Developing an Outcomes Model for Disabled Children and Young People in Scotland
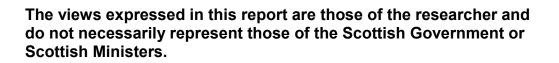
Health and Community Care

social research

DEVELOPING AN OUTCOMES MODEL FOR DISABLED CHILDREN AND YOUNG PEOPLE IN SCOTLAND

Children in Scotland

ChildreninScotland
every child - every childhood

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The views expressed in this report are those of the researcher and do not necessarily represent those of the Scottish Government or Scottish Ministers.

Table of Contents

1 INTRODUCTION

1.1 Scotland has clear goals and high aspirations for all of its children and young people. The Scottish Parliament has approved a Motion stating, in part, that: "Scotland will be the best place in the world to grow up" (Scottish Parliament, Official Report 14 March 2013). But is Scotland the best place to grow up if you have a disability? If not, then how will we begin to move more fully towards this goal?

1.2 Scotland has a very clear set of high-level national outcomes. There is also a set of more specific national outcomes many of which are supported by Getting it Right for Every Child (GIRFEC) and by achieving the four key Curriculum for Excellence (CfE) capacities.

1.3 Neither GIRFEC nor CfE provide the answer to what these outcomes mean, or how they can be applied in practice, to the lives of individual disabled children and young people.

1.4 This project focused on better understanding 'outcome models' for all children and young people and for children and young people in the diverse and challenging context of disability.

1.5 In undertaking this work we had to take account of:

- The very wide definition of disability being used, involving a large number of different disabilities and individual impairments, not to mention further variations on account of the age of the disabled child or young person.

- The wide range of situations within which many disabled children and young people live, including for example, whether they are looked-after children, in hospital, in secure accommodation, or in separate education facilities from their non-disabled peers.

- The wide range of agencies and services working with each disabled child or young person, all of which have their own assumptions, perspectives, terminology and working methods.

1.6 This suggested that an outcomes model would have to be extensive to address all these needs and situations. From the start of the project, it was apparent that many people are concurrently developing outcomes models at different levels and of varying degrees of complexity.

1.7 Additionally, the large number of outcomes models being developed around Scotland were addressing different issues according to whether they were giving priority to:

- Personal outcomes for individual disabled children or young people
- Service or organisational outcomes
- National and/or locally-determined outcomes

- Different fields (primarily education, health, and social services).

Ultimately, these have to feed into a set of national outcomes. So, do they all relate to each other? And if they do, how?

1.8 Our work focussed on mapping and understanding the work of the many different agencies and professionals across Scotland involved in identifying outcomes for disabled children and young people. The approach taken is described in Appendix A.

1.9 GIRFEC is the context for work with all children in Scotland and this work was framed in the context of GIRFEC's SHANARRI wellbeing indicators: "Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included". Any outcomes and measurement framework must address GIRFEC and how it applies to each disabled child and young person ..

1.10 This report provides an overview of how outcome models and approaches are being developed for disabled children and young people in Scotland. In this fast-evolving field, this work is a starting point providing a foundation for the considerable work still needing to be undertaken.

2 DISABLED CHILDREN AND YOUNG PEOPLE IN SCOTLAND

2.1   There are a number of recent, detailed research and policy reports about services for disabled children[1] in Scotland, each with a comprehensive up-to-date literature review[2]. This section summarises key research evidence related to:

*   The children's aspirations and hopes
*   How these findings might contribute towards a framework for developing outcomes models.

Our findings are grouped around a number of key themes that have direct or contextual implications for subsequent outcomes work.

*   The definition of disability
*   Disabled children's broad aspirations
*   Disabled children's foundational needs
*   Engaging disabled children in planning their services
*   The implications of children having multiple conditions
*   The availability and sharing of information
*   The role of technology in meeting disabled children's needs.

The definition of disability

2.2   'Disabled' children is the preferred term consistent with the social model of disability – a model that has become the norm for most people working in this field and adopted by all the studies reviewed as part of this project. It locates disability in relation to the social, cultural, material and attitudinal barriers that can exclude a person from mainstream life, rather than in relation to individual deficits. This links well with the literature about barriers to social inclusion (Stalker and Moscardini, 2012).

2.3   The legal definition of disability is more narrow and is provided by the 2010 Equality Act: The Act defines a disabled person as a person with a disability. A person has a disability for the purposes of the Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term, adverse effect on his or her ability to carry out normal day-to-day activities. This means that, in general:

*   The person must have an impairment that is either physical or mental
*   The impairment must have adverse effects that are substantial
*   The substantial effects must be long-term

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[1] The words 'child' and 'children' are used to include any child or young person up to the age of 18.
[2] This is not a full literature review but draws on one that was compiled previously. The documents included in the full literature review are listed in the bibliography.

- The long-term substantial adverse effects must have a meaningful impact upon day-to-day functioning.

2.4 This project was framed to include children with additional support needs, who may or may not be disabled in terms of this legal definition. These children are defined by the Education (Additional Support for Learning) (Scotland) Act 2004, as amended, which set in place a broader, more inclusive understanding of additional support needs (ASN), consistent with the social model of disability. The key words in the ASL Act are the ones granting eligibility/rights to children who are not benefitting adequately from their learning opportunities "for whatever reason". The Scottish Government's ASL Code of Practice outlines four factors that may give rise to ASN: the learning environment; family circumstances; social and emotional factors; and disability or health need.

2.5 So, taking these definitions together, we will find that there are children who have additional support needs because they are disabled (although all disabled children may not have additional support needs). There are also non-disabled children who do have additional support needs for other reasons (broadly, though not exclusively, connected with their situation). For example, a child may be subject to bullying, may be homeless, may live in a family where drug or alcohol use or other abuse is prevalent, may be in secure care, and so on. Clearly some of these family or social factors may overlap. These differ from the above definition of disability in that they may not always be long-term or permanent situations (e.g. bereavement, homelessness or being looked after).

2.6 This underlines the complexity around the matter of definition. The Doran Review published in 2012 noted the lack of consensus around the definition of complex ASN (Scottish Government, 2012a). Similarly, Stalker and Moscardini (2012) note that the social model can neglect: the implications of specific impairments; the role of personal experience; and diversity issues.

2.7 So, although in this report we talk about "disabled children", in line with the title of the project, this is an over-simplification. It is used, in the absence of a more accurate, broadly agreed, descriptor, to mean children with additional support needs, which may or may not include a legally-recognised disability.

2.8 This illustrates a tension underlying the whole of this work: legal definitions are inherently generalisations, which attempt to cover whole populations. Individuals do not always fit neatly into such definitions. This is broadly expressed by GIRFEC (the framework for this work). GIRFEC proposes that we should Get It Right for Every Child, and consequently starts from a focus on the individual child, rather than the whole population.

2.9   Unlike the ASL Act, GIRFEC is not restricted to concerns about educational inclusiveness. It is concerned with every child's access to and use of all services that they may need, from all or any agencies or services, at any time and for any length of time, i.e. with inclusiveness in all aspects of life and society. Children may present with additional support needs (for any services) for obvious and critical reasons, from birth onwards, but they may be identified as needing interventions and services only over time. We cannot, therefore, presume that a child has additional support needs until they have been assessed and their needs identified, or it is found that they do not, in fact, have any distinct and significant additional support needs.

2.10   This encapsulates both the problem and the solution. The problem of identifying just which children have additional support needs, given that all such needs are not immediately obvious; and the solution that the focus of GIRFEC is every child. The core of the GIRFEC approach is the process by which the child's needs are assessed and their services planned. This is intended to be a co-operative and where necessary multi-agency process that (while instigated by the agency or parent/carer raising the initial diagnosis or issue), will involve all agencies relevant to that specific child's needs working together. So, while GIRFEC is an approach defined and described on paper, the identification of an individual child's needs is a matter of practice. The particular children whose outcomes we are concerned about will be children receiving services from all or any agencies.(The working of GIRFEC is discussed further in Section 4.)

2.11   This broad definition has implications for the likelihood of developing a single coherent outcomes model. A wide range of different agencies will be involved, each with its own approach, working procedures and regulatory framework. Of course, they all also have their own professional staff trained, socialised and experienced in different sets of terminology, working practices and frameworks. While some promising initiatives are under way in Scotland to bring together staff and practice from health and social/children's services, these include only some of the services involved with, or needed by, particular children.

Disabled children's broad aspirations

2.12   The recent study by Stalker and Moscardini (2012) for Scotland's Commissioner for Children and Young People (SCCYP) (and based *inter alia* on six studies since 1969) provides a view of disabled children's lives from their own perspective. They found it striking that the main findings from these six reports are very similar.

2.13   A key finding is that disabled children are, in most respects, the same as their non-disabled peers. They have a similar range of interests, pastimes and aspirations, and want to access the opportunities and

experiences open to non-disabled children (though with support as needed).

2.14   This finding is reinforced by research from Sloper et al (2007), which explores the outcomes disabled children and their parents wish to achieve.

- Friendships: As with all children, friendship is important. There are often problems associated with losing friends when moving school, taking time out of school, or as a result of living far away from school, which limits access to social and leisure activities where friendships are formed.

  Although disabled children need friendships amongst their peers as a whole, they would also like, and need, to meet others dealing with similar realities and experiences.

- Foundational needs: Outcomes in certain areas of children's lives – physical and emotional wellbeing, communication and safety – were seen as fundamental and needed to be addressed before other outcomes could be achieved. This is a significant issue when planning outcomes, and is discussed in more detail below.

- Progress or maintenance: For some children, maintaining an existing situation was as important and significant as making progress. Maintenance (i.e. no deterioration in their condition or ability to function) could in itself be a successful outcome.

- Autonomy: Disabled children, and especially young people, want more autonomy as they grow older and mature (just like their non-disabled peers).

  Disabled children identify their parents, especially their mothers, as very important and usually their main source of support. Parents are typically the child's main advocates (Stalker and Moscardini, 2012). However, in developing autonomy, that means that the parents themselves also need to evolve in their relationship with their child. The movement towards greater independence can be problematic when parents are very protective, a natural aspect of having acted as advocates for their child since early childhood.

- Similarity and difference: Disabled children are "sometimes made to feel different in negative ways". They are commonly subject to prejudice and bullying. Such treatment is exacerbated by a lack of awareness of, as well as by negative attitudes towards, disabled people.

  The individual's sense of difference can be heightened by the institutional arrangements for their care and education. This is termed by Stalker and Moscardini as the "institutionalisation of

difference", with a child's impairment often being the dominant identity or status ascribed to them. Although 'inclusion' is the policy aspiration and framework for all children throughout Scotland (particularly by Curriculum for Excellence), inclusion policies are not always thought through, and can lead to a "denial of difference". In other words, there is a risk of not giving due recognition to the impact of a child or young person's disability.

2.15 It is clear that whilst disabled children share similar broad aspirations with their non-disabled peers, there are greater challenges for them in achieving parity and genuine social, educational and community inclusion.

2.16 Any framework for identifying and measuring outcomes for disabled children should, therefore, be rooted in the outcomes models used for non-disabled children; that is, they should be focussed on the individual talents, capabilities and interests of the individual child. However, there is an important proviso to this proposition, as suggested earlier and discussed in the next section.

Foundational needs: fundamental outcomes

2.17 Many disabled children have basic needs that must be met before others can be achieved – i.e. their 'foundational' needs and their 'fundamental' outcomes. Achieving these may be compounded by multiple conditions or disabilities, and by the problematic circumstances in which they live and grow.

2.18 Sloper et al (2007) identified research on what outcomes disabled children and their parents desire from support services. Their research included children:

- With complex health care needs
- Who do not communicate using speech
- With autistic spectrum disorders
- With degenerative conditions.

2.19 They found that the strong interdependence of outcomes indicates that:

- Particular attention should be paid to 'fundamental' outcomes
- What the same broad outcome (for instance 'successful learner') means for an individual disabled child could sometimes be very different than for a non-disabled child
- Outcomes needed to be conceived not only in terms of progress, but also in terms of maintenance, e.g. physical functioning.

2.20 Sloper and colleagues focused on a number of fundamental outcomes:

- Communication: Being able to communicate was considered fundamental to meeting a range of other desired outcomes and all those in regular contact with the child need the knowledge and skills

to understand a child's means of communication. Apart from giving a child effective 'voice', it opens up opportunities for socialising, being active and becoming more independent.

- However, Stalker et al (2010) note that many practitioners lack experience and confidence in communicating with disabled children. It is often difficult for practitioners who have infrequent contact with disabled children to be skilled at communication. Some disabled children, particularly those with learning disabilities, autism, communication impairments or who are deaf, may need support to communicate, a reality that needs to be in forthcoming statutory guidance on Getting it Right for Every Child (GIRFEC) implementation it is in the ASL legislation – chapter 7 of the Code of Practice.

- Being healthy: Physical and emotional wellbeing are important aspects of being healthy, which can be problematic for disabled children. For some, being comfortable and not in pain is central to achieving other outcomes. But, maintaining health and functioning could be threatened in using health services and by problems with the supply and availability of equipment in different settings. For others, psychological wellbeing may be a concern.

- For children with degenerative conditions, there was a conflict between maintaining physical health and abilities against quality of life. Emotional support was needed in order to cope with these changes and parents stressed the importance of meeting those emotional needs, especially in the end stages, to ensure the child did not feel anxious or abandoned.

- Concern among parents of children with autistic spectrum disorders and degenerative conditions about their child's emotional wellbeing were also noted, supported by the work of Health Scotland's 'Children With Exceptional Needs' project.

- Keeping children safe from exploitation: Abusive relationships and physical danger were highlighted as a concern when a child received care from a number of people, could not communicate well or lacked a well-developed sense of danger. A higher than average incidence of child abuse and neglect has been highlighted by Stalker and others in *Child Protection and the Needs and Rights of Children and Young People* (2010).

- Enjoying and achieving: Inter-related activities such as socialising and having friends have already been identified as a priority for many. Lack of contact with school friends (outside of school) was seen as a barrier to achieving friendships across all groups and was noted as a source of considerable frustration for some disabled children.

2.21 The foundational needs posed by particular disabilities need to be taken into account when creating appropriate lists of desired or expected outcomes.

2.22 Models need to be sufficiently flexible to accommodate individual outcomes. Definitions need to take account of children's views and their full range of capabilities. For example, full independence and making the same economic contribution as their non-disabled peers may not be feasible or reasonable outcomes for all disabled children.

2.23 What we define as 'success' for a disabled child depends on their own unique reality. Not meeting the norm for an age cohort does not necessarily indicate a poor outcome for a particular disabled child.

2.24 In order to create fair and achievable outcomes, we need to consider each individual child's abilities and potential, and recognise that sometimes, the maintenance of functioning is the equivalent to the mainstream norm of making progress for non-disabled children.

2.25 Further, outcomes need to be identified both by, and for, the child's parents/carers and the professional staff working with them, as well as for the children themselves. Outcomes need to be both realistic and ambitious and must also look to the overall path for that child in the future.

Engaging disabled children in planning their services

2.26 The importance of seeking children's views is a recurring theme in GIRFEC (which in turn, reflects Article 12 of the UN Convention on the Rights of the Child). At the same time, definitions of social inclusion involve the active participation of children and families in decision-making. The ASL Act also identifies a duty to seek and take account of the views of children and young people with additional support needs in decisions about their services and provision.

2.27 Stalker and Moscardini (2012) note that: "Service planners/providers need to tap in more systematically, and in a more varied range of ways, to the way young people view the routes they take through life and the barriers they have to face or envisage." (page 20)

2.28 Our society and its institutions/services need to pay better attention to all children's views and their perceived and expressed needs and aspirations. The degree to which this is successfully accomplished is one of the needs to be addressed in fully implementing GIRFEC and achieving inclusiveness for all children.

Multiple conditions, multiple situations

2.29 Disabled children often have more than one disability (co-morbidities), or have multiple needs such as having to cope with mental distress or social disadvantage as well as a physical or learning disability.

2.30 This can result under current arrangements in multiple professionals from different organisational and reporting structures working with the child, which in turn can lead to multiple outcome frameworks being applied to the child.

2.31 In addition, a higher proportion of disabled children may be looked after, in secure accommodation, on the child protection register, subject to school exclusion or in another educational institution away from the main school. For example, on March 2010: [3]

- 5% of children on child protection registers were reported as having some form of disability.
- 20% of children on child protection registers were reported with an "unknown" disability status.
- 81% of young people in secure care accommodation had at least one known additional support need, of which 26% were known to have medically diagnosed social, emotional or behavioural difficulties.

2.32 There were a disproportionate number of school exclusions among disabled children, especially those with social, emotional or behavioural difficulties (for Scotland's Disabled Children, 2010). The Doran Review noted that the exclusion rate of pupils with ASN is almost five times greater than for those without additional support needs (Scottish Government, 2012a).

2.33 Stalker and Moscardini (2012) also identified a number of groups that are relatively neglected in the literature, including children: with mental health issues; with learning disabilities and mental health issues; who are deaf or have hearing difficulties; who are looked after and disabled; who are disabled and from Black and Minority Ethnic families; with communication impairments; and who spend long periods in hospital or at residential schools. They say that there may also be disabled children from travelling families and those who are lesbian, gay, bisexual, and transgender (LGBT), but these subgroups are essentially invisible in the literature.

2.34 The immediate impact of these multiple or complex situations is that the children concerned are often engaged with multiple services, sometimes from the independent or third sector, as well as the statutory services from public education, social services and health agencies.

2.35 Each of these bodies will have its own approach to determining outcomes (some legally determined or required) and many more people are likely to be involved in the process of determining these outcomes.

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[3] Note: The way the statistics are collected was changed. They previously referred to "disabilities" and now refer to "additional support needs".

The availability and sharing of information

2.36   Better information is needed in two key areas: the numbers of disabled children and young people in Scotland and data about the services available in each area across the country.

2.37   There are no national data available that accurately count all disabled children and young people in Scotland. The National Review of Services for Disabled Children in Scotland (2011, 2012) noted that: "The exact numbers of disabled children is not known – different data sets span differing conditions and age groups." Whilst we do know how many pupils have disabilities, that does not include all children.

2.38   The Scottish Government funded *for Scotland's Disabled Children* (fSDC) to conduct a mapping exercise (*Setting the Scene*, 2010). It found that there are "Significant gaps in information about disabled children in Scotland." This project included setting up a database of disabled children receiving services or support in the public domain with the aspiration that local authorities, health boards and others would submit missing and new information. However, few agencies submitted new data and only one update was submitted. The project is no longer funded for this work.

2.39   fSDC noted that: "If an evidence based approach is to be taken to planning and delivering services, then the starting point must be knowing how many children and young people are likely to need services and support."

2.40   Further, because services for disabled children are potentially provided by so many agencies, there are concerns about consistency across the data produced by these agencies. However, "there is variation too between data gathered by local authorities and that collated by health boards... The different rates of capture shown for each NHS Board are a reflection of differing implementation and utilisation of the system in each NHS Board...This demonstrates the lack of an accurate baseline across the public sector about the numbers of disabled children in Scotland, in our communities and across service disciplines." (op.cit.)

2.41   This is not surprising since these various services operate separately and there has previously not been the desire to have such a coordination of outcome data. In addition, the coordination of such data would need to be effected at a higher level between the Scottish Government, COSLA and the NHS Health Boards. It cannot be accomplished by a small short-term project.

2.42   There are data collected, but only for some conditions and situations. For example, data are gathered at local authority level about the numbers of looked after children who have a disability. There are also Scotland-wide data about disabled children who are on the child protection register and also those in secure accommodation (for

Scotland's Disabled Children, 2010). Local authorities have been collecting data about additional support needs and the reason why support is needed, since 2005. There are also data in the 2011 census and in the Growing Up in Scotland study.

2.43 Audit Scotland gathers and publishes local authority indicators on the numbers of people assessed for a service or waiting for an assessment, as well as the numbers of people receiving a service - but only for adults. Similar indicators are not measured for children and young people (for Scotland's Disabled Children, 2010). Although Audit Scotland collates data on the number of respite weeks provided for disabled children under the age of 17 by each Local Authority. In 2006-07, a total of 22,610 weeks were provided in Scotland. This had changed little over 5 years with 22,970 provided in 2011-12. http://www.scotland.gov.uk/Publications/2012/10/7084/1

2.44 Creating a unified system of data collection can only be effected at a governmental level since it requires the matching of different systems that have different legal and regulatory frameworks. If all the sources mentioned above were brought together it would provide at least a better more accurate indicative number of children requiring services.

Information about services and their consistency

2.45 *for Scotland's Disabled Children* compiled information about the range of services and their availability in all local authority areas in Scotland. It compiled detailed information about the number and type of services and support provided by each local authority and health board and published it on the fSDC website. The survey "elicited a small number of responses; a web search was marginally more successful; there was very little Scottish Government data except on short break provision and self-directed support." (for Scotland's Disabled Children, 2010)

2.46 In terms of strategies, plans, services and support, fSDC found, among other things, that: "Single Outcome Agreements are all in place and, current but very few contain specific local outcomes or indicators relating to disabled children".

2.47 Stalker and Moscardini (2012) found that: "Post-Concordat, there is unevenness of provision across the country and funding for disabled children is not ring-fenced. The amount spent on services for disabled children is almost impossible to identify."

2.48 They also note that the costs of inclusion should be an integral part of service planning and that there is a need for stronger capacity building in mainstream organisations to welcome and properly assist disabled children and young people. There is a strong ethos and expectation of increased inclusion through Scotland's Curriculum for Excellence. This is a welcome development but CfE's potential has not yet been fully realised across the nation.

Disabled children and technology

2.49 Technology provides a huge range of support for all people with disabilities. This involves the technology that assists with communication and many other functions. It also applies to the use of the very rapidly developing range of communications technology available to everybody (not just computers, mobile phones but also the software and applications that are developing equally rapidly).

2.50 CALL Scotland provides critical and significant leadership, knowledge, expertise and support in this area.

2.51 It should be noted that the use of communications technology by young people themselves can provide them with: i) the means of communicating with their peers and with the wider world; ii) ways of accessing directly a variety of technology-based assessment and planning tools, including tools that are designed to help determine and monitor progress towards achieving outcomes; and, iii) using technology to enhance their general wellbeing.

SUMMARY OF FINDINGS

Disabled children share most of the same aspirations, goals and insecurities as their non-disabled peers. It is clear however, that there are greater challenges for these children in achieving parity and genuine social, educational and community inclusion.

Any framework for identifying and measuring outcomes for disabled children should, therefore, be rooted in the outcomes models used for non-disabled children but take into account the following:

- **The very broad definition of 'disability' means that a very diverse range of agencies could be involved. Each will have their own approach, working procedures and regulatory frameworks.**

- **As with all children, each disabled child has her/his own unique reality – a complex mix of strengths and support needs. What is defined as 'success' for one, may not constitute 'success' for another. This is even more important for children with complex needs, where not meeting the 'norm' for an age cohort may not necessarily indicate a poor outcome (acknowledged in CfE through the concept of the "jagged profile" which acknowledges the different levels at which children learn without any implied judgment).**

- **The nature of disability means the child is more likely to be engaged with a number of different services, all of which will need to collaborate and be involved in developing outcomes for the child (which should be achieved through the full implementation of GIRFEC).**

- **Ensuring that the children are actively engaged in developing their own outcomes is crucial (a duty under the Education (Additional Support for Learning) (Scotland) Act 2004, as amended). However, disabled children are more likely to experience communication difficulties, which means that professionals require specific knowledge and skills to be effective.**

- **Parents are often their child's main advocate. Outcomes need to be created for, and with the child's parents and/or carers, and for the professionals who work with them, as well as for the child themselves.**

- **There are inadequate data about the numbers of disabled children in Scotland, and the services available to them. Coordination of the data needs to be effected between the Scottish Government, COSLA and NHS Health Boards.**

3 OUTCOMES MODELS: FRAMEWORK AND CONTEXT

Context

3.1 An emphasis on measuring outcomes in children's services has become enshrined in Scottish Government policy. "In 2006 the Scottish Government stated that less time should be spent on measuring what goes into services and how money has been spent, and that more time should be invested in what funding achieves for individuals and communities. This was followed under the Concordat locally, by the overarching Single Outcome Agreement (SOA), which set out a new relationship between central and local government, allowing for more flexibility at the point of delivery.

3.2 However, implementing an outcomes policy and approach, affects more than just local authorities and Community Planning Partnerships. Cook and Miller (2012) distinguish between outcomes for individuals, and outcomes for services, organisations or nations. They stress that the personal outcomes need to drive outcomes activity. They place these personal outcomes in relationship to the others illustrated in Diagram 1, which expresses them as different 'levels'.

Diagram 1: Different levels of outcomes from Cook and Miller 2012

Outcome level	Focus	Examples
Individual/personal	Defined by person: what is important to them.	I want to be able to get back to the bowling club, so that I can spend time with my friends.
2. Service/project	Defined by a project or service as a key focus to work towards with people.	We work with older people to improve their ability to get out and about.
3. Organisational	Defined by local authority. NHS Board or provider as a key area to work towards. Will increasingly be required to be defined across organisations.	Improve the social inclusion of the older people we work with.
4. National	Defined by government to focus activity across sectors and organisations.	We live longer, healthier lives. Our people are able to maintain their independence as they get older and access appropriate support as they need it.

3.3 Their work is very helpful in locating (though perhaps not relating) the outcomes currently being defined in different areas of Scottish services. It also suggests a number of issues, in particular about the relationship

between the different levels, and raises a number of problems when applied to the situation of disabled children[4].

3.4   Miller (2011) cites the following benefits to all the outcome levels in this framework:

- For people who use services and their families, being involved in defining the outcomes they want to achieve can be empowering and result in increased relevance and support.
- Working with individuals to develop outcome-focussed plans, and reviewing the outcomes achieved, can help achieve clarity of purpose.
- An outcomes approach can help organisations to reconnect with their value base and ensure that they are focussed on the differences they make to people's lives as well as the activities undertaken.

Do the levels relate?

3.5   Personal outcomes are not achievable in isolation, nor can they be monitored outwith the context of the other outcomes. Individuals receiving services interact with staff from agencies. The agencies are part of local authorities, health boards or third-sector organisations, each with their own outcomes policy and each of which must report to government and/or funding agencies.

3.6   Ideally, for a complete system of outcomes, the lowest levels - those closest to the individual receiving a service - should feed upwards. The achievement of personal outcomes should inform and further the achievement of national outcomes.

3.7   However, policies about desired outcomes often feed down from the top, reinforced by legislation, regulations and/or financial systems. They are not necessarily congruent with the outcomes being sought by individuals receiving services. This tends to be true for children, in general, and disabled children in particular.

3.8   Looking at how the levels relate involves complex sets of interactions involving management, working procedures and reporting mechanisms, within and between levels.

Personal outcomes

3.9   Cook and Miller (2012) look at how the personal outcomes approach should be implemented in practice, but not the wider issue of how these relate to other outcome levels.

3.10   They contextualise the personal outcomes approach: "There is a widespread recognition that systems need to shift from an exclusive

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[4] The words 'child' and 'children' are used to include any child or young person up to the age of 18.

20

focus on what they do to include consideration of what difference they make to the people using services and support. A personal outcomes approach can support that. This means working with the person to identify what is important to them or what they want to achieve, and then working backwards to identify how to get there. It means supporting the individual to be as independent as possible, while paying attention to their quality of life... working like this means a shift from 'ticking boxes' to engaging with people."

3.11   They describe personal outcomes as: "what matters to people using services, as well as the end result or impact of activities and can be used to both plan and evaluate activity."

Implementing a personal outcomes approach

3.12   Cook and Miller identify three components of the 'Talking Points' approach:

- Engaging with the person, to identify what is important to them in life and planning how everyone is going to work together to achieve these outcomes. This means that conversation is important, with listening being an important part of that process.
- Recording the outcomes in a support plan, which is shared with everybody concerned.
- Using the information to ensure that what matters to the person is used to influence service planning and implementation.

3.13   Miller (2012) added: "It cannot be assumed that service users' views on their outcomes will correspond with those of organisations and practitioners". This is critical since it refers to the interface between an individual's views and the outcomes outlined in any pre-defined model.

3.14   Cook and Miller also identify three types of outcomes:

- Maintenance or quality of life outcomes: Aspects of a person's whole life that they are working to achieve or maintain, including being well.
- Change outcomes: Focus on short-term removal of barriers that relate to the improvements in physical, mental or emotional functioning that individuals are seeking from any particular service intervention or support.
- Process outcomes: Relate to the experience people have seeking, obtaining and using services and supports, which focus on how services are delivered. (Cook and Miller, 2012, and Miller 2011)

3.15   The outcomes above are interrelated and should not be considered in isolation. "Specific services may emphasise particular types of outcome but ... research with service users demonstrated that the process, or how services engage with people, is inseparable from, and shapes the outcome." (Miller 2011)

3.16　There are also outcomes for unpaid carers, which emphasise the importance of carers being included as partners in decisions about the person. This is a central issue when considering outcomes for disabled children.

3.17　Finally, this approach "involves a shift away from the way services currently do business ... so staff need time for the conversations involved and the organisation needs to support them in doing this ... the service needs to use the information about outcomes to make the improvements required ... so management needs to be outcomes focussed too ... strong leadership is required to live through the change at every level".

Applying this approach to disabled children and young people

3.18　Applying this framework to disabled children is complex for a number of reasons. The three dominant reasons are identified below:

- Multiple parties involved: Given that there are multiple people involved (from parents/carers to professionals), there are also multiple perspectives, preferences and priorities at work. For instance, agencies and professions usually have their own (sometimes complementary, sometimes contrasting), procedures, time-scales, information-sharing systems, training, and work cultures. This is the everyday working reality for these professionals and the outcomes devised for an individual child has to fit into these multiple frameworks.

- Multiple needs: Disabled children will frequently have more than one disability, condition or situation with which they must deal. This usually means that they relate to different agencies or frameworks, bringing with them a range of sometimes disparate outcomes.

- Engaging with the child: Disabled children may have foundational needs that must be addressed before others can be effectively resolved. This may involve communication issues or other issues affecting their ability to interact easily with the people with whom they are working. Disabled children of different ages, maturity, and personality do not always see eye-to-eye with some (or many) of the adults with whom, they are involved. This makes decision-making about whose preferred outcomes will prevail a complex and potentially contentious matter.

Challenges in implementation

3.19　Miller (2011) lists a number of challenges when measuring outcomes:

- Clarity of purpose: "It is important to be clear about the purpose of measuring outcomes. Is it primarily for improvement purpose or to make judgments?"

- Measurable or meaningful: "One of the policy priorities in service improvement is that the results should be measurable. Recent research highlighted the limitations of quality measurement including the tendency to miss areas where data are not available, and to miss less quantifiable aspects of quality. Evidence reveals the adverse effects of prioritising external reporting, particularly in the form of targets."
- Hard or soft outcomes: "Soft outcomes give a fuller picture of the overall value and success of projects... the most vulnerable users were viewed as missing out because they were less likely to achieve quick and measurable outcomes."
- Challenges of attribution: This addresses the "challenges of establishing cause and effect, or attribution... this is further complicated where there is multi-agency involvement".
- Variation in service users: "Variations in the characteristics of service users leads to challenges in interpreting the data... Responses can be influenced by service user characteristics unrelated to the quality of care", which is particularly pertinent when measuring outcomes for disabled children or young people.

A variety of approaches

3.20   Miller (2011) identifies a number of approaches to developing outcomes models including "Theory Driven Evaluation", "Logic Modelling" or "Choosing or Designing Outcomes Tools." It is not proposed to expand on these here but they are identified where used in the summary of outcomes activity taking place in Section 5.

3.21   A briefing from Community Care Providers Scotland and others, *An Outcomes Approach in Social Care and Support: An Overview of Current Frameworks and Tools* (2010) outlines a number of approaches that have been developed. Further information about some of these has been included in Section 5 and Appendix B of this report.

3.22   Multi-agency involvement with a child's outcome planning adds an additional layer of complexity as it raises the issue of "attribution". It is very challenging to clearly identify what factors have achieved particular outcomes. It can be more helpful to think about contribution rather than attribution, in aiming to identify the contribution of each agency involved towards achieving the outcomes. This will be helped by the idea of a "single plan" for each child, the child's plan. Different agencies may require their own more detailed plans depending on their role or statutory obligations but the single child's plan should embrace these specific issues.

SUMMARY OF FINDINGS

This section distinguishes between outcomes for the individual (personal outcomes) and outcomes for services, organisations and nations. These different outcome 'levels' are interrelated and are not achievable in isolation.

Ideally, the achievement of personal outcomes should inform the achievement of outcomes from services, organisations and nations.

A personal outcomes approach requires a systematic shift so that the focus is on working with individuals to identify what is important to them or what they want to achieve, and then working backwards to identify how to get there.

A number of challenges are identified in applying this framework to disabled children. These include:

- A child's multiple needs and the number of professionals and agencies involved, as well as the views of parents/carers.

- Communication or other issues that affect a disabled child's ability to communicate with people.

- Whilst soft outcomes provide a fuller picture, they are harder to measure. If measurable results are required, there may be concern that the most vulnerable users might miss out on equally important outcomes that are most challenging to measure.

4 GIRFEC: THE CONTEXT FOR DEVELOPING OUTCOMES

4.1 "Getting it Right for Every Child (GIRFEC) is the golden thread that knits together our policy objectives for children and young people... GIRFEC aims to put children at the centre of practice, improve outcomes for them and ensure that all agencies respond appropriately to individual children and any needs/ risks they may face. It requires systems, services, planners and practitioners to work in an integrated and consistent manner, using a single planning and delivery system, cutting out duplication and as much red tape as possible." (Scottish Government quoted in Stalker and Moscardini 2012)

4.2 GIRFEC also aims to help realise the National Outcome (highlighted in Scotland's Curriculum for Excellence), that children[5] should become successful learners, confident individuals, effective contributors and responsible citizens.

4.3 Whilst GIRFEC, as the framework for all work with children, has been well documented and is widely known, it is revisited briefly here for a number of reasons. Although it is national policy, it is not currently implemented fully across the country. It involves major culture change which takes time to embed across all services. Progress is being made but remains patchy and requires further work. This section therefore attempts to cover some ground which should be familiar, in order to note specific ways in which GIRFEC can be used in implementing outcomes with disabled children.

4.4 The *National Review of Services to Disabled Children* (Scottish Government, 2011) places policy and practice relating to disabled children in the context of the GIRFEC framework. It argues that: "The GIRFEC principles must be applied to the many complex problems besetting services for disabled children". It also identifies a need for "a 'more systematic plan of action' to enable the necessary changes to systems, practices and cultures (page 6) if the SHANARRI[6] well-being indicators are to be delivered for disabled children."

4.5 This project is framed in the context of GIRFEC and the SHANARRI Wellbeing indicators. Ultimately, the concern here is with how GIRFEC:

- Works in practice
- Connects at all the levels of outcomes identified
- Provides a framework for outcomes in relation to individual disabled children.

The implementation of GIRFEC

4.6 GIRFEC appears to be widely accepted and acknowledged as the framework for work with all children, including those who are disabled. Most people who

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[5] The words 'child' and 'children' are used to include any child or young person up to the age of 18.
[6] The SHANARRI Well-Being Indicators are Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included.

are developing outcomes models seem to be using GIRFEC directly or at least taking it into account.

4.7   However, there does not appear to be a consistent pattern across Scotland in terms of how the GIRFEC approach and framework are being used with disabled children.

4.8   There were a number of references to GIRFEC in this study's literature review. Stalker and Moscardini (2012) highlight the following issues:

4.9   "GIRFEC is intended to apply to all children. However, inclusive policies that do not highlight the particular needs of disabled children may inadvertently exclude them. These children often need additional support to benefit from mainstream services and there is concern that some children, particularly those with complex needs, may fall through the net".

4.10   "Disabled children have been relatively invisible within GIRFEC. What does 'healthy' mean for a life-limiting medical condition? What does 'achieving' mean for a child with complex multiple impairments'?" Stalker and Moscardini conclude that there is a long way to go before national priorities set out under GIRFEC, will be realised for disabled children.

4.11   "If the GIRFEC approach were to be thoroughly and effectively implemented for families with disabled children – a process likely to take some years given the entrenched problems already existing and the transformations in activity and in attitude and orientation that GIRFEC demands – then it would be hugely welcomed by families with disabled children." (Stalker and Moscardini, 2012).

4.12   A report to the Scottish Parliament (*Additional Support for Learning and Young Carers*, February 2013) included information about the implementation of GIRFEC based on a programme of visits by Education Scotland in 2011/12 in a sample of 11 education authorities.

4.13   The report noted variability in the extent to which the GIRFEC approaches are being used, with some authorities and services embedding the GIRFEC much more fully than others. (Scottish Government 2013)

4.14   It seems from early evidence that the ways in which outcomes are being developed (case-by-case and situation-by-situation) provide examples of how GIRFEC is being implemented in practice, at a local level. The development of policies such as identifying and monitoring outcomes is one way that GIRFEC will be implemented with individual children and in different programmes. As these cover a very wide range of conditions and situations, it will take time to see how GIRFEC works and is being developed through practice.

Survey data

4.15   The survey conducted as part of this study (see Appendix A) included some questions about GIRFEC in the context of outcomes development. The responses, though few, showed a range of commitment.

4.16   When asked whether they used any specific outcomes frameworks or approaches, only a few specifically mentioned GIRFEC. For instance, one said their practice team used GIRFEC, while their occupational therapy team used a different model.

4.17   However, when asked if their outcomes related to the GIRFEC framework, 24 said Yes, and 5 said No. (8 skipped the question).

4.18   When asked if the GIRFEC framework was a good fit with the outcomes framework they were using, 22 said 'Yes', and 3 said 'No'. Some thought GIRFEC was a good fit because it was broad enough to cover everything they would want in terms of outcomes or fitted well with their current frameworks. Others noted problems in how GIRFEC fits with other legislation e.g. the Additional Support for Learning Act, and how existing plans for children fit with the GIRFEC concept of a Single Child's Plan. This highlights a need for greater clarity on the fit between plans

4.19   Some specific comments are illustrative of the range of outlooks among people charged with working with disabled children:

"Although the Transition Team works closely with Children's Services, it is an adult resource."

"The GIRFEC framework, particularly the health and well-being indicators, sit well with the outcomes framework in use."

"The staged intervention process maps easily on to GIRFEC and supports the need to think beyond the academic outcomes which was a message some schools found hard to accept."

"There is a recognition of the interrelationship between the range of goals a young person will have and therefore the need to work in a multidisciplinary way in setting and achieving them."

"There is much to like about the framework. The broad framework is very helpful but descriptors (e.g. healthy, active, included, achieving) can appear devoid of meaning to many parents and disabled young people. Outcomes will differ, and priorities that are meaningful to the young person may have to be developed further."

"If applied properly it can enable children's outcomes to be put first and for children's and parents' outcomes to be balanced."

"Please do not get me wrong, they are not completely at odds, but there are some real difficulties with how the current legislation relating to ASN fits with

GIRFEC and CfE. In particular the CSP does not fit with the idea of a single child's plan."

4.20   The commissioning of this work by the Scottish Government signals an intention that disabled children should be fully included within the GIRFEC framework. In looking at the question of outcome models there are a number of elements of GIRFEC that provide practical support, and a direction for implementation, in addition to the SHANARRI wellbeing indicators themselves. The Scottish Government has made clear its intention that the Child's Plan will link with other statutory plans required by some children and young people.

GIRFEC framework tools and principles

4.21   GIRFEC does not provide a prescriptive method, nor a detailed procedure. It does however, provide a framework, some tools and some principles that could and should underpin and inform all outcomes work with disabled children.

4.22   Among GIRFEC's core components, there are a number that are fundamental to the development of outcomes relevant to disabled children:

   - An integral role for children, young people and families in assessment, planning and intervention.
   - A coordinated and unified approach to identifying concerns, assessing needs, agreeing actions and outcomes, based on the Wellbeing Indicators with a common approach to gaining consent and to sharing information, with consistent high standards of cooperation, joint working and communication, locally and across Scotland.
   - A Named Person for every child and young person, and a Lead Professional to coordinate and monitor interagency activity.
   - The use of the National Practice Model, common to all agencies, which sets out the steps practitioners should follow to identify and address difficulties.
   - The capacity to share demographic, assessment, and planning information electronically, within and across agency boundaries.

The role of children

4.23   The integral role of the child is central to GIRFEC, matching the increasing emphasis on Scottish public services being client-led. How this is done is one of the most difficult areas in implementing GIRFEC and related outcomes work. It is also an area in which GIRFEC to date provides the least specific guidance.

4.24   Enabling children to play a meaningful role, with their parents/carers and professionals, in planning for their needs will help ensure they become more than passive recipients of services. However, meaningful inclusion of disabled children involves a number of issues:

- The child/adult relationship is often not an equal partnership. Adults are often seen as, and deferred to, as 'experts' and controllers of resources.
- Even those closest to the child may be over-protective and not in the habit of giving them the space to express their own voice, or taking their views to heart in making decisions.
- The ability to express their needs and preferences, even in situations of unequal power is something that children can learn, with sensitive assistance.
- There may be communication issues for the child (e.g. if she/he is severely autistic, deaf or has other communication impairments), and for the adults (if they are not skilful or knowledgeable in communicating with children who have communication difficulties).
- It takes time to fully engage disabled children in this sort of discussion, something that many professionals feel they don't have. Relationship building and maintenance needs to be integral to the GIRFEC approach.
- Adults involved in the process will have to weigh the balance between risks and rights which is often settled in ways that limit children's inclusion.
- There may be legal or regulatory constraints on the freedom of disabled children to direct their own needs.

4.25 Stalker et al (2010) highlighted that: "many practitioners lack experience and confidence in communicating with disabled children".

Coordinated approach

4.26 The use of a single planning process can be very effective, as it should mean that:

- The child does not have to participate in multiple different meetings.
- The agencies involved with the child can coordinate their care plans, prioritise the most urgent needs, and identify the most effective care and treatment routes.
- One integrated set of outcomes should be identifiable, including a proper consideration of their priority order and of fundamental outcomes that need to be achieved.

4.27 There are, however, a number of problems and gaps that were identified by this research:

- Resources are allocated by each agency separately. Each has a different system for accessing the resources. Sometimes an agency employee will have to argue for the resources against other competing claims (even within the same public agency).
- Responsiveness and timely support, which is linked to improving the quality of services, has not always been a consistent feature.
- The involvement of multiple agencies with no-one currently having an overall coordinating, decision-making role or resource allocation role.

4.28   The implementation of GIRFEC's Lead Professional should resolve some of these problems. But it will take time for the creation and widespread adoption of this role to deal with issues of different chains of command, different training systems, different work cultures, and different reporting and evaluation/assessment chains (and funding streams).

Named Person and Lead Professional

4.29   Under GIRFEC, every child "will have a Named Person in the universal services of health and education". In the *GIRFEC Practice Briefing 1: The Role of the Named Person*, the identity of the Named Person is made explicit and their role is to act as the "first point of contact for children and families" (Scottish Government 2010a). Their role is part of their day-to-day work and their "responsibility is to take action to provide help and arrange for the right help to promote the child's development and wellbeing".

4.30   Where a child needs involvement from more than one agency, a Lead Professional will be involved. Since, by definition, a disabled child will need services from at least two agencies (and probably more), this means they will always be assigned a Lead Professional.

4.31   The Lead Professional "ensures that agencies act as a team and fit together seamlessly ... and have a significant role in co-ordinating a multi-agency care plan". (*GIRFEC Practice Briefing 2: The Role of the Lead Professional*, Scottish Government 2010b).

4.32   Under GIRFEC, the Named Person may be the Lead Professional, . However, "where statutory requirements are involved a worker from a specialist part of health, education, social work or another agency will need to take the lead" (e.g. in cases involving child protection, looked after children, anti-social behaviour or other compulsory measures) (op.cit, 2010b). The Lead Practitioner may be a third sector practitioner.

4.33   Data are not currently available as to how widely these two roles have actually been implemented, nor about how effectively they are working. However, it is clear that they will have a central role in planning, recording and monitoring outcomes.

Assessing Needs

4.34   GIRFEC's My World Triangle is a simple tool that can be used to gather information to understand what is happening to a child and family. It is being applied in a number of situations: for example, it has been developed to use with disabled children in Highland (see Section 5).

4.35   GIRFEC's Resilience Matrix provides a tool to summarise the strengths and pressures in a child's situation, from information gathered using the My World Triangle plus specialist assessments. The information collected is grouped under four headings: resilience, vulnerability, protective environment, adversity (Scottish Government 2012c). This tool builds on strengths and

assets, and fits well with the social model of disability. Again, as one of the tools for developing outcomes it is discussed further in Section 6.

Sharing Information

4.36   Sharing information is central to any coordinated working. It must happen laterally (horizontally) among the agencies involved in the care and support of the disabled child.

4.37   It must also be shared hierarchically (vertically) as part of the reporting process, and ultimately should contribute to reporting to national data collectors. In turn, such information should feed into national outcomes and performance data.

4.38   Until recently, it was hoped that the e-care programme would be developed to facilitate information sharing on a local and national basis. Responsibility for the programme was transferred to the Data Sharing Technologies Board (DSTB) who reviewed the programme in 2013. As a result of the review and the lack of take up by areas it was decided to halt the programme. Under the guidance of the DSTB areas are being encouraged to look to local needs and development opportunities for systems. This approach appears to be working with many areas in the process of developing local solutions. Most notable is the development of *AYRshare* across the three local authorities and health board in Ayrshire. The DSTB – now renamed as the Information Sharing Board - are aware of the need to share information across boundaries and are actively pursuing ways to achieve this.

THE HIGHLAND PATHFINDER PROGRAMME (HPP)

4.39   The GIRFEC pathfinder in Highland started in 2006, and was evaluated by a team from Edinburgh University (*Changing Professional Practice and Culture to Get it Right for Every Child: An Evaluation Overview of the Development and Early Implementation Phases of GIRFEC in Highland: 2006-2009.* Scottish Government, 2009).

4.40   Disabled children and those with mental health issues were priority groups for HPP.

4.41   Multi-agency strategic planning teams were set up around both groups to develop materials for the Integrated Children's Services Plan.

4.42   At one point, the research questions whether wellbeing indicators should apply to all children, but then suggests that, for disabled children they should be considered developmentally and not as measures of success or failure.

4.43   In the HPP, the GIRFEC approach is widely endorsed as "eminently suitable for disabled children". The adaptation of the My World Triangle in Highland is explained in Section 5.

GIRFEC Conclusions

4.44   It might be suggested that it is redundant to talk about implementing GIRFEC as a precursor to developing outcome models as the two are so inter-related. In fact, the full implementation of an effective outcomes model will assist the implementation of GIRFEC, as they both call for the same processes. It is not so much a chicken and egg situation as an iterative process - a continuous loop - rather than a straight sequence of cause and effect. The implementation of one affects the other (which, in turn, informs the first). The effective implementation of one takes the other further also.

4.45   This might be said also of the individual elements of GIRFEC. For example use of Lead Professionals, a key element of the GIRFEC approach, is also a key element in determining and monitoring outcomes for disabled children. However, it is still unevenly implemented in practice. As best could be determined by this study, most disabled children in Scotland do not yet have a Lead Professional or Named Person who meets the GIRFEC criteria and expectations.

4.46   Future work in this area might therefore take the form of monitoring a range of implementation models and documenting them. This would allow agencies to circulate examples of good GIRFEC-conforming practice as evidence of its effectiveness on the ground.

4.47   Given that many of the outcomes models are in the early stages of development and piloting (see Section 5), it may well be at least a couple of years before this can be done. However, a framework to do this could be put in place now.

4.48   One conclusion is that the wide and deep implementation of GIRFEC as the national approach and framework for assessing and meeting the needs of disabled children could become a global outcome in its own right.

Curriculum for Excellence

4.49   Scotland's Curriculum for Excellence (CfE) is the intensive curriculum for all children (ages 3-18). It sits alongside GIRFEC as part of the framework of Scottish Government policy for all children and young people. In principle, CfE is intended to meet, on an individual basis, the holistic *support* needs of every student. Therefore, in principle, it could greatly reduce the need for additional support. This aspiration has not yet been achieved in practice.

4.50   There is no scope within this small study to discuss the implementation of CfE in relation to disabled children, except to look at its implications for outcomes development. However, it should be noted that "there is a danger that for disabled children, CfE will simply be mapped onto existing practice with no real change taking place". (Stalker and Moscardini, 2012)

4.51   It was noted in Section 2 that many disabled children have foundational needs that need to be addressed in order to move on to other outcomes, and that communication is one of the widespread fundamental outcomes.

4.52   Stalker and Moscardini caution that "While the language used in the experience and outcomes of CfE portends to place the child at the centre through the use of the first person, it is very likely that the technical nature of the language used would not be meaningful to disabled pupils." For disabled pupils, there is a need for greater collaboration and consultation in education planning. These are, however, among the same issues as apply to the implementation of GIRFEC itself.

SUMMARY OF FINDINGS

This project is framed in the context of Getting it Right for Every Child (GIRFEC) and the SHANARRI Wellbeing indicators.

The survey indicated that most people found GIRFEC to be a good outcomes framework. However, there was concern that:

- **There is no consistent data yet available across Scotland to inform how GIRFEC is being used with disabled children.**
- **Policies where disabled children's needs are not highlighted can inadvertently exclude them. For example, what does 'healthy' mean for a child with a life-limiting medical condition? What does 'achieving' mean for a child with complex multiple impairments?**

GIRFEC was found to have the potential to provide practical support in the following areas:

- **The integral role of the child: Making sure that disabled children can play a meaningful role in shaping their outcomes.**
- **The single planning approach: The Lead Professional/Named Person could go some way to addressing this need for integration but will take time to implement. The current lack of someone with an overall coordinating role, particularly in relation to the allocation of resources, has been and sometimes remains a problem.**

The Highland Pathfinders Programme indicates that GIRFEC can be eminently suitable for disabled children.

The many outcome models that are being developed across Scotland are valuable examples of how GIRFEC is being implemented in practice and future work should involve documenting these further.

5   WHO'S DOING WHAT: OUTCOMES MODELS FOR USE WITH DISABLED CHILDREN AND YOUNG PEOPLE

5.1   This section presents an illustrative sample of some outcomes models and frameworks being developed for use with disabled children and young people. There is only space here to provide a brief synopsis of a few models and we indicate where possible, sources of further information. The list is not exhaustive as new work in this area is being developed continually. This selection was made on account of their providing insights into different elements of outcomes models.

5.2   This report was intended to be limited to outcomes models and frameworks with disabled children but a further selection of Scottish outcome models, not specifically for disabled children, is provided in Appendix B. There was some concern that wider child and family policies, for example, are likely to have implications for, or need to take account of, outcomes for disabled children[7].

5.3   A summary of some other models is in *An Outcomes Approach in Social Care and Support: An Overview of Current Frameworks and Tools* (CCPs and others 2010), so that work was not duplicated here. This is the only Scottish publication we have found that describes a range of outcomes models in social care. It includes a number of interesting models dealing with different populations. A brief note is made of most of these.

5.4   The four levels of outcomes identified in Section 3 (1: Individual/ personal; 2: Service/project; 3: Organisational; 4: National), have been used in grouping these pieces of work. But of course, outcome models involve interactions between different people and organisations (and so levels). The classification cannot therefore, be exact, and is used here mainly to identify the agency responsible for developing the model and their primary purpose.

LEVEL 1: Individual/personal outcomes

5.5   St Andrews Project, Camphill School, Aberdeen

The St Andrew Project at the Camphill School Aberdeen (an independent special school) works with children and young people at the margins of care and education. They have developed an outcomes tool based on *Outcomes That Matter* (Fulcher and Garfat, 2012).

"This model is based on a 'Circle of Courage', a framework that moves the focus from deficits to strengths, and considers four fundamental growth needs that all human beings share:

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[7] The words 'child' and 'children' are used to include any child or young person up to the age of 18.

- Belonging: the need to establish trusting connections.

- Mastery: the need to solve problems and meet goals.

- Independence: the need to build self-control and mastery.

- Generosity: the need to show respect and concern."

These have been mapped to Scotland's Curriculum for Excellence and are being mapped to GIRFEC. Ten internal and ten external outcomes are highlighted, based on the Circle of Courage. These are worked with on a weekly basis and they focus on the subjective experience of carers and young people, and in particular on daily life, events rather than on standardised outcomes. These are plotted graphically across the four dimensions. The assessments are "ecological", based on the internal logic of the young person, and focussed on how they experience themselves and the world. It is "child-led" rather than "child-centered".   Reviews are held six-weekly based on the outcomes data.

The model is being piloted with a small number of students and an evaluation is planned for this year.

Further information:

Fulcher, L.C. and Garfat, T., (2012) "Outcomes That Matter in Out-of Home Care", Reclaiming Children and Youth, 20 (4) pp 22-28.

Walter, C., and Costa, M., (2012) Camphill St. Andrew's Project: Building Inclusion Using Outcomes That Matter, summary of presentation to EUSARF Conference.

Walter,C. (2013) "St.Andrews' Project: Building inclusion using 'Outcomes that Matter". *Scottish Journal of Residential Childcare*.

LEVEL 2: Service project initiatives

5.6   Aberlour Child Care Trust

Aberlour Childcare Trust is using the 'Realist Evaluation' approach in its Housing Support Service, commissioned by Moray Council, working with 16-22-year-olds in and around Moray. The questionnaire used is based on a 'domains' approach.

This model and guidance was written with the help of service users. Aberlour hopes to increase the use of Realist Evaluation as part of its strategy to evidence outcomes" (CCPS 2010).

5.7   Educating Through Care Scotland (EtCS)

EtCS is the professional network in Scotland for residential special schools. They are collaborating on the development of an outcomes model for use in their member schools, developed by staff from their member organisations,

with strong support from Scotland Excel, the procurement organisation. This project started during the second half of 2012 and a pilot is now running (until June 2014). CELCIS is expected to undertake the evaluation.

The pilot involves four children from each of 15 schools taking part (residential students only) and involves 14 local authorities.

The starting point of the model was material developed by Barnardo's UK, adapted to suit the needs of the residential education sector.

The purpose is: "to develop a practical and tangible model for measuring outcomes, which ensures that children are at the heart of the process, and which can be easily used by staff; to develop a model which can be used in partnership with local authorities, children and families; to ensure that any model can be embedded in practice, with additional work minimised; to be a helpful tool for practice and reflection; to enable reporting to a variety of stakeholders; to be as simple as possible."

The components include an outcomes bank, scaling tool, and a range of supporting evidence.

The outcomes bank includes 43 outcomes grouped into the following five categories: education; relationships; health; self-awareness, and emotional wellbeing. Appropriate outcomes are selected for the individual through the assessment, care and planning processes.

The selection of core service outcomes (around ten) is up to each individual organisation within EtCS. The pilot will consider "consistency", and agreeing a common set of outcomes across all organisations.

The scaling tool is used to assess baseline levels for a number of outcomes chosen for each child, from the core services outcomes. It is not expected to focus on more than six outcomes (or less) for a child at one time. These are reviewed three to six times every month, to assess progress on a ten-point scale. NOTE: for some young people, holding steady will be a success.

The "wheel of change" provides a dynamic visual representation of progress for the children, to help them understand and participate in outcome evaluations.

The supporting evidence must be triangulated using at least three pieces of information, e.g. feedback from children, families/carers and professionals; use of assessment tools; key worker observations; and care plans and reviews. Paper recording is currently used.

GIRFEC: The children they work with have specific and complex sets of needs. They needed a set of outcomes that would allow them to work on more specific outcomes than the broad SHANARRI headings. This area is a work in progress as local authorities prefer them to list outcomes under the SHANARRI headings.

This is one of the few models being developed specifically for disabled children and young people.

5.8   Secure State Care Providers

There are five secure care providers in Scotland and the Scottish Government (SG) is working with them to develop an outcomes model that will fit with their service. It is hoped that all secure units will be able to embed an outcomes strategy in their work by the end of 2013.

The process to deliver this work started with a stakeholder event in May 2012. During this meeting it became clear very quickly that this process would not be straightforward. Participants at the event were not able to easily identify individual outcomes and when asked to do so often identified service outcomes or interventions. It was obvious there would be a great deal of work required to deliver a real shift in approach to enable units to measure outcomes for young people in their care. Following that event Scottish Government recognised units would require support and guidance to progress this work and Dr Emma Miller of Strathclyde University was commissioned to provide that support. From the outset Dr Miller advised the units that the best way to successfully deliver this work was through collaboration. Units were encouraged to work together to share their ideas and experiences. Unfortunately this approach proved difficult to implement. Due to the competitive nature of the Secure Care Framework agreement units were reluctant to collaborate. The new tender process was due to commence in early 2013 with the new contract due to be awarded in June 2013. It is hoped that, when the new contract is awarded, this will provide some stability across the estate and units will be more open to collaboration on this piece of work.

The models being developed apply to all children and young people within the secure units, although a proportion are disabled and covered by the ASL Act (as cited in Section 2 above).

This has been a steep learning curve for all the participants and described as a "hard task". Units have been encouraged to develop their own outcomes model by selecting a current outcomes tool then developing that tool to fit the needs of their organisation. The Scottish Government did not want to recommend the use of a particular tool as they felt none would fully meet the meet the needs of the secure estate and, more importantly, none of the tools had been adequately evaluated.

All the models currently being developed across the estate are based on GIRFEC and the SHANARRI wellbeing indicators to ensure that there is a basic consistency of approach.

Secure unit managers have been asked to ensure that the message comes from the top and that resources are in place to develop their outcomes strategy. To ensure there is buy-in from staff and children, managers have been encouraged to fully involve them from the start by asking for, and acting on, their comments.

Although there was initially a proposal to develop a pilot, the units decided to progress with embedding outcomes across their organisations.

All five units are now focused and working towards embedding outcomes in their service. Two of units are quite advanced in their implementation and are able to provide at least six months of evidence in assessing and improving outcomes for the young people in their care. The other three units are still working on developing their outcomes measuring tool.

The secure care outcomes working group will provide a report towards the end of 2013 to report and reflect on progress and discuss the next steps.

Further information: Reports have been written about this work in progress, but they are not public documents. More information can be obtained by contacting: David.cotterrell@Scotland.gsi.gov.uk

5.9 Scottish Women's Aid: Outcomes Evaluation for Children and Young People Experiencing Domestic Abuse

The Scottish Government expects Women's Aid to conduct monitoring and self-evaluation of their services each year. Scottish Women's Aid worked with local Women's Aid groups to refine a framework, developed by a Scottish Government working group in 2006.

They developed a set of outcomes/indicators for children experiencing domestic abuse. In particular, they wanted to determine whether: their needs are being met better; social and leisure activity needs are understood and acted upon; there is more involvement in decisions about their lives; there is increased understanding of how to maintain and develop healthy relationships; there is a better understanding of their feelings and how to deal with them; a better understanding of domestic abuse and how it affects themselves and others; and an enhanced sense of being safer.

The particular outcomes are selected on an individual basis according to how the children describe their own situation and needs. There is a toolkit to support workers to measure the new outcomes and indicators. A small trial has been carried out.

This example is drawn from CCPS and others (2010).

Further information:
www.scotland.gov.uk/Resource/Doc/1137/0087632.doc (framework) and
www.scotland.gov.uk/Resource/Doc/1137/0087638.doc (toolkit)

LEVEL 3: Organisational

5.10 Local Authorities

Most local authorities (LAs) appear to be implementing outcomes work through their regular assessment and reporting systems. One senior LEA

officer observed: "Generally, LA practice is engaged in a big shift to an outcomes-focussed approach. However, the legislation around ASL is still about prescribing inputs. It is now time for a paradigm shift to be more consistent with what we do with other children. But the approach to implementing an outcomes approach is devolved to individual schools."

The Association of Directors of Education in Scotland (ADES), at its last annual conference, held a workshop on the topic of outcomes. There was consensus about developing a set of outcomes and indicators to use in conjunction with the implementation of the ASL Act in all the schools.

Most LAs carry some information about the implementation of GIRFEC on their websites (though this has not been consistently reviewed within the context of this work).

There is no comprehensive, up-to-date list of what all local authorities are doing in this area. We received information about outcomes development work in Angus, the City of Edinburgh, Fife, Glasgow, Moray, North Lanarkshire, Stirling and Tayside. We also know of work in North Ayrshire and Dumfries and Galloway.

Projects within local authorities

5.11   Glasgow City Council Social Work Services

An outcomes model grounded in GIRFEC and the SHANARRI indicators has been developed within the Glasgow City. It is led by a district team leader seconded to the Child and Families Division.

The initiative is focussing currently on self-directed support for the funding of short breaks, starting with a pilot with 20 families who will "come up with their own ways of meeting their planned outcomes." The integrated assessment on which it is based is dominantly within Social Services – "Education and Health do not currently contribute".

The GIRFEC Child's Plan leads on the "desired outcomes and milestones for achievement", based on a "talking points" sheet. This is a chart with a series of SHANARRI indicators on one axis, applied to the child, the family and the community. The other axis is used to report the degree to which needs have been met.

Talking Points	Needs Met	Occasional Extra Support	Extra Support Sometimes	Extra Support Often	High Level of Support Always
Desired Outcome: How much support is needed for each of the following:	There is a support need but it is met by the family and/or community	The level of need is small, occasional, and/or temporary	The level of need is over the week and mid to long term	The level of need is significant, daily and long term	The level of need is complex, round the clock and lifelong
SAFE					
Ch: To understand about risks					

Ch: To keep myself safe					
F: To support and promote my child's safety at home					
Com: To ensure safe access to community resources					
HEALTHY					
Ch: For physical health					
Ch: For mental health					
F: To support my child and family's health & wellbeing					
Com: To access medical care					
ETC: for all the SHANARRI indicators					

This is supported by a range of documentation prepared for use by families and children,

5.12   Highlands

One piece of work in Highlands developed a set of "Targeted" *My World Triangles* for children and young people with different conditions or in different situations.

This is an online model, which the user personalises by selecting from the range of additional support needs, namely:

* Autism spectrum disorder
* Complex health conditions
* Difficulties at home
* Hearing impairment
* Learning disability
* Looked-after children
* Through-care, after-care
* Transition, and
* Young carer.

In each case the model provides a set of prompts around a series on each side of the Triangle (How I grow and develop; What I need from people who look after me; My wider world). Using the example of the autism spectrum disorder we have the following prompts:

How I grow and develop	My wider world	What I Need from People Who Look After Me
When I am well …	Play and fun …	Help with making choices …
Being responsible …	Listening …	Knowing what is going to happen and when …
What I am good at …	Help for my family …	My family …
How I communicate …	Why school is important …	The help and care I need
Confidence in who I am …	Out of school places and activities …	Keeping me safe …
Friends …	Money …	The house I live in …
Looking after myself …		The care I need …

Checking any of the prompts leads to a page seeking responses in a number of formats (e.g. multiple choice, free text, checklists etc). Combined, these allow the child to help develop statements specific to their condition and situation and so to create their own profile of needs by themselves, if they can and wish to do so, though of course this is still within pre-determined categories.

There are no suggestions about how the model should be used nor do we have any evidence of its effectiveness in practice, but it clearly demonstrates the potential to develop interactive software as part of outcomes models.

Further information: www.myworldtriangle.co.uk

SUMMARY OF FINDINGS

Developing an outcomes model, especially at Levels 1 (Personal/Individual) and 2 (Service/Project), needs to involve collaborative work both with professionals *and* with disabled children and young people, as well as their families and carers.

Developing an outcomes model also involves multiple professionals and therefore, an intensive collaborative process. It requires buy-in and active engagement from both front-line staff and management. Even if the process does work seamlessly, it is still time-consuming and must include a period of piloting, trial and evaluation.

Many of the outcomes models at Level 2 are being developed as a response to demands from commissioners or other funders. They tend to have a focus on

the efficacy of their work, while still being rooted in the needs of the children with whom they work.

Models at Levels 3 (Organisational) and 4 (National) do not involve children and families directly. There need to be defined mechanisms to relate all the levels to each other, with a common framework of indicators. GIRFEC being the context, these should be based on SHANARRI.

Given the work being devoted to developing outcomes models, any development of models at national level should be built around these initiatives with the aim of determining how best these feed, together and separately, into national outcomes for disabled children and young people. Development should be based on this practice and experience, not developed separately from the top down.

6 COMPONENTS OF OUTCOMES MODELS FOR USE WITH DISABLED CHILDREN AND YOUNG PEOPLE

Introduction

6.1   There is no single outcomes model suitable for all situations, and in view of the incomplete implementation of GIRFEC, even those under development must be local, and not encompass the whole range of levels of outcomes. This is all "work in progress". In this section we identify a number of elements critical to developing a successful outcomes model for use with disabled children and young people.

6.2   Scottish outcomes models that have been and are being developed, differ in some of their approaches. There are, nonetheless some commonalities emerging. Underlying principles that could and should be observed and that underlie any useful outcomes model include the following:

- GIRFEC is the framework, however incomplete its current implementation. New outcomes models should not reinvent it, but work with all the GIRFEC components as far as possible.
- There is an ongoing contextual tension (not conflict) between local flexibility/autonomy and central direction, a reality that must be worked with when planning any work within a Scottish Government framework. Anyone developing an outcomes model in this field must be aware of, and identify the boundaries of their particular work. They should also consider how it relates to different reporting structures.
- When discussing outcome models, it should be remembered that these are based on assumptions and theories.   It may be that the model or elements of it need to be changed in the light of practice. This underlines the importance of testing and evaluation.
- . Maximum flexibility needs to be built into the system to adapt the models case-by-case Moreover, there are reasonable and appropriate differences between for instance a model for deaf children in pre-school and students on the autistic spectrum in secondary education.

Care should be taken to avoid too much complexity, especially in the presentation of outcomes models to users. Graphic representations should not end up looking like "circuit diagrams for the Star Ship Enterprise" (to quote one respondent).

Pre-requisites

Local Ownership

6.3   This study supports the importance of engaging, including and respecting the contributions that children, parents/carers and practitioners can make to the design and implementation of outcomes models for disabled children. Outcomes models are ideally built on inputs from individuals who are going to be involved in implementing them in-practice.

6.4   The development of an outcomes model also requires: collaboration across and between agencies; leadership within the team developing it; and, buy-in from the wider professional staff that will be involved in making it real.

6.5   This implies active engagement from within each agency involved, including both the leadership and the front-line staff of the agency, which must both demonstrate strong buy-in.

Involving disabled children in identifying their outcomes

6.6   Engaging individual disabled children[8] in the process of defining their outcomes is at the core of a personal outcomes model. GIRFEC is, of course, about every child. Still, there is implicitly a tension between the needs of each individual child and the systems that beget outcomes models. 'Systems' are more generalised and appropriate to the many, rather than the few or the individual.

6.7   Even though the starting point is the individual child, the process of defining their aspirations and needs involves more than just themselves. The child exists in a network of people: familial, social, and professional. For disabled children this network is more extensive. The interaction of services and support needs to be taken into consideration when defining outcomes. We have alluded earlier to the inherent complexity of communicating effectively with children, especially disabled children with complex communication impairments, to ensure that their voices are fully heard (or in the words of the St. Andrews Project, to ensure a process that is child-led not just child-focussed). There is not space here for a review of the approaches that can be involved though there is a widespread literature on the issue rooted in a number of different fields and including both techniques (e.g. Talking Mats) and processes (notably built around listening.)

6.8   Many of the outcome models discussed previously use a process of *triangulation* to document the achievements being made by the child - using three or more sources of information to validate their achievement(s). This is an essential process especially when qualitative data or behavioural observations are involved. Triangulation

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[8] The words 'child' and 'children' are used to include any child or young person up to the age of 18.

is also a useful concept to describe the process of determining the child's desired outcomes.

6.9   Discussion with individual disabled children will usually involve their parent and/or their carer. This already poses complex questions: if the child is not severely disabled and lives at home with parents, one could expect (hope) that the parent and child will have discussed what the child needs and wants to achieve, and what support is required for their accomplishment. This will often be informal and part of everyday discourse. But if the child is more severely disabled, and/or has a carer as well as a parent, or is living away from home with a carer, then a more formal dialogue will have to take place periodically. In either case, both parent and/or carer ought to be involved in any discussion about the child's projected outcomes.

6.10   The third party involved in planning outcomes (in the context of services to be provided from education, health, social services or other agencies) would normally, under GIRFEC, be the Named Person. However, a disabled child will need services from more than one agency and the person responsible will be the Lead Professional.

6.11   These interactions take place within the context of the services provided by the Lead Practitioner's agency, which in turn are connected to a web of services provided by all the other agencies involved.

Framework for defining outcomes

6.12   GIRFEC has already provided a framework for framing outcomes using the SHANARRI indicators, through the My World Triangle. This has been used by many agencies and organisations: for example, it has been adapted in Highland (see Section 5) where it has been applied to a range of disabilities.

The disabled child's world: The context

6.13   GIRFEC has also provided a tool for documenting and analysing the child's world in the form of the Resilience Matrix.

6.14   The Resilience Matrix uses the following four data sets on two axes to identify the context within which the child lives, and the systems of support to which they have access: vulnerability compared with resilience; and adversity compared with protective environment. They can be extended to frame the issues typically facing disabled children, for example:.

    • Vulnerability: May refer to the particular impairment or disability that affects the child and also refer to secondary issues such as

mental health issues beyond the physical disabilities or medical conditions.

- Resilience: May be a statement about how well the child has been able to manage disability, and their consequent inclusion in the wider world.
- Adversity: May refer to issues faced by the child in managing the disability(ies), including the social climate within which they live, and with managing environmental factors, such as transport.
- Protective Environment: May refer to the effectiveness of the child's support system including in the first instance, immediate family.

These can be applied to the disabled child's life to highlight the pressures to which they are subject and the support they receive or need, which may well match some of the outcomes they want to achieve. Such considerations will often be central to the achievement of the desired and agreed outcomes for an individual disabled child.

Outcomes used

6.15 There is no absolute list of outcomes appropriate to all disabled children.

6.16 For many disabled children there are fundamental outcomes that need to be achieved as a foundation for others. Effective communication is one fundamental outcome for many disabled children but others vary according to the nature of their disability. These fundamental outcomes do need to be addressed to ensure that disabled children have a basic quality of life before looking at the wider SHANARRI indicators - in other words, outcomes that need addressing first and in the short term.

6.17 Section 5 shows that many outcomes models do use a limited selection of outcomes to start with and collaborative models may agree an "outcomes bank" from within which outcomes can be selected as appropriate.

Time

6.18 Early on in this study, there was an expectation that "short, medium and long-term" outcomes could be defined. However, it is apparent that these can be relatively meaningless terms in the abstract. There are many factors that can affect the time scale for achieving particular outcomes.

6.19 The first is the institutional context in which the child is living. If the outcomes are being measured in an educational context, then a school term (or year) may well be the context, or a period determined by the academic assessment system being used. The time-frame could be different if the child is under medical care, when the time frame of the treatment or care procedure may be dominant. If a child is living with a

legally determined framework (being Cared For, in the Juvenile Justice System, or in the Child Protection system for example), the framework will have its own criteria for measuring and documenting progress.

6.20   Some children, particularly those with short-term additional support needs may only have needs for a period, rather than life-long needs.

6.21   For others, especially those with complex health conditions (that may in fact indicate a limited life), the timescale will be very different and the outcomes may involve maintaining comfort and lack of pain rather than achieving new outcomes.

6.22   The notion of maintenance (stabilisation) may also be appropriate in situations where children have disabilities that involve behavioural issues.

6.23   The length of time involved in achieving whatever outcomes are defined for a child should be an integral part of the outcomes being planned, and not a separate external measurement. The timescale should record progress compared with maintenance, and can usefully record journeys or distance travelled. Timescale might also usefully record outcomes achieved en route to achieving longer-term goals (e.g. increased confidence leading to educational achievement).

Outcomes in the context of service delivery

6.24   The disabled child's personal outcomes are contextualised in terms of the professional staff of the different service agencies involved. This makes assumptions about collaboration between the staff of different agencies and joint planning being in place. Whether or not this is the case may depend upon the degree of progress achieved in implementing GIRFEC locally.

6.25   Having identified services needed from different agencies, several separate sets of actions are likely to be involved. Even if effective joint planning and collaboration is in place, services are, in actuality still provided by different agencies. Consequently, there will be a number of streams of activity within each agency involved, concerning probably, a minimum of four different areas of activity:

- Resource allocation and the financial procedures involved.
- Staff activity and inputs.
- Management systems and reporting.
- Data collection (which may be separate and in addition to the above).

6.26   There will be a flow of information within these streams to the other levels, though in actuality, there will be more intervening stages to account for administrative/political needs and community planning and regional data collection.

7   NEXT STEPS: RECOMMENDATIONS

7.1   There is value in the diversity of examples and perspectives that different stakeholders bring as they seek and secure the best outcomes for disabled children[9]. The continuing challenge, and opportunity, is to have greater clarity about the meaning of Scotland's already existing National Outcomes when applied to specific individuals, and especially to the spectrum of disabilities affecting individual children.

7.2   This will involve the continuing collection and sharing of emerging knowledge and experience. Above all, strong leadership is needed at all levels, and especially from the Scottish Government, in those areas where it can only exercise such leadership on a nationwide basis.

7.3   This section lays out some priorities to enable all stakeholders to move to a greater shared understanding of outcomes models for disabled children with consequent easier implementation of agreed outcomes and models.

Who's doing what?

7.4   Many people want to know more about outcomes models, both in general and as they specifically apply to disabled children, and about who is doing what. Knowledge generation and knowledge exchange are important in the development of innovation and continuous improvement of practice.

7.5   The aforementioned work being done by IRISS and the Joint Improvement Team provides an important contribution. More is needed from a wide variety of sources, and especially from those people who are innovating successfully.

7.6   It would be helpful to have more effective and widely known ways of sharing knowledge about the initiatives being conducted in the field, across Scotland. There is a widespread interest in documented examples of outcomes models that are up and running, especially those that have been evaluated (rather than just described).

7.7   It is important that information about developing models does not feed into different parts of Government and then disappear without connecting with all interested parties and with the many current pieces of work in progress.

7.8   **Recommendation: Facilitate the creation of a mechanism for sharing information (possibly a knowledge bank - new or pre-existing - preferably online), of outcomes work being done with**

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[9] The words 'child' and 'children' are used to include any child or young person up to the age of 18.

respect to disabled children across Scotland. This would not need to be permanent and could have a limited life to match the likely time period during which GIRFEC and related models are being more fully implemented and assessed. The knowledge bank should include inputs from all relevant departments of the Scottish Government as well as other relevant parties in the third sector, academia, NHS, local government and other community planning partners.

Evaluation

7.9　　Many of the initiatives being developed have evaluation built into their piloting processes. This seems to lead to a thoughtful development process and also results in good documentation of the model being developed..

7.10　　Emerging developments should be encouraged to evaluate their work, using a mix of: external and internal evaluation; qualitative and quantitative methods; and formative and summative evaluations. Some training and support would need to be provided to support staff skills in internal evaluation. The evaluation criteria and strategies being used are an important part of what needs to be shared.

7.11　　**Recommendation: Encourage and facilitate the widespread use of evaluation, with GIRFEC principles at its core and enhanced appropriately to take account of the specific wellbeing needs of disabled children. This should be adopted among all agencies that are developing their outcome models for use with disabled children.**

Piloting new models

7.12　　It is clear that there is a lot of local energy available across Scotland to develop outcomes models. This could be further encouraged through allocating resources, support, and the dissemination of good examples of outcomes models and frameworks as they are ready to be shared.

7.13　　There needs to be a balance between piloting new models and sharing those already developed in order to avoid duplication. To assist this process a distinction should be made between: i) new models that address all disabled children; and ii) new models tailored to each field of disability and/or specific age groups.

7.14　　**Recommendation: A partnership between disability organisations (including children and parent-led groups) and public agencies, should identify where outcomes work is, and is not, being developed in each field of disability, and for all age groups, and then seek to jointly plan, develop and implement such work. The purpose would be to support and consolidate ongoing work and allow people newly addressing the issue to avoid redoing work that has already been done.**

Collaboration and sharing

7.15 Outcomes models can only be implemented successfully on a nationwide basis through a process of meaningful collaboration among all parties concerned. This is also true of GIRFEC, and in Section 3 we suggested that the implementation of GIRFEC and the development of outcomes models should proceed together as a symbiotic relationship.

7.16 Yet the realities for staff working in different bureaucratic environments mean that this can be difficult to achieve. It requires leadership, buy-in within the organisations, and commitment from the staff involved. GIRFEC is based on the importance of meaningful collaboration and the statutory guidance must reinforce the collective efforts required to achieve improved outcomes.

7.17 **Recommendation: Statutory guidance on reporting on wellbeing outcomes within integrated children's services planning approach is proposed under the Children's and Young People (Scotland) Bill. Such guidance should emphasise that we aspire for the same outcomes for all children but for disabled children and young people, there is an extra step required – the achievement of their foundation outcomes. Training and development at local level for public bodies and their third sector partners and simpler communication methods that support information sharing within and between organisations, must also be encouraged in the guidance.**

Involving disabled children

7.18 Involving disabled children in determining the direction of their lives (including outcomes from services received) is a central principle of GIRFEC but can be difficult to implement within existing systems and structures. It involves both considered work practices, with an assumption of the centrality of the children to the process, and also knowledge and skills about communication with children with disabilities, including the range of communications issues.

7.19 The third sector, universities and SCCYP have taken the lead in showing how to engage meaningfully with children. Involving children properly is their right, has benefit for them, and their lived experience is often insightful and of value to the adults around them about what's needed and to their benefit. However, poorly conceived and poorly handled 'involvement' can be worse than doing nothing.

7.20 There is a range of knowledge, techniques and skills available upon which to build. Again, this needs to be more widely disseminated and needs to become mainstream knowledge for all professional staff working with disabled children.

7.21 **Recommendation: Share what has been done already more widely, to make full use of the existing and continuously evolving methods of meaningful involvement and engagement.**

Disabled children and technology

7.22 Technology can provide a huge range of support for all people with disabilities. This involves both the assistive technology that can assist with communication and with many other functions and also the use of the very rapidly expanding range of communications technology available.

7.23 Organisations such as CALL Scotland provide significant leadership, knowledge, expertise and support in this area.

7.24 It is critically important for disabled children and young people to have full access to the technology available as it can provide them with the means of communicating with their peers and with the wider world. The same is true for their parents/carers. Additionally this will mean providing access directly to technology based assessment and planning tools, including tools that are designed to help determine and monitor progress towards achieving outcomes.

7.25 Technology can be expensive and not available to all disabled children, especially those living in poverty or in constrained situations.

7.26 Because inequalities are a consistent challenge in relation to disabled children, there is a need to give priority to overcoming these inequalities. This can be accomplished both through the technologies that help manage particular disabilities and the technologies that help overcome issues such as living in a remote location or lack of direct contact with peers having similar conditions.

7.27 **Recommendation: Focus on making effective communication facilities and technology equally available across Scotland and equally accessible to all disabled children.**

Supporting and involving parents and carers

GIRFEC

7.28 The implementation of GIRFEC and the development of outcomes should proceed together in a symbiotic relationship. Statutory guidance that is now in development, needs to address how the child's wellbeing needs will be fully assessed and supported, and how improved outcomes for disabled children will be achieved. For example, *Supporting Our Children's Learning Code of Practice,* the guidance that accompanies the ASL Act and is about to be revised, should be clear about how the ASL Act and GIRFEC can complement each other and interact seamlessly.

7.29 GIRFEC is an example of a national framework that is locally implemented. However, care is needed to prevent a 'postcode lottery' where local interpretation and implementation lack consistency across Scotland in relation to disabled children. The forthcoming "GIRFEC provisions" in the Children and Young People Bill should help alleviate this but its implementation will need review.

7.30 Additionally, outcomes for disabled children should be mainstreamed throughout all services (not just the very specialised that are often so good at focussing on individuals and their personal outcomes). By focussing on every child's wellbeing, GIRFEC implementation has the opportunity to better include the many disabled children who fall between the gaps between services or whose disability is not recognised. Guidance should support local systems to achieve this.

7.31 **Recommendation**: **The following three steps could usefully be taken:**

- **Greater understanding of and commitment to, the GIRFEC ethos of supporting all children's needs, by seeing the child first, then their wellbeing needs, is required across the children's and adult sectors and including parents and carers. Robust guidance supported by a communications and engagement programme, which is focussed on professionals to ensure that communication with children and families is better..**
- **The inclusion of work with disabled children and their outcomes in any future local evaluations of GIRFEC implementation.**
- **In the forthcoming Children and Young People Bill and, if the Bill is enacted, accompanying statutory guidance the Scottish Government should: i) minimise the degree to which multiple outcomes frameworks are applied to children, as a result of services being provided by multiple agencies; ii) consider the implications of multiple legal and regulatory frameworks for disabled children, which may constrain their freedom to direct their own needs and plan their own outcomes.**

Data and information

7.32 There are key issues around the nature of data collection to document the wellbeing and progress of disabled children. These include: the flow of data between different levels of government; the coordination and matching of data collected; and ensuring that data are collected for all key aspects of the lives and situations of disabled children.

7.33 Better coordination and matching of data from different care systems is required in order to create a seamless flow of data from individual disabled children up to national level organisations. There are currently many separate systems for the collection of data, within different statutory frameworks, and some relevant areas where none appears to be collected at all.

7.34 Creating a unified system of data collection can only be accomplished at a governmental level since it requires the matching of different systems that have different legal and regulatory frameworks. Data collection should involve both qualitative and quantitative data. Qualitative data is more difficult to document in standardised forms and these are often undervalued. Yet they are often the data that provide deeper insight into children's lives and experience. Both types of information are needed. The ways in which such data are recorded, collated and reported should become a normal part of the projects serving disabled children (and their parents and carers).

7.35 **Recommendation: The Scottish Government should lead in:**

- **Making sure that all key aspects of disabled children's lives are equally documented, not just those subject to particular regulatory frameworks.**
- **Helping to make the different information and data systems integrate effectively.**

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Section 5

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APPENDIX A
METHODOLOGY: OBJECTIVES, SCOPE, AND APPROACH OF THE PROJECT

This section outlines the remit for the project and outlines some issues that arose early in the work that framed the approach to the data collected.

Remit

Aims

The overarching aims of the project as outlined in the Research Specification[10] were:

- To identify and develop an outcomes model based on the principles of GIRFEC for disabled children and young people in Scotland.
- To identify a suite of appropriate measures to monitor and report on progress towards achieving these outcomes for disabled children and young people as part of the overall model for improving children and young people's outcomes.

Objectives

The specific objectives of the project were:

- Develop a map illustrating the short, medium and long-term outcomes for disabled children and young people, based on the eight SHANARRI well-being domains.
- Provide suggestions for future development and measurement of progress. (op.cit., Section 7)

However, this is not about defining original or new outcomes or about developing new ways of documenting them. The Research Specification goes on to say:

"There is currently a range of available indicators which have been developed with significant input from stakeholders and it is not the purpose of this study to introduce another set but rather *to work with what has already been identified and provide a greater understanding of whether / how they can be used in the context of monitoring outcomes for disabled children and young people*." (emphasis added) (op.cit., Section 6)

Consequent issues

In looking at the initial data suggested, at the literature around disabled children and young people and around outcomes, as well as through some initial conversations

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[10] Scottish Government (2012), *Developing an Outcomes Model for Disabled Children and Young People in Scotland*, Edinburgh: Scottish Government, Social Research.

with public officials and key stakeholders, it quickly became evident that there were a number of issues that would frame much of the work.

We had started with a simple working definition of outcomes but this had to be developed and expanded in the light of the Literature Review and of the data collected during the research.

In particular it became apparent that the use of the term "outcomes" is becoming widespread if not universal, consequent upon Scottish Government policy in addition to changing perceptions of good practice. As a result there are many ways in which "outcomes" are being interpreted and developed. In the first instance, the meaning of the term depends on the context in which it is being used.

Understanding this has been helped by the use of a simple model involving several "*levels*" of outcomes according to whether they are at the level of Scottish Government policy, local authority work, the work of service delivery agencies or practice with individual children and young people.

The Research Specification (Scottish Government, 2012) is accompanied by a list of Scottish Government initiatives to consider, to which the Children and Families Analytical Services (who commissioned the work) subsequently added others.

These are primarily initiatives framed by the Scottish Government outcomes approach and in fact refer to social policy or organisational outcomes. However, on looking at the core literature for the project (again based on lists from the Research Specification, the Tender Document and suggestions from the Research Advisory Group), it is immediately clear that there are many initiatives being developed, by local authorities, by charities, by universities (often in partnership with each other) and by others.

Since this work was intended not to duplicate such initiatives, but rather to identify and document them (in order to complete a map of work in progress), it was necessary to document the range of outcomes work in progress with disabled children and young people, and this became the focus of the survey on which the main data collection was based.

It also became evident early on, partly as a consequence of our making known the project and the early compilation of contacts, that a number of people and organisations were in the process of developing outcomes models for use across Scotland with particular groups of disabled children and young people. Anxiety was expressed by some of these parties that our work would duplicate other pieces of work currently in progress. However, many of these projects involved extensive consultation with relevant stakeholders over lengthy periods, and included direct work with disabled children and young people themselves. This in fact provided further evidence of work in progress and helped sharpen the focus of the research.

Revised strategy

Consequent upon these early findings, the focus of the work was reframed not only to make it more achievable, but also to ensure that its own outcomes had some credibility. This involved identifying and documenting:

- Who's doing what in developing outcomes for disabled children and young people.
- What models of outcomes looked like in practice.
- What overlaps, commonalities and gaps appeared in these models.
- What issues were consequently identified in relation to developing outcomes models further, for both policy and practice.
- How the various approaches to outcomes modelling connect to GIRFEC, again in policy and practice.

Doing so would meet the objective listed earlier of "developing a map illustrating the short, medium and long-term outcomes for disabled children and young people based on the eight SHANARRI well-being domains". It would also provide suggestions for "future development and measurement of progress". These would be important steps towards developing an outcomes model in relation to disabled children and young people in Scotland.

The Study

We started the project knowing that many people were developing outcomes models, and that some of these were for use with disabled children. We did not know however, who was doing what nor what types of models were being developed. The literature review, which focussed both on disabled children and young people, especially in Scotland, and also on outcomes development work, did not greatly extend our knowledge in this area.

As outlined in the project proposal, we planned a survey of what was being done in the field. The first phase was a questionnaire distributed to 286 people and organisations working with children and/or disability across Scotland. The purpose of this survey was to involve key stakeholders, secure their interest and permission to participate, and to collect baseline information about their work and how/whether it involved outcomes.

A total of 78 people responded positively. 10 local authorities were involved – either completing a survey, taking part in a face to face or phone interview or providing information. In terms of organisations primarily concerned with children and young people's welfare, 4 agencies were involved in the study – some providing multiple survey responses. 11 organisations which would primarily be classed as disability organisations participated. Most were not concerned with a specific disability or condition or working only with children and young people. Other agencies/organisations involved in the study included University academic staff, NHS agencies, and other national bodies. One national network organisation was also involved.

A second more detailed questionnaire was distributed to this group and we received replies from 39 people. The data was collected using a Survey Monkey questionnaire, with the alternative of a downloadable version in Word.

Additionally, ten people were interviewed, either by phone or face-to-face.

From the point of announcing the work and distributing the first survey, we received a steady flow of inquiries, which continued throughout the project with most of the inquiries from people seeking to be involved in the project in some way. It also triggered some expressions of anxiety from people who were developing outcomes models, or who knew of such work, that this work would duplicate work already underway.

The data collected provided us with an understanding of the different ways in which outcomes were being approached in different contexts and of the ways in which this was being related to GIRFEC.

Together with data from the interviews, the survey data also provided us with the material for a series of case studies of the different contexts in which outcomes models were being developed, some of which are summarised in Section 5 and Appendix B, but which also inform and/or support the discussions in the other sections.

APPENDIX B
SOME MORE OUTCOMES MODELS

This section provides descriptions of further outcomes models, including several that have been influential for people developing new models or that are frequently cited.

<u>Barnardo's</u>

This is a significant source model for many projects.

<u>Angus Local Community Planning</u>

This is a well-developed model that was designed to be flexible enough to use in a variety of situations with a variety of people. It aims to be compliant with the GIRFEC national practice model.

<u>Moray Council</u>

"Moray Council has been using the 'Realistic Evaluation' approach for over ten years, within Children and Families Social Work Services, where a questionnaire based on the GIRFEC *My World Triangle* was developed, as well as within its Youth Justice Team." (CCPS 2010).

<u>Health Scotland: National Parenting Strategy</u>

This model was commissioned by Early Years and Social Services Workforce Directorate of the Scottish Government and is being completed within the Evaluation Team at NHS Health Scotland. This is a work in progress and the next draft is due during 2013.

- The policy context: developing an outcomes-focussed approach to the development and implementation of the National Parenting Strategy (NPS), which in turn has a focus on supporting parents as a key way of improving the life chances of children.
- The purpose is to link local activities with the National Performance Framework (NPF), to align intended outcomes, to identify issues and how partners might work together.
- The target audience includes both national policy makers and local planning partners (Community Planning Partnerships).
- The approach is based on a "logic model" and "results chains". Multiple results chains show the contribution of different sectors to achieving higher level outcomes; an outcomes triangle provides an overview of the topic area; logic models; and, results chains make explicit the link between activities and outcomes, as well as interconnections between outcomes.
- Issues:
    - "Often presented with equivocal evidence, use of different terminologies, definitions and outcome measures, uncertainty about direction of causality and attribution of outcomes to activities."

- There is a need for clarity about the language to see what is an outcome for the child/ parent/ community.
- There is a divergence on the use of terminology and language with the range of "Intermediate" to "long-term outcomes" being about movement between levels, not about timescale for individuals.
- The model does not at present connect to the level of individual families and children, nor is it about disabled children or families with disabled children (although this is a significant population among "parents").
- The outcomes are not framed in terms of the GIRFEC SHANARRI indicators.

Generic models

Realist Evaluation/Real Time Evaluation

"Realist evaluation" measures and evaluates service intervention and delivery. Service users complete questionnaires that record how individuals feel and how this changes over time. The person's progress is fed back into the service planning process, including the extent to which the objective of intervention has been met." The system is being used by the Aberlour Child Care Trust and by Moray Council. The approach requires external validation by an academic partner, namely, Dr M.F.Kazi (University of Buffalo, New York).

Further information:
http://www.ccpscotland.org/assets/files/hseu/information/Better%20Futures/Aberlour%20evaluation%20strategy_%20CCPS%202010.doc

Outcomes Star

This model was developed by the London Housing Foundation to chart changes in the lives of people using services aimed at more independent living. It can be used with a paper-based system or with an electronic recording tool. The Outcomes Star has been further developed and applied to a range of situations (currently 14 versions) one of which is the Autism Spectrum Star, developed in England.

Autism Spectrum Star

This was instigated because "service commissioners were emphasising that they needed a specific autism outcome measurement tool to assess how service users were working their way through their care pathway" and was the "first outcomes measurement tool to help assess the progress and changing needs and abilities of people with autism who are in care". Traditionally autism professionals have had to use a "generic outcomes measurement tool designed for people with mental health problems or learning disabilities but these are inaccurate with autism spectrum conditions."

This version was developed during seminars involving professionals and service users facilitated by Triangle Consulting. The outcomes developed

include nine "Journey of Change" areas: physical health; living skills and self-care; wellbeing and self-esteem; sensory differences; communication; social skills; relationships; socially responsible behaviour; time and activities. The Star allows service users to work alongside professionals in rating their abilities on a spectrum from 1-10 in the Journey of Change areas. It can be computer-generated. It has been piloted with 92 people and a professional and is now being implemented.

Further information: Hahn, S. (2012) "Gonna make you a star: how the world's first autism measurement tool, the spectrum star, was created", *Learning Disability Today*, December 2012 (30-31). www.outcomesstar.org.uk/work/

Other models listed in CCPS (2010) but not described here include:

- **Better Futures***:* Housing. www.ccpscotland.org/hseu/information/better-futures
- **ASCOT:** Adult Social Care Outcomes Toolkit*.* **Improvement in the use of services www.pssru.ac.uk/ascot**
- **REACH Standards in Supported Living***:* For people with learning disabilities to check the quality of their own support and housing: www.paradigm-uk.org
- **Social Return on Investment (SROI):** Measuring social, environmental and economic outcomes, expressed in monetary terms. www.sroiproject.org.uk
- **Carista/Intrelate:** A web browser based modular database system designed for social care: www.intrelate.com/?mid=68

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