shared to their respective social media accounts, the advertisement of the research via the Down’s Syndrome Association website proved to be the most beneficial group collaboration resulting in the collection of 2 EHC plans from this platform. These parents of these participants got in contact with the researcher through email following seeing the posts.

2.4.2 Data Collection

Data collection was done directly through the parent or guardian of the participant and the steps for securely submitting the EHC plan to the researcher was outlined to the family in following steps;

1. Read the parent information letter.
2. Read, check, fill out and sign the statement of consent.
3. Submit your child’s most recent EHC plan and the signed statement of consent to the University of Oslo’s secure platform; Nettskjema at this link [link to submission]

Despite the sending of the Nettskjema link in email correspondence, 4 of the 17 participant parents sent the participants’ EHC plan via email. For these 4 plans, the EHC plan remained attached to the email with the outcomes anonymized and copied to the separate outcome document for analysis with no identifying information. As the information contained within the EHC plan fall under the “red” category stipulated by the *University of Oslo and The ICT infrastructure company for Norwegian research and Education*, the EHC plans and statements of consent were stored and accessed electronically and securely through the platform *TSD – Service for Sensitive Data* which is in compliance with Norwegian privacy regulations.

2.5 The Final Sample

The final sample in this thesis was comprised of 17 EHC plans, which provided 226 education outcomes for evaluation. The plans came from 17 different schools (16 of which are mainstream schools and 1 being a special school setting), in 16 different local authorities and belong to 10 boys and 7 girls from 5 to 12 years of age. There were 6 plans belonging to students in Key Stage 1 and 11 plans coming from students in Key Stage 2; Key Stage 1 consists of students aged 5-7 and Key Stage 2 ages 7-12. Each EHC plan varied in number of education outcomes present, ranging from 4 to 29 per plan. Due to this high variance, it is important to note that there are large sections of high outcome concentration for various criteria. For example, broken down by number of outcomes, 98% of the outcomes come from mainstream schools, 47% of the outcomes evaluated are coming from the London Region and 64% of the outcomes come from students aged 5 and 10; 29% and 35% respectively (see Table 2 on the following page for an overview of the frequency of outcomes per region, gender, type of placement, age and Key Stage). Questions of outcome quality in relation to school type were unable to be explored due to only 4 of the 226 outcomes coming from a special school. The distributions among characteristics are of great importance when looking at the significance of results found in the thesis. These limitations will be discussed in Chapter 4 of this thesis.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Table 2

Frequency of plans and outcomes per region, gender, type of placement and age.

Sample characteristics		Frequency of children/plans	Frequency of outcomes
Region	North East	0	0
	North West	3	32
	Yorkshire	2	14
	East Midlands	1	17
	West Midlands	0	0
	South East	3	32
	South West	0	0
	East of England	3	24
	London	5	107
Gender	Male	10	143
	Female	7	83
Placement	Mainstream school	16	222
	Special setting	1	4
Age ^a	5	4	66
	6	1	10
	7	1	20
	8	1	7
	9	1	11
	10	6	78
	11	2	30
	12	1	4
Key Stage	Key Stage 1	6	96
	Key Stage 2	11	130

Note:

^a Age is the students' age as of January 1, 2021

2.6 Scoring the Outcomes

Through the utilization of R.A. McWilliam's Goal Functionality Scale (GFS)III (2014), the quality of outcomes was scored as meeting or not meeting criteria present within each of the seven items within the scale. The GFS III (2014) consists of the following items;

- a) Item 1: Emphasize the child's *participation* in a routine (i.e., activity)?
- b) Item 2: State specifically (i.e., in an observable and measurable manner) what the child will do?
- c) Item 3: Address a skill that is either *necessary* or *useful* for participation in home, "school," or community routines?"
- d) Item 4: State an acquisition criterion (i.e., an indicator of when the child can do the skill)?

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

- e) Item 5: Have a meaningful acquisition criterion (i.e., one that shows improvement in *functional* behavior)?
- f) Item 6: Have a generalization criterion (i.e., using the skill across routines)
- g) Item 7: Have a criterion for the timeframe?

Each outcome was rated independently on each of the seven items; receiving a score of 0 if they *did not* meet the criteria of the item and receiving a score of 1 if they *did* meet the criteria of the item. Scores for the seven items were then summed to receive their total outcome score; receiving a minimum of 0 of 7 points and maximum of 7 of 7 points. Table 3 (on the following page) presents examples of outcomes and their respective ratings. Through correspondence with GFS III developer, Robin McWilliam, items were scored with the guidance of his GFS III Manual (see Appendix D) and a researcher created scoring manual was created and utilized as a tool for independent scoring (see Appendix E) and shared with individuals doing the second scoring of a set of outcomes as described in the next section.

Table 3

Examples of outcomes and ratings using the Goal Functionality Scale III (McWilliam, 2014)

Criteria according to McWilliam (2014)	Outcome 113: <i>By the end of year 5, X to walk through the school gate and to the Key Stage 2 playground without support. At the end of the school day to walk out of school to her parents car independently.</i>	Outcome 52: <i>To develop my learning skills and early literacy skills, so that, by the end of key stage 1, I will be able to consistently write the letters of my name “_ _ _” and copy all pre-writing shapes /_ + X O / \</i>	Outcome 123: <i>By the end of Key Stage 1: X will be able to fully engage in a range of social routines with partial adult prompting.</i>	Outcome 163: <i>X will shift her attention from one task to another more willingly with adult and visual support.</i>
Participation in a routine? [item 1]	1	0	1	0
Observable and measurable? [item 2]	1	1	1	0
Necessary/useful skill? [item 3]	1	1	1	1
Acquisition criterion? [item 4]	1	1	0	0
Meaningful acquisition criterion? [item 5]	1	1	0	0
Generalization criterion? [item 6]	1	0	0	0
Timeframe criterion? [item 7]	0	0	0	0
Total	6	4	3	1

2.7 Reliability

In order to ensure reliability of researcher scoring of outcomes, a random 10% of the outcomes were scored by independent raters from the University of Manchester who were trained by the researcher via virtual meetings. Due to great variability in the number of outcomes per EHC plan, a random 10% of outcomes were chosen per EHC plan to receive a second rating from the independent rater. Twenty-nine outcomes were rated independently by a second rater and due to low reliability in the first independent rating, a second set of 29 outcomes coming from 10% of each EHC plan were independently rated by a third rater. The random 10% of

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

outcomes were chosen using a random number generator for each of the 17 EHC plans. Each outcome was numbered from 1-N (N being the number of outcomes in the plan) and the number N was input as the max number into the random number generator. The number generator was then refreshed to select another number depending on how many outcomes were to be chosen per plan. The number of outcomes chosen were broken down in the following way;

- 1-10 outcomes in the plan: 1 outcome randomly selected;
- 11-20 outcomes in the plan: 2 outcomes randomly selected;
- 21-30 outcomes in the plan: 3 outcomes randomly selected;
- 31-40 outcomes in the plan: 4 outcomes randomly selected;
- 41-50 outcomes in the plan: 5 outcomes randomly selected.

2.7.1 Second Rater

In mid-June, 2021, training with the second rater began via the digital meeting platform *Zoom*. Prior to meeting, the second rater was sent relevant information relating to the thesis including the similar study done by Castro, Grande and Palikara (2019), official Goal Functionality Scale III manual with annotations and notes directly sent via email from Scale creator McWilliam (see Appendix D), the scoring manual created by the researcher (see Appendix E) and an Excel document with examples, explanations of scorings and practice outcomes for rater training (see Appendix F).

The researcher and second rater then collaborated via email and video-conference meetings to discuss the project, scoring methods and complete the example training document. The second rater then completed outcome ratings independently, explaining score justifications for each item to the researcher. After consensus was reached and the second rater gained confidence in using the GFS III in ranking the example outcomes, the researcher sent the 10% of EHC plan outcomes to the second rater via Excel. This was done on a rolling basis until the end of the data collection period at the end of June 2021. Ratings of the 10% of outcomes completed by the second coder were then compared to researcher ratings and tested for interrater reliability using the statistic of Cronbach's Alpha. Interrater reliability is presented in Table 4 below.

Table 4

Interrater Reliability between Researcher and Second-Rater Ratings

Criteria According to McWilliam (2014)	Cronbach’s Alpha (α)
Participation in a routine [item 1]	0.950
Observable and measurable [item 2]	0.382
Necessary/useful skill [item 3]	0.787
Acquisition criterion [item 4]	1.000
Meaningful acquisition criterion [item 5]	1.000
Generalization criterion [item 6]	0.872
Timeframe criterion [item 7]	---
Total score	0.979

A Cronbach’s alpha of above 0.70 to determine interrater reliability, was selected as the cut off value as it is commonly defined as representing a ‘good’ and ‘relatively high’ level of reliability (Taber, 2018). There were high levels of interrater reliability on 5 of the 7 items and in the total scores. However, a Cronbach’s alpha of just 0.382 for item 2 and not able to be calculated for item 7 as the researcher rated none of the 29 outcomes as meeting criteria and the second rater scored 3 meeting criteria. Due to the lack of reliability in scoring of items 2 and 7, another individual was contacted to do an additional second rating of 10% of outcomes.

2.7.2 Additional Second Rater

Training with the additional second rater (referred to as ‘third rater’) began in September of 2021. Prior to meeting, the third rater was sent relevant information relating to the thesis including the similar study done by Castro, Grande and Palikara (2019), official Goal Functionality Scale III manual with annotations and notes directly sent via email from Scale creator McWilliam (see Appendix D), the scoring manual created by the researcher (see Appendix E) and an Excel document with examples, explanations of scorings and practice outcomes for rater training (see Appendix F).

Trainings emphasized clarity regarding items 2 and 7. A new selection of outcomes (different than those scored by the second-rater) were selected and scored. These outcomes were selected using a random number generator using the same methods as detailed above and sent to the third rater via email on Excel. Interrater reliability is presented on the next page in Table 5

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

and shows high reliability between researcher and the third-rater on all seven items of McWilliam's Goal Functionality Scale III and in the total score. Using the value of 0.7 as a cut off statistic (Taber, 2018), it is clear that the interrater reliability in this third rater is strong and of high reliability.

Table 5

Interrater Reliability between Researcher and Third-Rater Ratings

Criteria According to McWilliam (2014)	Cronbach's Alpha (α)
Participation in a routine [item 1]	1.00
Observable and measurable [item 2]	1.00
Necessary/useful skill [item 3]	0.881
Acquisition criterion [item 4]	1.000
Meaningful acquisition criterion [item 5]	0.950
Generalization criterion [item 6]	1.00
Timeframe criterion [item 7]	1.00
Total score	0.985

2.8 Ethics

As this thesis dealt with sensitive data with highly personal information regarding education and health details regarding children and young people, all regulations and requirements regarding anonymity and confidentiality for red level data were met. Despite the data coming from outside of Norway, the data handling and ethical requirements mandated by the *NHS Health Research Authority's Research Ethics Committee* also meet the requirements mandated by the *Norsk Senter for Forskningsdata (NSD)*. EHC plans were stored securely and electronically according to the University of Oslo and Norwegian national guidelines as stipulated by *The ICT Infrastructure company for Norwegian Research and Education* through the use of the platform *TSD: Service for Sensitive Data*. All personal information on outcomes were anonymized with the use of "X" for the child's name and outcomes were evaluated independently of their plan using data software to ensure confidentiality of information. A letter detailing the thesis, its methodology and related components were presented to the families and after being read, consent to participate in the thesis was given to the researcher via the signature

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

of a statement of consent. The statement of consent (found in the appendix) specified points regarding the collection of general information, including what was found in Sections B and E of the EHC plan to be used in the project. The right to withdraw from the project, have any information corrected or withdrawn from the project and receive a copy of the information gathered were clearly stated in both the parent information letter and statement of consent. Ethical approval was granted by *NSD* in January of 2021 with an extension granted through December of 2021.

Chapter 3: Results

This chapter will present the results, descriptive and statistical analysis and correlations found related to the research question “what is the quality of education outcomes for primary students with Down syndrome in England?”. Reliability measures indicated strong and excellent values of reliability (Taber, 2018) coming from an inter-rater agreement percent of 93% and Cronbach’s alpha statistics for each of the 7 item criteria scores ranging from 0.881 to 1.00 (displayed in Table 5 above). Results will be displayed in tables along with their relevant statistics and explanations will be provided.

3.1 Descriptive Statistics

3.1.1 Frequency of Objectives per EHC Plan

A total of 17 EHC plans, totaling 226 outcomes were evaluated in this thesis. The number of outcomes per EHC plan ranged from 4 to 43 ($M = 13.3$; $SD = 10.5$). Over half (58.8%) of the EHC plans consisted of 10 or less outcomes, 6 of the EHC plans had between 11 and 29 outcomes and one EHC plan had 43 outcomes. Table 6 (on the following page) summarizes the frequencies of outcome counts seen in the EHC plans.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Table 6

Frequency of Outcomes per EHC Plan

Number of outcomes	Number of EHC plans	% of total EHC plans
4	1	5.9%
5	2	11.8%
6	1	5.9%
7	2	11.8%
8	3	17.6%
10	1	5.9%
11	1	5.9%
14	1	5.9%
17	1	5.9%
20	1	5.9%
24	1	5.9%
29	1	5.9%
43	1	5.9%

3.1.2 Overall Quality of EHC Plan Outcomes

Outcome quality of each EHC plan outcome scored using McWilliam's GFS III (2014) had the potential of receiving a minimum score of 0 (lowest possible outcome quality) and a maximum score of 7 (highest possible outcome quality). The highest score total given to an outcome in this thesis was a 6/7 and no outcomes received the maximum score of 7/7 on the GFS III (McWilliam, 2014). The mean score calculated based on the 7 item criteria of the GFS III for the 226 outcomes was 2.91/7 (SD = 1.20). Table 7 (on following page) presents the frequencies of total outcome scores across all outcomes analysed.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Table 7

Frequencies of Total Outcome Score (N = 226)

Total score	Counts	% of total
0 [<i>poorest quality outcome</i>]	2	0.9%
1	23	10.2%
2	56	24.8%
3	90	39.8%
4	25	11.1%
5	27	11.9%
6	3	1.3%
7 [<i>highest quality outcome</i>]	0	0.0%

Each outcome was scored according to the seven items on the GFS III and received a score of 1 for each item if they met criteria for that item or a score of 0 if they did not. The scores across the seven items were then added to get the outcomes total score which is what determines overall outcome quality. When looking at trends across item scores, the majority of the outcomes related to the first three items of the scale met the GFS III criteria; 61.9% meeting criteria relating to the emphasis of emphasizing the child's participation in a routine or activity (Item 1), 81.9% of outcomes meeting criteria relating to observed and measured (Item 2), and 96.5% of outcomes addressing a necessary or useful skill for participation in home, school, or community routines (Item 3). When comparing the GFS III criteria to SMART criteria, this suggests higher frequencies of quality in regards to outcomes being specific, attainable and relevant. Outcome quality in regard to indicators of the scale then decreased dramatically across the other 4 scale items. Related to the presence of acquisition criterion (Item 4) and relevance of said acquisition criterion (Item 5), less than a quarter of the outcomes; 23% and 19.5% respectively met the criteria. Outcomes relating to items 6 and 7 of the Goal Functionality Scale III (2014) concerning the presence of a generalization and time frame criterion displayed the lowest aspects of outcome quality with 7.1% meeting criterion for item 6 and less than 1 percent (0.4%) of outcomes meeting criteria for item 7. The poor quality of scores across items 4-7 correlate with outcomes being measurable, relevant and time-bound in reference to SMART criteria standards. Table 8

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

presents the overall mean score and the mean score for each item on the GFS III (McWilliam, 2014).

Table 8

Mean quality ratings across all objectives (N = 226)

Goal Functionality Scale III (McWilliam, 2014)	% of outcomes meeting criteria
Participation in a routine [item 1]	61.9%
Observable and measurable [item 2]	81.9%
Necessary/useful skill [item 3]	96.5%
Acquisition criterion [item 4]	23.0%
Meaningful acquisition criterion [item 5]	19.5%
Generalization criterion [item 6]	7.1%
Timeframe criterion [item 7]	0.4%

3.2 Statistical Analysis

Due to the small sample size of 17 EHC plans, the large amount of variance in the number of outcomes seen in each plan and small cell frequency counts in some cases; any results or inferences made when interpreting the data cannot be applied to the quality of EHC plans for the population of primary students with DS as a whole. The following should therefore be interpreted with caution. Chi-squared tests of independence and their corresponding Cramer's V were reported and analysed in order to determine relationships or lack-there-of between outcome quality, key stage and region. Due to limitations within the sample, the relationship between outcome quality and type of school attended by the student was unable to be evaluated.

3.2.1 Outcome Quality and Key Stage

Due to low numbers of EHC plans across age, it was not possible to analyse the data for age effects. In order to rectify this problem and still get an evaluation of outcome score related to age grouping, the Chi Squared test of association was used to determine independence of the outcome score in relation to student age as grouped by key stage, key stage 1 consists of students aged 5-7 and key stage 2 ages 7-12. Six EHC plans came from students in Key Stage 1 and 11 EHC plans came from students in Key Stage 2. While overall total score showed a non-significant relationship; ($\chi^2(6, N=226) = 8.73; p = 0.189$), the item by item scoring analysis

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

revealed a relationship in relation to *state specifically what the child will do* [item 2] ($\chi^2(1, N=226) = 5.02$; $p = 0.025$; $V = 0.149$) and *presence of a generalization criterion* [item 6] ($\chi^2(1, N=226) = 3.97$; $p = 0.046$; $V = 0.132$). This indicates a potential relationship between outcomes for students in Key Stage 1 being more observable and measurable and students in Key Stage 2 having higher quality outcomes in regard to generalization. Table 9 below presents the descriptive statistics regarding outcome quality and key stage.

Table 9

Outcome Quality and Key Stage

Criteria from GFS III (McWilliam, 2014)	Key Stage 1 % of outcomes met criteria	Key Stage 2 % of outcomes met criteria	χ^2 value	p-value
Participation in a routine [item 1]	63.5%	60.8%	0.180	0.671
Observable and measurable [item 2]	88.5%	76.9%	5.02	0.025
Necessary/useful skill [item 3]	97.9%	95.4%	1.04	0.309
Acquisition criterion [item 4]	26.0%	20.8%	0.867	0.352
Meaningful acquisition criterion [item 5]	22.9%	16.9%	1.27	0.261
Generalization criterion [item 6]	3.1%	10%	3.97	0.046
Timeframe criterion [item 7]	1.0%	0.0%	1.36	0.244

3.2.2 Outcome Quality and Region

There are 9 official regions of England; North East, North West, Yorkshire, East Midlands, West Midlands, South East, South West, East of England and London. The 17 EHC Plans collected in this thesis represent only 6 of the 9 regions of England as no plans were

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

received from the North East, West Midlands and South West regions of England. From the regions represented in the data, almost half of the outcomes analysed in the thesis (47.3%) came from the region of London while the number of EHC plans from London made up only 29.4% of the 17 plans received. While only one EHC plan was received from the East Midlands, its 17 outcomes account for a larger percentage of total outcomes than the 14 outcomes coming from 2 outcomes in Yorkshire. The 24 outcomes coming from the East of England scored highest in regard to outcome quality and the 17 outcomes from the East Midlands showed the lowest quality of the six regions. Patterns in unequal and highly varied distribution of outcomes per plan are seen in Table 10, which presents the descriptive statistics of the plans and outcomes from these 6 regions.

Table 10

*Outcome Quality and Region**

Region	# EHC Plans	# Outcomes [% of total]	M Outcome Score (/7)	SD
North West	3	32 [14.2%]	2.94	1.11
Yorkshire	2	14 [6.2%]	3.00	1.18
East Midlands	1	17 [7.5%]	2.59	1.62
South East	3	32 [14.2%]	2.97	1.15
East of England	3	24 [10.6%]	3.46	1.18
London	5	107 [47.3%]	2.80	1.16

**Note: While recruitment documents were sent to all 9 regions of England, the 17 EHC Plans collected came from only 6 of the 9 regions. The 3 regions not represented by the data are; North East, West Midlands and South West.*

Chapter 4: Discussion

The purpose of this thesis was to answer questions of quality within the outcomes defined for English primary school students with DS who have an EHC plan. Through the use of McWilliam's GFS III 7 item criteria scale, the results of this thesis broadly showed that the outcomes are not of overall high-quality. Analysis of results across the dimensions of quality demonstrated within the rating scale has also shown that the quality of outcomes varies dramatically across the criteria. Evaluation also demonstrated dramatic variance in regards to the number of outcomes contained within each EHC plan, which while landing outside the scope of the research question, is still pertinent to the quality of the EHC plan and implementation of interventions leading to achievement of the outcomes. These findings have implications which will be discussed in this chapter within the context of previous research, related literature and definitions of quality within the SEND policy. Suggestions will be made for the development of outcome quality and further research within the field. Limitations related to the scope and methods of the thesis will also be presented.

4.1 Results of Outcome Quality within the Larger Context

The results of the thesis which indicate overall low-quality outcomes for English primary students with DS are in agreement with results seen in previous studies evaluating the quality of outcomes or learning goals for students with SEND. Most recent and applicable to the current thesis was the 2019 evaluation of EHC outcomes for students with SEND across England completed by Castro, Grande and Palikara. The Castro et al., study utilized an earlier 2009 version of the GFS III (McWilliam) which scored the 7 indicators of quality on a scale from 1-4 based on how strongly the outcome met the criteria of that indicator; *1: not at all meeting criteria, 2: somewhat, 3: much, and 4: very much*. Ratings of 1 and 2 indicated low quality whereas 3 and 4 indicated high quality. Results of the 2813 outcomes evaluated in the Castro et al., study showed that the majority of the ratings across all 7 items fell into the *not at all* or *somewhat* ratings which suggested that the outcomes were of considerably low quality (Castro et al., 2019) which is comparable to the results of the thesis indicating an overall quality score of 2.91/7 according to McWilliam's GFS III (2014). Outside of the English context, studies rating the quality of IEP goals (outcomes) for preschoolers in both Turkey (Rakap, 2015) and Portugal (Boavida et al., 2010) discovered similar, poor quality outcomes across ages and developmental domain in their evaluations. The importance of functional, measurable and generalizable

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

outcomes that are taught within daily routines and activities are argued by Pretti-Frontczak and Bricker as fostering individualization of services and promoting the development of students with SEND based on their individual needs (2000).

Outcome quality varying across the 7 quality indicator items of the GFS III in the thesis, demonstrated much higher frequencies of outcomes meeting the scale criteria in regards to the first three items (participating in a routine [item 1], being observable and/or measurable [item 2] and the behavior or skill being necessary or useful for participation [item 3]) when compared to items 4-7 of the rating scale (stating an acquisition criterion [item 4], having a meaningful acquisition criterion [item 5], having a generalization criterion [item 6] and a time-frame being present [item 7]). Similar results were found in Castro et al., which found more frequent ratings of *much* and *very much* across items 1, 2 and 3 of the 2005 version of the GFS (2019). Low quality outcomes within the realm of items 4, 5 and 6 of the GFS were also seen in Rakap's evaluation of 2235 Turkish preschool IEP goals in which none of them were found to meet the criteria of stating an acquisition criterion, having a meaningful acquisition criterion or having a generalization criterion (2015). Similarly, Boavida et al., discovered that Portuguese preschool IEP goals lack specificity and measurability, however, they also discovered a lack of functionality in regards to the skills not being addressed within routines or settings (2010), which was an area of strength found in the results of current thesis relating to items 1, 2 and 3 of the GFS III.

Special education needs and disability policy documents have no mandates for a minimum or maximum number of outcomes to be included per EHC plan. The Code of Practice guides practitioners writing outcomes that they should be centered around skills and behaviors that will enable their progression and development into learning and adulthood and moving towards long-term aspirations, but also can also include wider outcomes relating to social and emotional development (Department for Education & Department of Health, 2015). The broad definition of outcome determination is mirrored by the broad range of the number of outcomes included in the plans evaluated in this thesis and was also seen in related studies. The number of outcomes per EHC plan from the population of English primary students with DS in this thesis ranged from 4-43, which brought implications and limitations related to type of methods of statistical analysis able to be completed. The wide variation of the number of outcomes belonging to each plan was not unique to this thesis and was also discussed in Rakap's 2015

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

study which noted a range of 8-38 goals per IEP under analysis and even more dramatically in Boavida et al., which found that outcome frequency ranged from 4-95 goals per IEP (2010). Beyond implications related to statistical analysis in research, the large variation in outcomes or goals in plans can make it more difficult for teachers and related service providers to implement levels of individual instruction based on the students' strengths and functioning profile as well as difficulties in monitoring the progress of students' achievements in reaching their outcomes when there are such large amounts of outcomes per plan (Rakap, 2015).

While results revealed a slight relationship between outcome quality and key stage, this is an area which no related research found relationship or insight to. Outcomes of low quality were found not to vary based on the age of the preschool child in Rakap's study on Turkish preschool IEP outcomes (2015). No evaluation of age or key stage was made by Castro et al. (2019) or Boavida et al., (2010). The fact that the GFS was designed by McWilliam specifically to investigate the outcomes and goals for early childhood intervention or preschool children could have something to do with the lack evaluation related to age specifics.

As national and international policy and pedagogy has become more participation focused and as outcome quality is defined by SEND policy as meeting criteria of being *specific, measurable, achievable, relevant and time-bound* (SMART) it is important to discuss the results in context to the GFS III overlap with SMART criteria. According to the overlap between the seven items of the GFS III and the SMART criteria (represented in *Table 1*), the outcomes for primary students with DS were suggested to be specific, achievable and relevant but not necessarily measurable or time-bound. As the dimensions of quality differ from the GFS III and SMART criteria, the areas of overlap can only be inferred or suggested but not concluded. This highlights the issue in evaluating quality without a SMART criteria specific tool or EHC plan outcome quality indicator developed alongside the SMART criteria or SEND policy.

4.2 Limitations

This thesis presented limitations within the context of the participants and in the use of McWilliam's GFS III (2014). Wide variation within the participants includes having a small sample size of EHC plans with a wide range of outcome frequencies per plan and a not normal distribution of participants within categorical variables. The limitations in the thesis are highly relevant and important to keep in mind when examining the results and implications of the thesis.

4.2.1 Limitations within the Sample

While sample numbers of 50 or more EHC plans to be included in the thesis were hoped for in the planning phases of this thesis, only 17 EHC plans were collected and included in the thesis. Recruitment of participants to take part in the thesis took place entirely online in the midst of the COVID-19 pandemic while school classrooms were transitioned to virtual ‘rooms’ online in the homes of students and their families. Despite various virtual recruitment strategies used such as emailing, social media tools (sharing, posting, direct messaging, tagging and post boosting), direct communication with participants to share word of the project and collaborating with various Down syndrome organizations, low participant numbers remained. EHC plans were collected directly through the families of primary school students reported experiencing feelings of loss, negative mood, emotions, behaviors and being overwhelmed during the time-frame of recruitment due to the Covid-19 Pandemic (Asbury, Fox, Deniz, Code, & Toseeb, 2021). This is suggested as being a reason of difficulty in encouraging participation in the research project. Feedback given from the point of contact for many of the DS Support Groups contacted for recruitment referred to the lack of participation and communication from families in the group due to the circumstances related to the pandemic and low sample size numbers can be attributed to this.

Of the 17 EHC plans collected, there were 226 outcomes in total. While there was a high number of outcomes available to be evaluated, their unequal distribution across characteristics due to high variance in number of outcomes per plan created limitations in interpreting results outside the context of their categorical variables. The limitation of small sample size and their respective distributions across characteristics is a central point in the project and due to this, statistically significant conclusions couldn’t be made. Especially seen in regards to type of school attended by the participant and their region, analysis or conclusions were unable to be drawn. Ranging in count from 4 to 43, the number of outcomes per was highly varied and 4 of 17 EHC plans accounted for over half of the 226 outcomes. Just 6 of the 9 regions of England were represented in the thesis and of those, almost half of the outcomes came from the region of London which implies that the results of the thesis are more applicable to the status of outcome quality within London and not across England as a whole. Similarly, with only 4 of the 226 outcomes coming from a special school, no insights were gained in regards to the conversations surrounding the placement of primary students with DS in the mainstream versus special school

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

setting which is highly debated within the DS community. A 2006 longitudinal study found that teenagers with DS who were educated in mainstream classrooms displayed significant gains in literacy skills, expressive language and improved behavioral difficulties, but less in regard to social participation (Buckley, Bird, Sacks, & Archer). Differences in outcome quality relating to school placement was seen in the Castro et al., study which found that the outcomes from special schools were found to have higher scores of meeting criteria related to *specifying a routine in which the child will participate* [item 1], *specifying a behavior or skill* [item 2], *targeting a skill relevant for participation* [item 3], *mentioning a specific acquisition criterion* [item 4] and *mentioning a time frame* [item 7] (Castro et al., 2019).

4.2.2 Limitations within the use of McWilliam's Goal Functionality Scale III (2014)

McWilliam's Goal Functionality Scale III was used in this project as the tool of quality evaluation for the outcomes. The GFS III (as well as previous versions of the scale) has been used in similar studies as the method of evaluating the quality of education outcomes, goals and targets within English EHC plans and individual education documents in various countries. The GFS III encompasses multiple dimensions of quality seen in its exhaustive framework and its criteria does overlap with SMART criteria (Castro et al., 2019), however, it presents its own set of limitations when applied to the context of this thesis.

The GFS III was developed by McWilliam in the context of early childhood education in the United States which was designed to evaluate the quality of goals and objectives in Individual Education Plans and Individualised Family Service Plans. While it has been used in studies associated with Post-16 EHC plan outcomes (Castro et al., 2019), the manual developed by McWilliam emphasized skills, behaviors and routines relevant to the pre-school setting and due of this, interpretations about how to apply the scale to a primary school context with academic skills was required. As the GFS III was developed within the context of American pre-schools, it was not developed specifically in alignment with the SMART criteria meaning that while the 7 items on the scale overlap with the SMART criteria, it isn't a standardized tool designed for the EHC plan context which implies limitations. Additionally, as the GFS III scale examines the outcomes as separate entities from the other information, provisions and input from those involved in the actual implementation and monitoring of the outcomes, there is a lack of information regarding the effect of the outcome on literal service provision implementation and its effect on student development and learning.

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

In the methodology of using the GFS III to rate the quality of outcomes, difficulties in applying the scale to the context of the EHC plan outcomes was seen in requiring a second independent rater to score 10% of the outcomes to ensure inter-rater reliability. Low Cronbach's alpha scores relating to scoring outcomes according to criteria set forth in *items 2* and *7* of the GFS III from the first independent rater is a necessary point of discussion. McWilliam's defines an outcome as meeting criteria for *item 2* as stating specifically in an observable and measurable manner what the child will do, but then goes on to include that an outcome being *able* to be seen or heard is sufficient for meeting criteria; including an example of meeting criteria to include, "Karen will participate in [routines] by approaching another child" because "approaching another child" is criteria that is able to be seen or heard (2014). This expansion on what is sufficient for meeting the criteria of caused confusion from the first independent rater who believed the observable and measurable needed to be more specific and thus rated many outcomes as not meeting criteria for *item 2* when according to the definition expansion and explanations by McWilliam, they did. Similarly, confusion regarding the specificity needed to fit the criteria of *item 7* was reflected in the Cronbach alpha of the inter-rater analysis. McWilliam's scale defines meeting criteria for *item 7* of as the student demonstrating the behavior or skill during a defined period of time being framed in examples as either a certain number of days a week, or number of times per day. This item was interpreted by the first independent rater in their ratings as including "by the end of the school" or "by the end of the key stage" which was incorrect according to the scoring manual. Due to these discrepancies, a second independent rater was trained and scored a second set of 10% of the outcomes which had a high level of inter-rater reliability.

4.3 Future Research and Recommendations

While limitations made statistically significant conclusions not possible in the realm of the thesis, recommendations can still be made in regards to future research and development of higher quality EHC plan outcomes. As this project consisted of a small sample size implying caution in interpreting the results found, a future study which analyses the outcomes coming from population of primary students with DS with a larger sample size, potentially gathered in collaboration with Local Education Authorities, Special Educational Needs and/or Disabilities Coordinators or different recruitment methods could provide greater insights and conclusions in regard to the quality of outcomes and relationships existing within the categorical variables

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

featured in this thesis. With a greater number of plans coming from school type and region of England, recommendations of creation of guidance documents and professional training and education for the development of the EHC plans and the outcomes that could be catered specifically to the differences in quality found among the variables.

After looking at the limitations involved in the GFS III and the lack of a standardized tool developed with the EHC plan and SMART criteria in mind, future research into the development of such a tool would support better evaluation of plans and their outcomes. Despite the GFS III overlapping with aspects of the SMART criteria, it was not developed with the EHC plan or SMART outcomes in mind, nor was it developed for the up to 25 age range which the EHC plan and its outcomes serves to cover. An evaluation tool designed specifically for the evaluation of EHC plan outcomes would help to increase outcome quality and support provision standardization (Castro et al., 2019).

Future research into the quality of not only the writing of EHC plan outcomes for primary students with Down syndrome and other students with SEND but the actual implementation of those outcomes is paramount to drawing conclusions regarding the actual effectiveness of the EHC plan service provisions. A possible longitudinal study which examines the relationship between outcomes, which interventions or pedagogical methods are used in the implementation of said outcome, challenges in implementation, and the tracking of student development and progress monitoring for the outcome could be helpful in displaying a complete picture of outcome quality impact. As the current thesis examined the outcomes separately from the other 10 sections of the EHC plan, it could be interesting to see if a relationship exists between quality of other sections and outcome quality.

Some of the families who participated in the research provided feedback to the researcher regarding problems in communication between collaborating with their Local Authority and child's school in the development of the EHC plan which in some cases, led to tribunal cases in court in order to get amendments or changes made to their child's plan. One parent wrote to the researcher in the thesis and said "the one [EHC plan] issued was not fit for purpose. I ended up rewriting it and going to tribunal. The one he has now is good – but only because I wrote it based on the actual reports and put in provisions which were missing". After explaining the perceived inequality of care and provision due to living in a rural county who often has to travel far and pay for private assessments wrote, "unless you really fight your case and can either afford a

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

private assessment or have access to that assessment being funded there is no DS knowledge embedded in the EHCP”. An investigation into the relationship between plan or outcome quality and parent involvement and/or tribunal cases seems to be something of need based on this feedback.

Further guidelines and development of outcomes that are SMART is something that is clearly needed based on the current and past research. Outcomes evaluated in this project were written in a wide variety of formats, varying levels of specificity, from different points of view and lengths varying from one simple sentence to a 5-sentence paragraph. Consistent, clear and precisely written objectives allow professionals who work with the student know not only what to teach, but in which context and how to elicit them (Lignugaris/Kraft, Marchand-Martella, & Martella, 2001). Previous research has suggested the utilization of the ICF (International Classification of Functioning, Disability and Health) as a tool for the development of high quality-outcomes Castro et al. (2020), argues that the use of the ICF would be a way to bridge the gap between policy in ideology and the implementation special education provisions in practice and a useful tool in developing high quality outcomes for students with SEND. While the ICF was not developed for the purpose of outcome or goal facilitation, it can in fact, support the development of outcomes that are participation focused and SMART as it is an exhaustive taxonomy of activities, forms of participation, body functions and structures as well as environmental issues, provides a universal qualifier scale, differentiating between functioning features, organized using a developmental hierarchy and is participation-focused international taxonomy (Castro et al., 2020).

Bettering the development of SMART outcomes could be achieved through increasing professional development trainings for SEND professionals writing outcomes and the potential of incorporating a quality indicator into the outcome writing process which could help point out areas of weakness in the written outcome and examples of improvement. Training programs for teachers and related service members should be related to both the writing and the implementation of high-quality outcomes meeting SMART criteria as well as the strengths and needs of the individual student the outcome is written for. Emphasis should also be placed on the consistent monitoring of student progress towards meeting said outcome. As mentioned above in future research, the development of a scale or quality indicator specific to EHC outcomes would be essential in this.

Chapter 5: Conclusion

The Education, Health and Care plan outcomes for English primary school students with Down syndrome were found to be of overall low quality with high variance across items on the Goal Functionality Scale III, showing higher frequencies of meeting quality criteria relating to participation in a routine [*item 1*], being observable and measurable [*item 2*] and demonstrative of a necessary or useful skill [*item 3*]. While limitations related to the large variance of outcomes per plan and the distribution of outcomes across categorical variables cause caution in interpreting results in relation to the larger population of primary students with DS not included in the sample, the implications and suggestions for further research and development can still be applied. If students with DS are to receive high quality education and have the greatest potential for achieving their aspirations, their outcomes must be that of high quality. Researching the effects of outcome quality on pedagogy and implementation of provisions, the development of a tool of quality indication specifically in line with the context of the EHC plan, English SEND policy and SMART criteria, utilization of the ICF as the language of outcomes and better training programs for teachers and related service members to write and implement these outcomes are all suggested points of development from the thesis.

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Appendices

Appendix A: Parent Information Letter

Evaluating the Quality of Education, Health and Care Plan outcomes for primary school students with Down syndrome in England

Parent Information Letter

Are primary school students with Down syndrome receiving high quality, functional and relevant education outcomes in their Education, Health and Care (EHC) plan? If your primary school child receives education services stipulated by the EHC plan, their most recent EHCP can help answer this question and guide further outcome development. This research project aims to evaluate the quality of (EHC) plan outcomes for primary school students with Down syndrome in England who are enrolled in both mainstream and special schools. This letter provides information about the goals of the project and what participation in the project will mean for you.

What is this project about?

It has been more than six years since the introduction of the Education, Health and Care Plan (EHCP) in England, which intends to detail a holistic view of children with special educational needs and disabilities, their strengths, areas of need and goals to guide service providers in enabling the student to reach their greatest potential. Since its' introduction, an evaluation of the quality of education outcomes for students with Down syndrome has yet to be completed. Students with Down syndrome have unique strengths, gifts and needs and should receive high quality outcomes in order to provide them with the best opportunities for success. This research study, *Evaluating the Quality of Education, Health and Care Plan outcomes for primary school students with Down syndrome in England* is a Master's thesis project. The project aims to evaluate the EHCP education outcomes of students with Down syndrome; specifically to examine to what extent they meet the SMART (specific, measurable, achievable, realistic and time-bound) standards of quality as defined by McWilliam's Goal Functionality Scale III (2009). This evaluation will shed light on the overall quality, strengths and weaknesses of EHCP outcomes and can be used to guide and inform policy guidelines, outcome planning and writing tools for educators and professionals responsible for writing, implementing and assessing students according to their EHCP outcomes. It is hoped that the results from this study will also be included in a future international study comparing the quality of education outcomes for students with Down syndrome from a range of different countries.

Who is responsible for the research project?

This is a Master's Thesis project completed by Camilla Brooks. Camilla is completing her Master's in International Special Needs Education at the University of Oslo (UiO), Norway. Project supervisors are Professor Kari-Anne Bottegaard Næss from the University of Oslo, Norway and Dr Kelly Burgoyne from The University of Manchester, UK (UM).

Why are you asked to participate?

As this project aims to discover gaps in educational outcomes for at least fifty English primary school students (from Key Stage 1 & 2) with Down syndrome; your child must fit these inclusion criteria; (a) age between 5 and 12, (b) diagnosis of Down syndrome, (c) attending primary school in England (mainstream or special school); (d) have an EHCP. If your child fits these parameters, I am hoping to systematically examine their most recent ECHP in order to evaluate quality of their outcomes and provide further evidence to the importance of high-quality outcomes in regard to student success.

What does it mean for you to participate?

Should you choose to participate in this project, you will be asked to send a copy of your child's EHCP. Information regarding their gender, school setting and age will be linked to outcome data to compare the connection between, however, their personal information will be anonymized in accordance with Norwegian privacy standards and educational outcomes will then be coded, analyzed and evaluated using McWilliam's *Goal Functionality Scale* as detailed above in '*What is this project about*'. Information necessary for the research is found in the following sections of the EHCP (a) general information (age, gender, grade, school type, local authority); (b) Section B: a summary of the child/young person's special educational needs; (c) Section E: A description of the outcomes identified.

It is voluntary to participate

It is voluntary to participate in this project. If you choose to participate, you can at any time withdraw consent without giving a reason. All of your data will then be deleted. There will be no negative consequences for you if you do not want to participate or later choose to withdraw consent. If you choose not to participate you need not do anything further.

Your privacy – how your information will be used and stored

We will only use the information from your student's EHCP for the purposes we have described in this letter. We treat information with confidentiality and in accordance with related policy. Those involved with this project and who will have access to the EHCP include the authorized parties; Master's student Camilla Brooks, Supervisor Kari-Anne Bottegaard Næss (UiO), Supervisor Kelly Burgoyne (UM) and an independent rater from the respective institutions who will code and evaluate 10% of the objectives in order to ensure objectivity and rigor in the rating of outcomes. Your student's EHCP will be stored securely and electronically according to the University of Oslo and Norwegian national guidelines as stipulated by *The ICT infrastructure company for Norwegian research and Education*. In compliance with strict Norwegian privacy regulations, your student's EHCP will be stored and accessed securely through the platform *TSD: Service for Sensitive Data*. Participants will not be recognizable in the publication and no sensitive personal information will be published.

What happens to the information when we finish the research project?

The information will be anonymized and archived upon completion of the project via the secure electronic platform *TSD*. It is hoped that the results from the study will be used in a future international comparison looking at the quality of educational outcomes for children with Down syndrome across various nations, however, all personal information will be anonymized and there will be no link between individual student information and their data.

Your rights

As long as your student can be identified in the analysis, you have the right to:

- access any personal information registered about your student and to receive a copy of the information,
- to have personal information about your student corrected,
- to have personal information deleted about your student, and
- to send a complaint to the Data Inspectorate about the processing of your personal data.

Have you given us the right to treat your personal information?

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

We process information about your student based on your consent.

On behalf of the University of Oslo, NSD – Norwegian Center for Research Data AS has assessed that the processing of personal data in this project is in accordance with the privacy regulations.

Where can I find out more?

If you have questions about the study or want to exercise your rights, please contact:

- Master's Student
 - o **Camilla Brooks**
 - o By email: camiljb@student.uv.uio.no
 - o By phone: +47-980-93-516
- University of Oslo Supervisor
 - o **Kari-Anne Bottegaard Næss**
 - o By email: k.a.b.nass@isp.uio.no
- Collaborating University of Manchester Supervisor
 - o **Kelly Burgoyne**
 - o By email: kelly.burgoyne@manchester.ac.uk
- University of Oslo Privacy representative
 - o behandlingsansvarlig@uio.no

If you have questions related to NSD's assessment of the project, you can contact:

- **NSD – Norwegian Center for Research Data AS**
- By email: personverntjenester@nsd.no
- By phone: +47-555-82117

With best regards,

Camilla Brooks (UiO) / Kari-Anne Bottegaard Næss (UiO) / Kelly Burgoyne (UM)

Appendix B: Consent Statement

Participation and Consent Statement

Thank you for your interest in the *“Evaluating the Quality of Education, Health and Care Plan outcomes for primary school students with Down syndrome in England”*. By completing this form you are confirming that you have understood:

- The information letter provided to you
- That participation is voluntary and you can withdraw at any time
- That if you have any questions, you can contact Camilla Brooks by email camiljb@student.uv.uio.no or phone +47 980 93 516

Please tick the boxes that you agree with below. If you do not tick a box, we will assume you do not agree to that point

**if you do not agree with points 1-4, unfortunately, you will be unable to participate as pertinent information regarding your child’s EHCP cannot be evaluated*

No.	Statement	Please tick if you agree
1	I agree that information found in the <i>general information</i> section of my child’s most recent EHCP (full name, date of birth, sex, school and address) can be collected as part of this research project as outlined in the information sheet and privacy notice. *	
2	I agree that information found in <i>Section B</i> of my child’s most recent EHCP (educational needs) can be collected as part of this research project as outlined in the information sheet and privacy notice. *	
3	I agree that information found in <i>Section E</i> of my child’s most recent EHCP (outcomes identified) can be collected as part of this research project as outlined in the information sheet and privacy notice. *	
4	I agree that findings from the research project utilizing information and evaluation from my child’s EHCP from above points <i>No. 1-3</i> can be used in future follow-up research regarding quality of outcomes. *	
5	I agree for the research team to retain my contact details in order to contact me during the research project and provide me with a summary of the findings for this study.	

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the [Privacy Notice](#).

Your Child's Details:

First Name:		Last Name:	
Date of Birth: (DD/MM/YY)			
Parent/Guardian Phone:		Parent/Guardian Email:	

By signing this form, you are agreeing to participate in the research project, share your child's most recent EHC Plan document with researchers and the statements you have ticked above.

Name of Parent/Guardian

Signature

Date

You will be given a copy of this participation agreement form to keep and refer to at any time. A second copy of the participation agreement form will be kept by the research team.

Appendix C: Associated Flyers

ARE PRIMARY SCHOOL STUDENTS WITH DOWN SYNDROME RECEIVING HIGH QUALITY EHCP OUTCOMES?

Your child's EHCP can help us answer this question!

ELIGIBILITY CRITERIA

- AGE 5-12
- ATTENDS A MAINSTREAM OR SPECIAL PRIMARY SCHOOL IN ENGLAND
- HAS A DOWN SYNDROME DIAGNOSIS
- HAS A RECENT EHCP

DOES YOUR CHILD FIT THE ELIGIBILITY CRITERIA?

SEND US A MESSAGE FOR DOCUMENTS AND THE SUBMISSION LINK!

OR EMAIL CAMILJB@STUDENT.UV.UIO.NO

STEPS FOR PARTICIPATION

1. READ THE PARENT INFORMATION LETTER
2. READ AND SIGN THE STATEMENT OF CONSENT
3. SUBMIT THE STATEMENT OF CONSENT AND YOUR CHILD'S MOST RECENT EHCP TO THE SECURE DATS PLATFORM NETSKJEMA

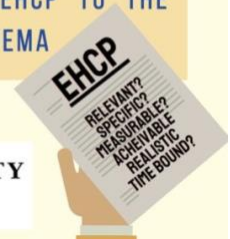


CONTACT: camiljb@student.uv.uio.no

Camilla Brooks: International Special Needs Education Master's Student



UNIVERSITY OF OSLO



ARE PRIMARY SCHOOL STUDENTS WITH DOWN SYNDROME RECEIVING HIGH QUALITY EHCP OUTCOMES?

WE ARE LOOKING FOR EHCP'S TO ANSWER THIS QUESTION!

ELIGIBILITY CRITERIA

- Age 5-12
- Attends a mainstream or special primary school in England
- Has a Down syndrome diagnosis
- Has a recent EHCP



STEPS FOR PARTICIPATION

1. Read the Parent Information Letter
2. Read and sign the statement of consent
3. Submit the statement of consent and your child's most recent EHCP to the secure dat platform Netskjema

ALL LINKS CAN BE FOUND [HERE](#).

WHERE TO FIND MORE INFORMATION

EMAIL: camiljb@student.uv.uio.no

FACEBOOK: @DSoutcomesEHCP

TWITTER: @DSoutcomesEHCP

PHONE: +47.980.93.516



UNIVERSITY OF OSLO

Camilla Brooks: International Special Needs Education Master's Student

DO YOU HAVE A CHILD WITH DOWN SYNDROME THAT HAS AN EHCP & ATTENDS PRIMARY SCHOOL IN ENGLAND?

IF SO, WE ARE INTERESTED IN REVIEWING AND EVALUATING YOUR CHILD'S EHCP OUTCOMES!

A graduate student at the University of Oslo is conducting a study evaluating the quality of educational outcomes in ECHP's for English primary school students with Down syndrome.



THE RESEARCH QUESTION

Are primary school students with Down syndrome receiving high quality, functional and relevant education outcomes meeting SMART criteria in their EHCP?

WHAT WOULD I BE ASKED TO DO?

Provide a copy of your child's most recent EHCP

WHO CAN TAKE PART?

You are eligible to take part if you have a child who

- Attends a mainstream or special primary school (age 5-12)
- Has a Down syndrome diagnosis
- Has a recent EHCP

INTERESTED IN PARTICIPATING?

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Appendix D: GFS III Manual from McWilliam

GOAL FUNCTIONALITY SCALE III MANUAL

R. A. McWilliam

Siskin Children's Institute

2014

VERSION

Various versions of the Goal Functionality Scale III (GFS III) have been used in different projects. This manual is for the simplest one, which is similar to the one published in the book *Routines-Based Early Intervention* (McWilliam, 2010), but with each item answered as YES or NO. This version was used in a study of the quality of individualized family service plans (IFSPs) (Ridgley, Snyder, & McWilliam, 2013; Ridgley, Snyder, McWilliam, & Davis, 2011). Each goal is scored on the same seven items, described below.

GENERAL DIRECTIONS

WHAT YOU ARE SCORING

The aim is to have one score for each early intervention/early childhood special education plan. In the U.S., these plans are the individualized family service plan (IFSP) or individualized educational program (IEP). In some systems, worldwide, the question is whether the unit of analysis is the goal or the objective. Generally, the GFS III is used to score the statement of what the child will do. Therefore, on plans that have general statements that essentially announce the domain for each goal, such as *Sam will improve language skills*, would not be scored. Assuming under this goal an objective such as *Sam will use two-word combinations to let his needs and wants be known* exists, that objective that would be scored. If the goal is quite general, such as *Sam will use words to make his needs and wants known*, and the information under it is strategies, short-term objectives, task-analysis steps, and so on, the goal is scored. The simple rules to follow are

- Score goals that state what the child will do and
- Do not score statements not really qualifying as goals but that announce the domain; instead score objectives;

SCORES FOR EACH PLAN

Plans have different numbers of goals, so the GFS III must be averaged across goals. Users should still document the number of goals because that might be an indicator of quality in itself. For example, many IFSPs have only two or three goals (called outcomes on most IFSPs). I have stated that this is too few (Jung & McWilliam, 2005; McWilliam, 2010, 2011; McWilliam, Casey, & Sims, 2009). On the other hand, some IEPs have so many goals (sometimes masked as objectives) that it would be hard to have any focus on instruction. Although views differ on the subject of the ideal number of goals, in my Unified Model of Early Intervention 0-5, is 10-12.

Because means are more reliable the greater the number of scores being averaged across, 10-12 is a reasonable number. *Remember these are child-level goals only.*

ITEM 1

Emphasize the child's *participation* in a routine (i.e., activity)? (*Child will participate in outside play time not child will participate in running*).

PURPOSE

This item is designed to give credit to goals reflecting engagement in home, school, or community activities, events, and settings.

CRITERIA

Yes if the goal states that the child "will participate in" one or more typically occurring routines, such as bath time, reading time, snack time, outside time. *No* if the goal simply states the skill the child will do (e.g., "Naomi will look for a hidden object"). *No* if the goal states the child will "participate in" a behavior, such as talking, eating, bathing, and so on. Participating in a behavior is the same as doing a skill. Participation must be in a routine, a time of day, or an event. *No* if the goal is for the child to be passive.

EXAMPLES

Yes: George will participate in bedtime by lying quietly within 5 minutes of being put to bed.

Yes: Harriet will participate in breakfast, lunch, and dinner by eating with a spoon.

No: Ian will say mama and dada.

No: Janey will participate in walking.

No: Kent will wear a weighted vest.

ITEM 2

State specifically (i.e., in an observable and measurable manner) what the child will do?

PURPOSE

This item is designed to give credit to goals that are behaviors that a person can see or hear.

CRITERIA

Yes if the goal describes a skill, such as drinking, pulling to stand, grasping an object. *No* if the goal describes a mental process such as understanding, knowing, thinking, or wanting. *No* if the goal describes a mental or emotional state such as being happy, being satisfied, or tolerating. *No* if the goal is for the child to tolerate something. *No* if the goal is to *learn* to do something.

EXAMPLES

Yes: Karen will participate in [routines] by approaching another child.

Yes: Liam will participate in dressing time by pushing arms through shirt sleeves.

No: Monica will participate in [routines] by knowing her colors.

No: Neil will participate in [routines] by recognizing his parents.

No: Olive will participate in [routines] by enjoying herself with blocks.

No: Paul will tolerate prone over a ball.

No: Lakweesha will allow shaving foam to be put on her palms.

No: Maria will participate in dressing time by leaning to dress herself without help.

ITEM 3

Address a skill that is either *necessary* or *useful* for participation in home, "school," or community routines?

PURPOSE

This item is designed to give credit to goals that are meaningful for daily living and are not simply test or curriculum items with no relevance in routines or indicators of internal processing

CRITERIA

Yes if the goal describes a behavior one typically expects to occur in a normalized situation, such as walking outside; coloring at play, centers, or art time; and waving bye-bye at pick-up-from-child-care time. *No* if the goal describes a behavior that does not enhance participation in a routine, such as kneeling for 20 seconds, putting pellets of paper into a small jar, or making the "buh" sound. *No* if the goal describes a so-called clinical skill, which is sometimes considered a prerequisite to another skill, such as increase mean length of utterance (MLU) to 2.0 words, use alternative communication styles, complete exercises to improve stability of oral structures (all these examples from an online goal bank). *No* if the goal describes something going on inside the child's mind or body that cannot be documented as directly useful, such as complete activities to enhance proprioceptive and kinesthetic awareness. *No* if the goal is to participate in a therapy exercise.

EXAMPLES

Yes: Paul will... by playing with different toys.

Yes: Queenie will... by playing by herself.

Yes: Robbie will... sitting in his high chair without slumping to the side.

No: Sarah will... identifying sounds (phonemes) as same or different.

No: Tommy will... auditorially discriminating the target sound.

No: Uma will... using appropriate number of syllables.

No: Vasco will... by standing in a prone stander.

ITEM 4

State an **acquisition criterion** (i.e., an indicator of when the child can do the skill)?

PURPOSE

This item is designed to give credit to goals that have a measurable value for when we will know the child can perform the skill. Acquisition criteria can be measured in frequency, duration, distance, volume, and so on.

CRITERIA

Yes if the goal has a number indicating how we would know the child could “do this.” *Yes* if the goal has a level of assistance (e.g., with minimal physical assistance), but it would still need a number (e.g., “when he walks with minimal assistance 10 feet”). *No* if the goal is written without an indicator of completion, such as “Vic will participate in diaper change by holding on to a toy.” *No* if the goal has a generalization criterion but no acquisition criterion.

EXAMPLES

Yes: We will know she can do this when she plays with toys for 10 minutes.

Yes: We will know he can do this when he sits in his high chair without slumping for 15 minutes.

Yes: We will know he can do this when he walks 10 feet.

No: We will know he can do this when he walks with minimal physical assistance.

No: Karen will participate in [routines] by approaching another child.

No: We will know this when she eats with a spoon at breakfast, lunch, and dinner. [How many bites, for how long?]

ITEM 5

Have a meaningful acquisition criterion (i.e., one that shows improvement in *functional* behavior)? (*We will know he can do this when he holds a spoon for 2 minutes not ...when he holds a spoon on 5 out of 7 trials*)

PURPOSE

This item is designed to give credit to goals that measure the attainment of the goal with an ecologically relevant index.

CRITERIA

Yes if the acquisition criterion for the goal is how a parent or a teacher would judge whether a child could now perform the skill. *Yes* if the acquisition criterion is relevant for participation in

a routine. *No* if the acquisition criterion is measured by proportion of trials or percentage of time, because (a) most skills are not taught with massed, repeated trials; and (b) most people do not monitor the denominator, let alone the numerator, in calculating percentage of time. *No* if the acquisition criterion is a technical measure that parents or teachers would not be measuring or estimating (e.g., mean length of utterance).

EXAMPLES

Yes: We will know he can do this when he eats one cup (almost .25 liters) of food in this manner.

Yes: We will know he can do this when he tries to use three different pieces of playground equipment.

No: We will know he can do this when he eats with a fork in 8 out of 10 trials.

No: We will know he can do this when he plays on different pieces of playground equipment 80% of the time.

ITEM 6

Have a generalization criterion (i.e., using the skill across routines, people, places, materials, etc.)? (*...when he holds a spoon for 2 minutes at lunch and dinner*)

PURPOSE

This goal is designed to give credit to goals that require performance in more than one place, in more than one routine, with more than one person, with more than one object, and so on.

CRITERIA

Yes if the goal needs to be observed in more than one routine. *Yes* if it needs to be observed in more than one place, with more than one person, or with more than one object. *No* if no generalization is programmed.

EXAMPLES

Yes: We will know he can do this when he holds an object with two hands for 5 minutes at eating time, once a day, and at play time, once a day.

Yes: We will know he can do this when he sits independently for 10 minutes during two of the following: play time, bath time, dressing time, and dinner preparation time.

No: We will know she can do this when she crawls 6 feet.

No: We will know she can do this when she crawls 6 feet at play time.

ITEM 7

Have a criterion for the timeframe? (*...when he holds a spoon for 2 minutes at lunch and dinner on three consecutive days or ...at lunch and dinner on 3 days in 1 week*).

PURPOSE

This item is designed to give credit to goals establishing over what amount of time the child is supposed to demonstrate the acquired and generalized skill.

CRITERIA

Yes if the goal states a length of time during which the acquisition and generalization criteria must be seen. *No* if the goal could be accomplished over an indefinite time.

EXAMPLES

Yes: We will know he can do this when he approaches another child three times daily, once each at morning outside, afternoon outside, and free play, on 3 of 5 school days in a week.

Yes. We will know she can do this when she puts on both shoes, even if on the wrong feet, at dressing time, every day for 2 weeks.

No. We will know he can do this when he approaches another child three times daily, once each at morning outside, afternoon outside, and free play.

No. We will know she can do this when she puts on both shoes, even if on the wrong feet, at dressing time, every day.

RESEARCH USE

As part of a study examining IFSP quality, 687 goals were rated with the Goal Functionality Scale III (Ridgley et al., 2013). Interobserver agreement scores were calculated for 20% of the IFSPs that had at least 2 goals (i.e., 137) and they ranged from 56.9% to 100%.

In a Portuguese study, a translated version of the instrument was used (Boavida, Aguiar, & McWilliam, 2014). Thirty-three percent of the 292 IEPs/IFSPs were scored for interrater agreement. "The obtained interrater exact agreement was 79.75%, with a weighted kappa of .59 and an intraclass correlation coefficient of .70" (p. 208). The following figure shows the scores for the items, in reverse order, for pre- and posttraining.

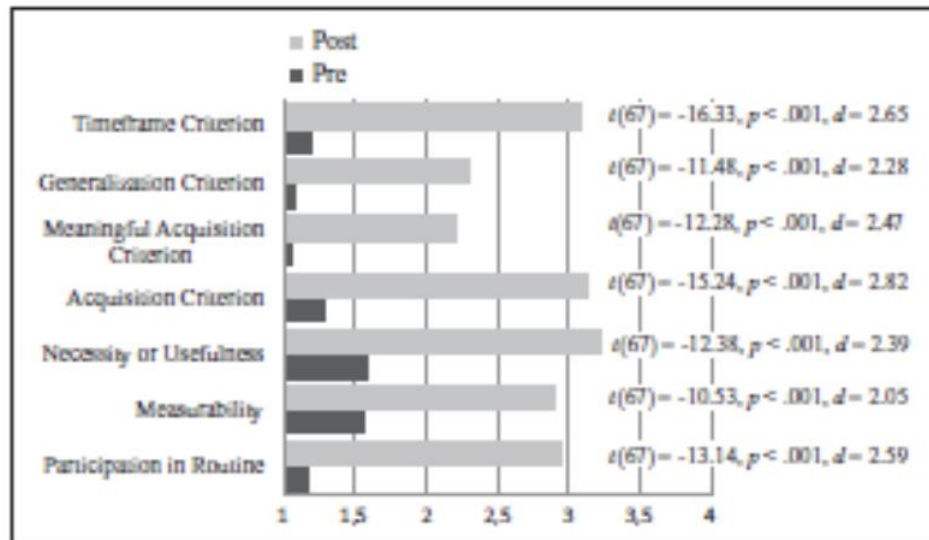


Figure 1. Pre- and posttraining overall mean quality by GFS III item. GFS III = Goal Functionality Scale III.

From Boavida et al. (2014), page 209.

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- Boavida, T., Aguiar, C., & McWilliam, R. A. (2014). A training program to improve IFSP/IEP goals and objectives through the Routines-Based Interview. *Topics in Early Childhood Special Education, 20*, 200-211. doi: 10.1177/0271121413494416
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- McWilliam, R. A. (2011). The top 10 mistakes in early intervention— and the solutions. *Zero to Three, 31*, 11.
- McWilliam, R. A., Casey, A. M., & Sims, J. L. (2009). The Routines-Based Interview: A method for assessing needs and developing IFSPs. *Infants & Young Children, 22*, 224-233.
- Ridgley, R., Snyder, P., & McWilliam, R. A. (2013). *Using empirically validated strategies to examine IFSP quality*. Paper presented at the Division for Early Childhood's Annual International Conference on Young Children with Special Needs and their Families, San Francisco, CA.
- Ridgley, R., Snyder, P. A., McWilliam, R., & Davis, J. E. (2011). Development and initial validation of a professional development intervention to enhance the quality of individualized family service plans. *Infants & Young Children, 24*, 309-328.

Appendix E: Researcher Created Scoring Manual

Using R.A. McWilliam’s Goal Functionality Scale III (2014) to rank EHCP Outcomes

The goal functionality scale is made up of 7 items and each are scored as “yes” or “no” (quantified as 1 or 0, respectively) dependent on meeting the set criteria. The maximum score an outcome can receive is 7/7 and minimum is 0/7. The items are as follows...

- Item 1: Emphasize the child’s participation in a routine (i.e., activity)? (*Child will participate in outside play time not child will participate in running*)
- Item 2: State specifically (i.e., in an observable and measurable manner) what the child will do?
- Item 3: Address a skill that is either necessary or useful for participation in home, “school,” or community routines?
- Item 4: State an acquisition criterion (i.e., an indicator of when the child can do the skill)?
- Item 5: Have a meaningful acquisition criterion (i.e., one that shows improvement in functional behavior)? (*We will know he can do this when he holds a spoon for 2 minutes not... when he holds a spoon on 5 out of 7 trials*)
- Item 6: Have a generalization criterion (i.e., using the child across routines, people, places, materials, etc.)? (*... when he holds a spoon for 2 minutes at lunch and dinner*).*
- Item 7: Have a criterion for the timeframe? (*... when he holds a spoon for 2 minutes at lunch and dinner on three consecutive days or ... at lunch and dinner on 3 days in 1 week*).

* R.A. McWilliam now states that “we now only use generalization across routines”

Item 1

Definition by McWilliams: Emphasize the child’s participation in a routine (i.e., activity)? (Child will participate in outside play time not child will participate in running).

Purpose from McWilliams: This item is designed to give credit to goals reflecting engagement in home, school or community activities, events, and settings

Criteria and Examples (from McWilliams)

YES	NO
- If the goal states that the child “will participate in” one or more typically occurring routines such as bath time, reading time, snack time, outside time	- If the goal simply states the skill the child will do
- the outcome indicates a routine or activity that the child is or must actively participate in and be a part of	- If the goal states the child will “participate in” a behavior, such as talking, eating, bathing and so on
	- If the goal is for the child to be passive.
<i>George will participate in bedtime by lying quietly within 5 minutes of being put to bed.</i>	<i>Ian will say mama and dada</i>
<i>Harriet will participate in breakfast, lunch, and dinner by eating with a spoon.</i>	<i>Janey will participate in walking</i>
	<i>Kent will wear a weighted vest.</i>

In the context of the Goal Functionality Scale III, the following terms are defined.

Participation: any language referring to the student being actively engaged in partaking in or participating in a routine.

Routine: Routines are repeated, predictable and take place regularly. A routine is **not** a skill or behavior.

Observable: Can be seen or heard

Measurable: Can be quantified

Meaningful: Something that has value and importance for the learner to participate actively and effectively in their environment

Information in black is taken directly from the McWilliam Guide.

YES	NO
criteria of yes from McWilliam’s Goal Functionality Scale (2014)	criteria of no from McWilliam’s Goal Functionality Scale (2014)
examples of yes (score 1) from McWilliam’s Goal Functionality Scale (2014)	examples of no (score 0) from McWilliam’s Goal Functionality Scale (2014)

Information in color is from researcher collaboration.

McWilliam, R. A. (2014). Goal Functionality Scale III. In G. F. Scale (Ed.): SISKIN Children’s Institute

Important notes:

Participation

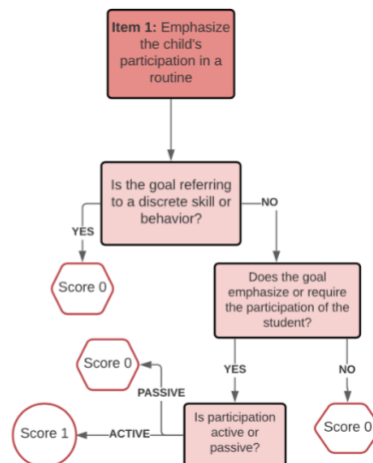
IS:
- the active, taking part in a routine

is NOT:
- doing a skill
- participating in a behavior
- a discrete task

A routine IS:

- a typically occurring activity, event, series of steps in a routine
- repeated, predictable and take place regularly

Examples: lunch time, reading lesson, hygiene routines, recess time, centers, etc.



QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Item 2

Definition by McWilliams: State specifically (i.e. in an observable and measurable manner) what the child will do?

Purpose from McWilliams: This item is designed to give credit to goals that are behaviors that a person can see or hear

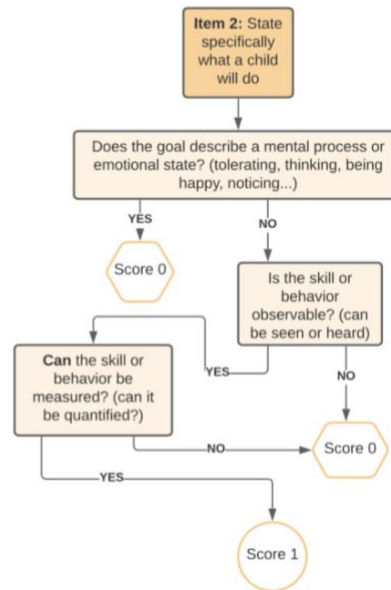
YES	NO
<ul style="list-style-type: none"> - If the goal describes a skill, such as drinking, pulling to stand, grasping an object. - If "understanding" is followed by detailing how the understanding will be observed (by responding, communicating, or doing something) 	<ul style="list-style-type: none"> - If the goal describes a mental process such as understanding, knowing, thinking or wanting - If the goal describes a mental or emotional state such as being happy, being satisfied, or tolerating - If the goal is for the child to tolerate something - If the goal is to learn to do something
<i>Karen will participate in [routines] by approaching another child.</i>	<i>Monica will participate in [routines] by knowing her colors.</i>
<i>Liam will participate in dressing by pushing arms through shirt sleeves</i>	<i>Neil will participate in [routines] by recognizing his parents.</i>
	<i>Olive will participate in [routines] by enjoying herself with blocks.</i>
	<i>Paul will tolerate prone over a ball.</i>
	<i>Maria will participate in dressing time by learning to dress herself without help.</i>

Important notes:

- to be scored a 1; the outcome must be something that **can** be measured (doesn't have to specify how, but needs to have the ability to be measured)

Observable: can be seen or heard

Measurable: can be quantified



Item 3: continued on next page

Definition by McWilliams: Address a skill that is either *necessary or useful* for participation in home, routine or community routines?

Purpose from McWilliams: This item is designed to give credit to goals that are meaningful for daily living and are not simply test or curriculum items with no relevance in routines or indicators of internal processing.

YES	NO
<ul style="list-style-type: none"> - If the goal describes a behavior that one typically expects to occur in a normalized situation - Normalized situations such as: walking outside; coloring at play, centers or art time; and waving bye-bye at pick-up-from child-care time. <p><i>normalized situations at the primary school level could include: classroom activities, participating in lessons, social situations or other relevant activities for their age and grade.</i></p>	<ul style="list-style-type: none"> - If the goal describes a behavior that does not enhance participation in a routine, such as kneeling for 20 seconds, putting pellets of paper into a small jar, or making the "buh" sound. - If the goal describes a so-called clinical skill, which is sometimes considered a prerequisite to another skill, such as increase mean length of utterance (MLU) to 2.0 words, use alternative communication styles, complete exercises to improve stability of oral structures (all these examples from an online goal bank). - If the goal describes something going on inside the child's mind or body that cannot be documented as directly useful, such as complete activities to enhance proprioceptive and kinesthetic awareness. - If the goal is to participate in a therapy exercise.
<i>Paul will... by playing with different toys.</i>	<i>Sarah will... identifying sounds (phonemes) as same or different.</i>
<i>Queenie will... by playing herself</i>	<i>Tommy will... auditorially discriminating the target sound.</i>
<i>Robbie will. sitting in his high chair without slumping to the side.</i>	<i>Uma will... using appropriate number of syllables.</i>

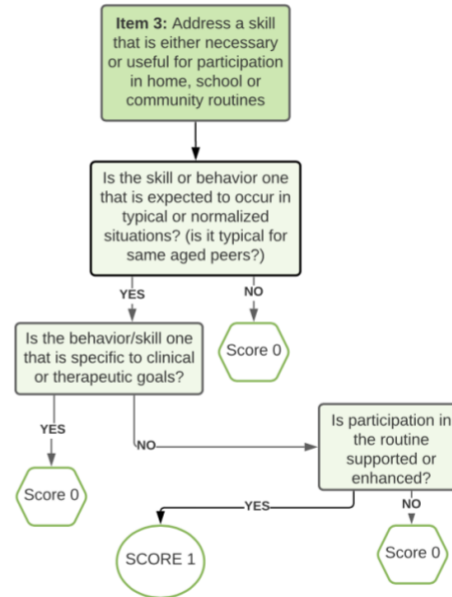
QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Item 3: continued

Important notes:

The outcome must support or enhance participation in order for it to be scored a 1. This can include participation in a variety of areas:

- **School:** skills that are useful in order to participate in academic lessons or routines such as numbers, mathematics, reading, writing, etc.
- **Social skills:** social skills are considered to be necessary and useful
- **Independence:** outcomes regarding independence are to be scored a 1 as independence is part of participation
- **Communication:** communication and interactions



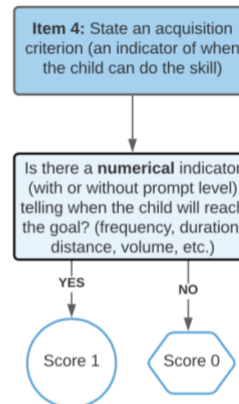
Item 4

Definition from McWilliam: State an acquisition criterion (i.e., indicator of when the child can do the skill)

Purpose from McWilliam: This item is designed to give credit to goals that have a measurable value for when we know the child can perform the skill.

Acquisition criteria can be measured in frequency, duration, distance, volume, and so on.

YES	NO
- If the goal has a number indicating how we would know the child could "do this"	- If the goal is written without an indicator of completion, such as "Vic will participate in diaper change by holding on to a toy."
- If the goal has a level of assistance (e.g., with minimal physical assistance), but it would still need a number (e.g., "when he walks with minimal assistance 10 feet")	- If the goal has a generalization criterion but no acquisition criterion.
<i>We will know she can do this when she plays with toys for 10 minutes.</i>	<i>We will know he can do this when he walks with minimal physical assistance.</i>
<i>We will know he can do this when he sits in his high chair without slumping for 15 minutes.</i>	<i>Karen will participate in [routines] by approaching another child.</i>
<i>We will know he can do this when he walks 10 feet.</i>	<i>We will know this when she eats with a spoon at breakfast, lunch, and dinner. [how many bites, for how long?]</i>



Important notes:

Quantity can also be seen in statements such as:

- "all letters in the alphabet"
- "letters in name"
- "numbers 1-50"

* as long as there is specification and parameters indicated in the outcome: it can be scored a 1

QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Item 5

Definition from McWilliam: Have a meaningful acquisition criterion (i.e., one that shows improvement in functional behavior)?

Purpose from McWilliam: This item is designed to give credit to goals that measure the attainment of the goal with an ecologically relevant index.

YES	NO
- If the acquisition criterion for the goal is how a parent or a teacher would judge whether a child could now perform the skill	- If the acquisition criterion is measured by proportion of trials or percentage of time, because (a) most skills are not taught with massed, repeated trials; and (b) most people do not monitor the denominator, let alone the numerator, in calculating percentage of time.
- If the acquisition criterion is relevant for participation in a routine.	- If the acquisition criterion is a technical measure that parents or teachers would not be measuring or estimating (e.g., mean length of utterance).
<i>We will know she can do this when he eats one cup (almost .25 liters) of food in this manner.</i>	<i>We will know he can do this when he eats with a fork in 8 out of 10 trials.</i>
<i>We will know he can do this when he tries to use three different pieces of playground equipment.</i>	<i>We will know he can do this when he plays on different pieces of playground equipment 80% of the time.</i>

Item 6

Definition from McWilliam: Have a generalization criterion (i.e., using the skill across routines) (... when he holds a spoon for 2 minutes at lunch and dinner)

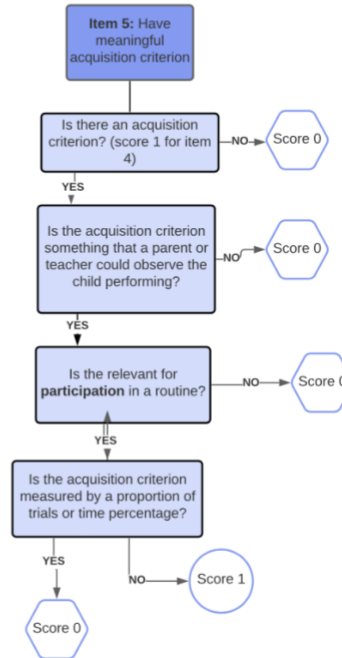
Purpose from McWilliam: This goal is designed to give credit to goals that require performance in more than one place, in more than one routine

YES	NO
- If the goal needs to be observed in more than one routine.	- If no generalization is programmed.
<i>We will know he can do this when he holds an object with two hands for 5 minutes at eating time, once a day, and at play time, once a day.</i>	<i>We will know she can do this when she crawls 6 feet.</i>
<i>We will know he can do this when he sits independently for 10 minutes during two of the following: play time, bath time, dressing time and dinner preparation time.</i>	

Important notes:

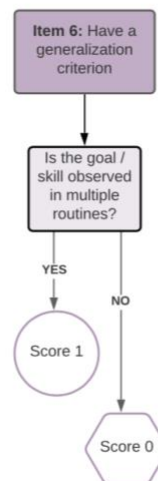
If there is no acquisition criterion (score 0 for item 4); then there is no meaningful acquisition criterion. It is impossible to receive a score of 0 for item 4 and a score of 1 for item 5

Meaningful for individual: example; knowing the letters in their name, etc.



Important notes:

- the other routines must be specified; not assumed or inferred based on raters interpretation



QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Item 7

Definition from McWilliam: Have a criterion for timeframe? (... when he holds a spoon for 2 minutes at lunch and dinner on three consecutive days... or... at lunch and dinner on 3 days in 1 week)

Purpose from McWilliam: This item is designed to give credit to goals establishing over what count of time the child is supposed to demonstrate the acquired and generalized skill.

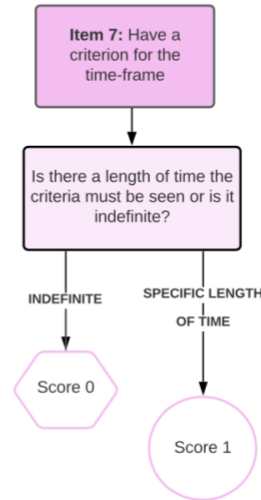
YES	NO
- If the goal states a length of time during which the acquisition and generalization criteria must be seen.	- If the goal could be accomplished over an indefinite time.
<i>We will know he can do this when he approaches another child three times daily, once each at morning outside, afternoon outside, and free play, on 3 of 5 school days in a week.</i>	<i>We will know he can do this when he approaches another child three times daily, once each at morning outside, afternoon outside, and free play.</i>
<i>We will know she can do this when she puts on both shoes, even if on the wrong feet, at dressing time, every day for 2 weeks.</i>	<i>We will know she can do this when she puts on both shoes, even if on the wrong feet, at dressing time, every day.</i>

Important notes:

- "at the end of the Key Stage" is NOT a sufficient time frame

This is all about:

- How will we know that the student has mastered the goal and can move on to another goal?
- How many times must the goal be achieved for mastery?



QUALITY OF EHC OUTCOMES FOR PRIMARY STUDENTS WITH DS

Appendix F: Outcome Scoring Document for Trainings

	A	B	C	D	E	F	G	H	I
	<p>Goal Functionality Scale III McWilliams</p> <p>YES: 1 NO: 0</p>				<p>X will eat at snacktime and lunch by eating with a spoon or fork. He will independently feed himself his meal (20 minutes) minutes using utensils with minimal spillage.</p>	<p>X will be able to develop functional communication skills in line with her overall abilities. By the next review, X will consistently and independently ask for help more and toilet when she needs it.</p>	<p>X will be able to extend her early learning skills so that she starts to build the foundations for basic literacy and numeracy skills. By the next review, X will match and read new familiar words and letters.</p>	<p>By the end of year 4, X will have an improved vocabulary, and will be able to recognise all letters, read the 100 most common word so that he demonstrates progress as assessed by his teachers.</p>	
1	<p>Item 1: Emphasize the child's participation in a routine (i.e., activity) (child will participate in outside play time NOT child will participate in running)</p>	<p>0 sitting quietly in a seat is passive and does not emphasize participation of the child. No routine or activity is mentioned</p>	<p>1 child is actively participating in the reading lesson and routine.</p>	<p>1 child is actively participating in the routine of meal times</p>					
2	<p>Item 2: State specifically (in an observable and measurable manner) what the child will do</p>	<p>1 sitting quietly <i>can</i> be observed and measured</p>	<p>1 turning pages and answering yes or no questions are specific, measurable and observable things.</p>	<p>1 eating with a spoon or fork, ten minutes independently and minimal spillage are all observable and measurable</p>					
3	<p>Item 3: Address a skill that is either necessary or useful for participation in home, school or community routines</p>	<p>0 it does not enhance participation in a routine</p>	<p>1 participating in reading lessons, answering questions and actively taking part in the reading process are meaningful for primary school children</p>	<p>1 independent meals and routine of eating are necessary and useful across routines</p>					
4	<p>Item 4: State an acquisition criterion (i.e., an indicator of when the child can do the skill)</p>	<p>0 there is no numerical indicator of when the child will meet the goal</p>	<p>0 there is no numerical indicator of when we know the child has met the goal (should say "answering 5 yes or no questions correctly, turning 3 pages" etc.)</p>	<p>1 numerical indicators are clear: 10 minutes, minimal spillage (could be quantified with volume)</p>					
5	<p>Item 5: Have a meaningful acquisition criterion (ie: one that shows improvement in functional behavior)</p>	<p>0 item 4 received a 0 so item 5 cannot receive a 1 (there is no acquisition criterion so it cannot be meaningful)</p>	<p>0 item 4 received a 0 so item 5 cannot receive a 1 (there is no acquisition criterion so it cannot be meaningful)</p>	<p>1 the criteria is meaningful because is obvious, easy to judge and relevant for participation.</p>					
6	<p>Item 6: Have a generalization criterion (ie using the skill across routines)</p>	<p>0 no generalization is programmed; nothing referencing sitting across routines</p>	<p>0 no generalization is programmed; nothing referencing sitting across routines. If this included bedtime story, centers or other lesson it would score 1)</p>	<p>1 generalization is programmed across snack and lunch time</p>					
7	<p>Item 7: Have a criterion for the timeframe</p>	<p>0 "by the end of Key Stage 1" is not a sufficient timeframe; this timeframe should be short term and specific</p>	<p>0 no timeframe is given</p>	<p>0 no short term time frame is given (would need to specify... for both meals 3 days a week... one meal 5 days a week... etc.)</p>					
8	<p>Total Score for outcome (/7)</p>	<p>1/7</p>	<p>3/7</p>	<p>6/7</p>					
9									
10									
11									
12									
13									