Progressing Disability Services for Children and Young People - Report on the Findings of Consultation on draft Outcomes Statements

Progressing Disability Services for Children and Young People - Report on the Findings of Consultation on draft Outcomes Statements

1 Introduction ................................................................................................................................. 3
  1.1 Progressing Disability Services for Children and Young People ................................. 3

2 Outcomes framework for Early Intervention and School Age Disability Service teams ................................................................................................. 6
  2.1 Consultation with key stakeholders ................................................................................. 7

3 Consultation participants.............................................................................................................. 9

4 Stakeholder views on draft outcome statements ................................................................... 13

5 Comments on draft outcome indicators .................................................................................. 15
  5.1 Outcome statement 1: Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity ................................................................. 15
  5.2 Outcome statement 2: Children and young people are safe and enjoy the best possible health .................................................................................................................................................................................. 19
  5.3 Outcome statement 3: Children and young people have friends and get on well with other people in their lives ........................................................................................................................................................................................................ 21
  5.4 Outcome statement 4: Children and young people learn skills that help them to be independent ........................................................................................................................................................................................................ 25
  5.5 Outcome statement 5: Children and young people take part in home life, school life and community life in the same way as other children .................................................................................................................. 29
  5.6 Outcome statement 6: Families understand their child/young person's needs, what they are able to do well, and what they find difficult as they are growing up .................................................................................................................................................................................................................................................................................................................. 32
  5.7 Outcome statement 7: Families look after, take care of, and support their child or young person .................................................................................................................................................................................................................................................................................................................. 37
  5.8 Outcome statement 8: Families try to make sure that their rights and the rights of their child or young person are respected .................................................................................................................................................................................................................................................................................................................. 41
5.9  Outcome statement 9: Families take part in community services and supports............................................................................................................................ 45
5.10  Outcome statement 10: Families feel supported by family, friends, and neighbours in their local community............................................................................................................................ 47

6  Outcomes not covered in 10 draft outcome standards ............ 51

7  Other issues raised in relation to draft outcome statements .... 56
7.1  Gap between outcome statements and current service delivery........ 56
7.2  Measurement of outcome statements................................................................. 56
7.3  Resources............................................................................................................. 56
7.4  Supports in mainstream education inadequate ........................................ 57
7.5  Access to services.................................................................................................. 57
7.6  Access to information .......................................................................................... 58
7.7  Variable quality of services................................................................................ 59
7.8  Choice.................................................................................................................... 59
7.9  Public attitudes toward children and young people with disabilities............. 59
7.10 Community service ill-equipped / supports to participate .............................. 60

8  Consistency of draft outcome statements with current service delivery ............................................................................................... 62

9  Processes of gathering and reporting on data on outcomes currently in operation ............................................................................................................................... 65

Appendix 1 ............................................................................................................. 67
Progressing Disability Services for Children and Young People - Report on the Findings of Consultation on draft Outcomes Statements

1 Introduction

1.1 Progressing Disability Services for Children and Young People

The National Progressing Disability Services for Children and Young People’s programme was established in 2010 to change the way services are provided across the country. The objectives of the programme, which is based on the recommendations of the Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years¹, are to ensure:

- a single, unified system of disability services for children and young people
- equity in access to services across the country
- effective teams working in partnership with parents
- resources are used optimally in a challenging fiscal environment

In Ireland, disability services delivered by the HSE and non-statutory organisations, have developed independently over time, so there is wide variation in the services available in different parts of the country and for different categories of disability. As a consequence of this, some children and their families have little or no access to services.

Progressing Disability Services for Children and Young People’s programme aims to develop a clear pathway for all children with disabilities living in a locality. This means that health professionals and parents will know where a child should be referred and how to do this. Importantly the objective is that no family will be left without a service.

When the programme is completed, early intervention and school age disability teams will provide health services for all children with complex needs and their families in a defined geographic network area, regardless of the nature of the child’s disability. These teams will be supported by specialist services in areas of high expertise through consultation, training and direct intervention when

¹ Health Services Executive, 2009, Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years
necessary.

The National Co-ordinating Group for the programme has established a number of sub groups to form recommendations and direction on particular areas of relevance. One of these is the Standards and Performance Reporting Working Group which was convened in January 2012. The Groups’ terms of reference are to develop a draft performance reporting framework that supports programme accountability and performance reporting for multidisciplinary, in some cases multi-agency children’s disability teams,, with a focus on outcomes for children with disabilities and their families.

The members of the Standards and Performance Reporting Working Group are:

- Ann Bourke (Chair) Senior Manager National Disability Unit, HSE
- Caroline Cantan Coordinator, Progressing Children’s Disability Services programme HSE
- Margaret Farrell Outcomes Network of Ireland Representative
- Toni Gleeson Disability Federation of Ireland Representative
- Anna Shakespeare Federation of Voluntary Bodies Representative
- Gabrielle Jacob* Assistant Principal Officer Department of Health
- Anne O’Byrne\x NFPBA Parent Representative
- Martin O’Connor\ Clinical Leader, Clare Children’s Services, HSE
- Aisling Ryan\ Children’s Services Manager HSE Mid West
- Aisling Lenihan^ Early Intervention Lead HSE South
- Michael Shemeld\ Development Manager National Disability Unit HSE
- Maria Walls^ Federation of Voluntary Bodies Representative
- Fionnuala O’Donovan^ Not-for-Profit Business Association Representative
- Denise Keoghan^- Performance and Development HSE DML
- Sorcha Murray / Assistant Principal Officer Department of Health
- Brian Muldoon /// Manager, West Limerick Children's Services
* Chair until April 2012, member until September 2012
x Member from January 2012 to September 2012
+ Member from January 2012 to March 2012
^ Member from January 2012 to May 2013
- Member from January 2013
/ Member from March 2013
// Member from May 2013
2 Outcomes framework for Early Intervention and School Age Disability Service teams

A Standards and Performance Reporting Working group of Progressing Disability Services for Children and Young People group programme has developed a draft Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Services. These outcomes which apply to all children and their families are based on international research, experts and in consultation with key stakeholders, including a parent group.

The framework will apply to all network early intervention and school age disability services and its purpose is to:

- maintain a focus on desired outcomes for the individual child and the family through a process of clarifying expectations (personal outcomes, functional outcomes and clinical outcomes) as appropriate
- ensure a standardised outcomes-focused approach to the delivery of services and supports for each child and their family in accordance with their needs and priorities
- provide a framework for the governance, including the clinical governance, and accountability of early intervention and school age disability services

An outcome is defined, in the Outcomes-Focused Performance Management and Accountability Framework, as a benefit experienced by a child, their family or the wider community as a result of the services and supports provided.

The ten draft outcome statements on which the consultation sought the views of stakeholders are:

- Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity
- Children and young people are safe and enjoy the best possible health
- Children and young people have friends and get on well with other people in their lives
- Children and young people learn skills that help them to be independent
- Children and young people take part in home life, school life and community life in the same way as other children
- Families understand their child/young person’s needs, what they are able to do well, and what they find difficult, as they are growing up
• Families look after, take care of, and support their child or young person
• Families try to make sure that their rights and the rights of their child/young person are respected
• Families take part in community services and supports
• Families feel supported by family, friends, and neighbours in their local community

2.1 Consultation with key stakeholders

As part of the process to develop the Outcomes-Focused Performance Management and Accountability Framework, the Standards and Performance Working Group carried out a consultation with staff of disability services, parents of children and young people with disabilities, young people with disabilities themselves and adult former service users. The consultation, which took place from the 30th of October to the 30th of November 2012, was conducted using an online survey.

The main aim of conducting the survey was to gain feedback from the relevant groups on the outcomes framework and to find out:

• if outcome statements were appropriate and whether they accurately reflected needs and
• to rank the importance of each outcome statement
• to encourage staff to begin thinking in an outcomes way

The survey also facilitated staff, parents and young people to express their views in an open-ended way.

For technical reasons it was not possible to append the draft Outcomes-Focused Performance Management and Accountability Framework to the online survey. While respondents were given the option to request a copy of the Framework most did not make such a request. Clearly, it would have been preferable if the consultation design had afforded respondents a convenient opportunity to consider the draft outcome statements in the wider context of the overall Outcomes-Focused Performance Management and Accountability Framework before providing their responses.

To do justice to the breadth and richness of the qualitative responses received from stakeholders this report deals with data in two different ways:

• qualitative comments which explicitly address a draft outcome statement are presented in the analysis of data under the relevant outcome statement
• qualitative comments which address the provision of disability services to children and young people more generally are captured in Section 7 and are analysed and organised by theme.
3 Consultation participants

A large number of stakeholders completed the online survey. However, participants self-selected to participate in the survey. The sample of respondents was, therefore, not randomly selected from the overall populations of relevant parents, professionals and children / young people with disabilities. Therefore, the survey respondents may be more or less knowledgeable, engaged or satisfied with services, etc., than the average parent, professional or child / young person with a disability actually is. This is known as “self-selection bias”. As a consequence it would be unwise, for example, to generalise about the views of all parents of children with disabilities on the basis of the views expressed by those parents who responded to this survey.

Overall, 500 participants took part in the consultation exercise by completing the online survey. Parents of children aged 6 – 18 accounted for more than two thirds of the parents who participated. Speech and Language Therapy Services, Occupational Therapy Services and Psychology Services were the services which children of responding parents most frequently received. The percentages in Table 3 below need to be treated with caution. A significant number of parents clarified that:

- they had accessed some of these service privately
- they were receiving or had received less services than was required
- services which they had previously accessed were no longer available to them
- they were on a waiting list but not currently receiving those services

Throughout this report reference is made to the views of “children and young people” though it should be noted that this group mostly provided yes, no answers without additional comments. These comments are contained in this report where relevant. The consultation aimed to also capture the experience of adult former users of children’s disability services, only 3 adult former service users responded who are now 25 years or older. See Table 4 below for details.
### Table 1 – Numbers of consultation participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff</td>
<td>283</td>
<td>56.6</td>
</tr>
<tr>
<td>Parents</td>
<td>199</td>
<td>39.8</td>
</tr>
<tr>
<td>Children and young people</td>
<td>18</td>
<td>3.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>500</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 2 – Numbers & percentage of parents with children in age ranges

<table>
<thead>
<tr>
<th>Age range</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 6 years</td>
<td>58</td>
<td>24.1</td>
</tr>
<tr>
<td>6 – 18 years</td>
<td>137</td>
<td>68.9</td>
</tr>
<tr>
<td>19 – 24 years</td>
<td>5</td>
<td>2.5</td>
</tr>
<tr>
<td>Not known</td>
<td>3</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>199</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 3 – Numbers & Percentage of parents with children who receive or in the past have received services

<table>
<thead>
<tr>
<th>Service type</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech and Language Therapy Service</td>
<td>183</td>
<td>92.9</td>
</tr>
<tr>
<td>Occupational Therapy Services</td>
<td>158</td>
<td>80.2</td>
</tr>
<tr>
<td>Psychology Services</td>
<td>108</td>
<td>75.1</td>
</tr>
<tr>
<td>Early Intervention Educators</td>
<td>148</td>
<td>56.9</td>
</tr>
<tr>
<td>Physiotherapy Service</td>
<td>112</td>
<td>54.8</td>
</tr>
<tr>
<td>Social Work</td>
<td>76</td>
<td>38.6</td>
</tr>
<tr>
<td>Aids and Appliances</td>
<td>39</td>
<td>35.5</td>
</tr>
<tr>
<td>Disability Nurse</td>
<td>70</td>
<td>19.8</td>
</tr>
</tbody>
</table>

n = 197
Table 4 – Children and young people age ranges

<table>
<thead>
<tr>
<th>Age range</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 6 years</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>6 – 18 years</td>
<td>14</td>
<td>78</td>
</tr>
<tr>
<td>19 – 24 years</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>25 + years</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 5 – Services received by children and young people respondents

<table>
<thead>
<tr>
<th>Service type</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech and Language Therapy Service</td>
<td>15</td>
<td>83.3%</td>
</tr>
<tr>
<td>Occupational Therapy Services</td>
<td>13</td>
<td>44.4%</td>
</tr>
<tr>
<td>Psychology Services</td>
<td>9</td>
<td>50.0%</td>
</tr>
<tr>
<td>Early Intervention Educators</td>
<td>8</td>
<td>72.2%</td>
</tr>
<tr>
<td>Physiotherapy Service</td>
<td>7</td>
<td>38.9%</td>
</tr>
<tr>
<td>Social Work</td>
<td>3</td>
<td>16.7%</td>
</tr>
<tr>
<td>Aids and Appliances</td>
<td>3</td>
<td>16.7%</td>
</tr>
<tr>
<td>Disability Nurse</td>
<td>1</td>
<td>83.3%</td>
</tr>
</tbody>
</table>

n = 18

Table 6 – Profession of staff respondents

<table>
<thead>
<tr>
<th>Profession</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapist</td>
<td>25</td>
<td>15.9</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>36</td>
<td>22.9</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>60</td>
<td>38.2</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>17</td>
<td>10.8</td>
</tr>
<tr>
<td>Social Worker</td>
<td>19</td>
<td>12.1</td>
</tr>
</tbody>
</table>

n = 157

Staff respondents, whose occupation was not covered by the professions listed in Table 6, were asked to provide further details. 121 staff provided further detail though in fact much of these responses were just further clarification of respondents’ exact roles, for example, “quality co-ordinator and psychotherapist”. However, these additional comments make it clear that the staff respondents represented a significantly wider group of professions than are represented in Table 6. Other professions / occupations / positions represented among the staff respondents include:

- School Principal
- Psychotherapist
- School nurse
- Liaison nurse
- Special Educational Needs Organiser Educational Psychologist
- Psychiatrist (child and adolescent)
- Service Manager
- Teacher
- Dietician
- Team Leader of multi-disciplinary disability team
- Care assistant
- Instructor / facilitator
- Early Intervention Nurse
- Family Resource Worker
- Doctor
- Pre-school Liaison Teacher
- Advanced Paramedic
- Clinical nurse manager
- Case Manager
- Paediatrician
- Special School Principal
- Behaviour Analyst
- Child and Family Support Worker
- Teacher for pre-school children with intellectual disability
- Residential services manager
- Social Care leader
- Disability service administrator
4 Stakeholder views on draft outcome statements

Survey respondents were asked to indicate how important they felt the ten draft outcome statements were. Table 6 presents a summary of the results. In general, stakeholders viewed the draft outcome statements as being very relevant. The most notable feature of the responses on the outcome statements is the broad consensus among respondents on the draft outcome statements. For example, the outcome statement with the lowest percentage of staff indicating that it was important or very important was rated as important or very important by 94.2% of staff respondents. Similarly, the draft outcome statements which were rated as important or very important by the least amount of parents and by the least amount of children and young people were, nonetheless, rated as important or very important by 93.8% and 76.5% by the respective stakeholders.

The ten draft outcome statements are ranked according to the percentage of respondents, within each group, in Table 7. Given that all of the ten draft outcome statements are within a very narrow range (the lowest to highest range in terms of outcomes statements viewed as important or very important for staff is only 94.2% to 97.8%) the rankings should not be over interpreted.

Therefore, as Table 7 demonstrates clearly, there is broad support among stakeholders for the ten draft outcome statements. Section 5 below sets out important observations and clarification raised by stakeholders in relation to specific draft outcome indicators. Also, Section 7 contains a more general feedback, much of it critical, on current service provision from stakeholders. However, these observations and criticisms are made in the context of a broad endorsement of the ten draft outcome statements.

More detailed tables on stakeholder responses are located in Appendix 1.

---

2 In Table 7 the draft Outcome Statements are ranked by the percentage of respondents who indicated that a particular draft Outcome Statement was very important and also ranked by the percentage who indicated that they were either important or very important.
<table>
<thead>
<tr>
<th>Outcome statement</th>
<th>Staff views ranked</th>
<th>Parents' views ranked</th>
<th>Children's views ranked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity</td>
<td>8th (73.7%)</td>
<td>8th (74.2%)</td>
<td>3rd (83.3%)</td>
</tr>
<tr>
<td>Children and young people are safe and enjoy the best possible health</td>
<td>1st (95.4%)</td>
<td>1st (100%)</td>
<td>1st (94.1%)</td>
</tr>
<tr>
<td>Children and young people have friends and get on well with other people in their lives</td>
<td>6th (80.3%)</td>
<td>7th (86.8%)</td>
<td>9th (58.8%)</td>
</tr>
<tr>
<td>Children and young people learn skills that help them to be independent</td>
<td>2nd (88.9%)</td>
<td>3rd (94.4%)</td>
<td>4th (82.4%)</td>
</tr>
<tr>
<td>Children and young people take part in home life, school life and community life in the same way as other children</td>
<td>7th (79.2%)</td>
<td>6th (87.2%)</td>
<td>7th (70.6%)</td>
</tr>
<tr>
<td>Families understand their child/young person's needs, what they are able to do well, and what they find difficult, as they are growing up</td>
<td>4th (86.1%)</td>
<td>4th (92.9%)</td>
<td>2nd (87.5%)</td>
</tr>
<tr>
<td>Families look after, take care of, and support their child or young person</td>
<td>3rd (86.7%)</td>
<td>5th (92.9%)</td>
<td>6th (70.6%)</td>
</tr>
<tr>
<td>Families try to make sure that their rights and the rights of their child/young person are respected</td>
<td>5th (82.8%)</td>
<td>1st (94.9%)</td>
<td>10th (53.3%)</td>
</tr>
<tr>
<td>Families take part in community services and supports</td>
<td>9th (70.5%)</td>
<td>9th (73.8%)</td>
<td>8th (64.7%)</td>
</tr>
<tr>
<td>Families feel supported by family, friends, and neighbours in their local community</td>
<td>10th (66.9%)</td>
<td>10th (69.7%)</td>
<td>1st (87.5%)</td>
</tr>
</tbody>
</table>
5 Comments on draft outcome indicators

This section contains comments from stakeholders on each of the ten draft outcome statements. Stakeholders were asked for additional comments on each outcome statement after indicating how important that outcome statement was for them. While some responses received clarified why a particular outcome statement was important to the respondent, others took the form of observations which highlighted, for example:

- the relationship between the draft outcome statement and current practice
- the practical implications of operating a service in accordance with the particular outcome statement
- the practical implications for families and children with disabilities if services were delivered in accordance with the particular outcome statement
- impediments for families/services to delivering in accordance with the particular outcome statement

Stakeholder comments on each draft outcome statement have been grouped by theme and by stakeholder group.

As mentioned above, comments received which did not directly relate to the draft outcome statement, but which, nonetheless, raised important issues relating to Progressing Disability Services for Children and Young People programme or children’s disability services more generally, are analysed and discussed separately in Section 7 below.

5.1 Outcome statement 1: Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity.

This means: Children and young people are encouraged to express their views.

5.1.1 Parents’ comments

Almost 97% parents indicated that this outcome statement was important or very important. Set out below are the main themes identified in the 31 additional feedback comments from parents

5.1.1.1 Views heard and decision made

A number of parents noted that the language of the draft outcome statement refers to children having their voices heard rather than children being able to influence decisions on issues which were important in their lives. For example,
“To have a view is one thing, but to have trust that their views will be acted upon in the best interest of the child/young person, irrespective of location or means is quite another”

“These are two separate statements and should be two separate outcomes as one does not necessarily follow the other […] [that is] 1. Children are encouraged to express their views 2. Children are confident that their views are taken seriously”

5.1.1.2 Some children need support to be heard
A number of parents noted that some children will need support to have their voices heard. Children may need support to have their voices heard because:

- they are non-verbal
- they have a communication difficulty
- they have a cognitive difficulty
- professionals are not skilled in dealing with children who use non-standard means of communication

As one parent commented:

“Many children/young people with disabilities don’t use standard ways to express their views. It is important that any listener/spokesperson involved in planning the person’s life understands and facilitates the individual’s means of communication”

5.1.1.3 Children’s / young’s views and parents’ views
Some parents suggested that there is a lack of clarity in the outcome statement relating to the circumstances where a child’s or young person’s view is to be considered and where their parents’ views are considered.

“very important depending on chronological age and developmental age. Other than that it should be parental views should be taken seriously”

“[…] I do feel that parents should still have a vital role in the way their child is treated by professionals and school authorities etc….the parents are the ones who have to do their best for their own child”

Other comments from parents emphasised the importance of not assuming that children, including children who may intellectual or cognitive delays, cannot make decisions in their own best interests. For example:
“People with ID may need time to express their views, more time than can sometimes be allowed. Often they can surprise us with the vision they have of what they would like their lives to be like— even those who are relatively non verbal. We should consider their wishes, rather than deciding on their futures purely with financial and traditional service delivery practices in mind”

“For individuals with intellectual disability, the level of intellectual disability will at least partly determine, surely, the perceived level of 'maturity' of the individual concerned, which implies possible low weighting of such a person's view”

A related comment queried the legal status of decisions made by children and young with diminished capacity, “especially when laws governing legal competence are so out of date”.

Therefore, although 97% percent of parents indicated that this outcome statement was important or very important, there appears, nonetheless, to be a lack of consensus among parents on the appropriate balance between the role children and young people in decision making and the role of their parents.

5.1.2 Comments from children and young people
Almost 89% of children and young people indicated that this outcome was important or very important. There were two comments by children and young people. The first related to some children's capacity to make informed decisions; the second related to children with disabilities building capacity through interactions with their peers with disabilities.

“It’s from speaking with children with disabilities that we get [an] insight as to what is best for them”

5.1.3 Staff comments
96% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 57 additional comments made by staff respondents.

5.1.3.1 Some children need support to be heard
Similar to the point made by parents, staff stakeholders highlighted that, for a variety of reasons, some children and young people will need support to have their voices heard.

An additional comment expressed the view that capacity building for children and families would be required to ensure that children do have their voices heard. Some staff suggested that building the capacity of the child or young person to
see themselves as a key decision maker in their own support should a central goal of services.

“I think that this starts early on - engaging children actively in their therapy process and making sure they are not just passive participants. (This includes, for example, negotiating therapy decisions and timing of goals). It takes a long time for some children to learn to express choice, and then to later articulate their own ideas. Children who have disabilities often attend many therapies, which can mitigate against them developing this sense of them taking charge of their own fate in any way - unless therapy process take it on board to engage the child to do so”

“In order for young people to be fully enabled to express their views they require preparation and support and there is a piece of work to be done with their parents/carers also who may be reluctant especially where there has not been open discussion regarding the child’s disability throughout progression through services”

5.1.3.2 Children’s / young’s views and parents’ views
The lack of consensus on the views of parents and children and young people is also reflective of the comments expressed by staff.

“Is this statement ambiguous? Children’s views can be given due weight but it is the adults responsibility to make decisions”

“Many vulnerable, disabled or needy children cannot articulate what they need as easily as one might think”

“All service users should be encouraged to listen to the advice given by experienced professionals as well as having a say themselves”

“It is essential that all children are given a full opportunity to express their views”

5.1.3.3 Children and young people’s voice and advocacy
Some staff highlighted that parents can make decisions which they as professionals feel are not in the child’s interests and that in some case independent advocacy is required to ensure that a child’s voice can be heard. For example, staff expressed the following views:

“Often parents over ride their views and there is a need for independent advocacy services for children who are not in care”
“Children with parents should be allowed an independent advocate if deemed useful when dealing with services as occasionally their parents do not act in their best interests for whatever reason”

5.2 Outcome statement 2. Children and young people are safe and enjoy the best possible health

This means:

- children and young people have the best possible health
- children and young people are safe at home, at school, and in their community
- children and young people are free from abuse and neglect

5.2.1 Parents’ comments

100% of parents indicated that this outcome was very important to them. Set out below are the main themes identified in 26 additional comments received from parents.

5.2.1.1 Timeliness of service delivery & appropriateness of services setting

Some parents commented that the outcome statement should take account of the fact that there are frequently delays on access services and this can have negative impacts on children’s and young people’s health outcomes. For example,

“Waiting lists for children need to be considered particularly in areas such as ENT [Ear, Nose and Throat] where there are large waiting lists and the impact is so important at this formative age”

A parent also commented that children’s health can suffer if they are placed in an inappropriate setting and that, therefore, the outcome statement may need to refer to service being delivered in an appropriate settings.

“Children’s health can be adversely impacted if they are in an inappropriate setting to their needs. This in turn can lead to troublesome behaviours and the person medicated - not a good outcome but sometimes inevitable if staff shortages are to be the way of the future”

5.2.1.2 Abuse and prejudice

A parent raised the issue of whether being free from abuse also covered being free from prejudice.

“Children can also be protected from prejudice by raising the awareness among the general public about disabilities”
5.2.1.3 Health and dental health
A parent suggested that “health” should also include dental health.

5.2.1.4 Safety and risk
A number of parents raised the issue that keeping children safe had to be balanced with promoting independence and facilitating risk taking to achieve personal goals.

“We should make sure that the word 'safe' is not used as an obstacle when people are trying to expand their horizons. Words like 'safe' and 'we’re not insured for that' can be used as management tools. Let’s be sure we’re using these words and themes correctly”

“Health also means movement so please don’t equate safety with doing nothing and banning every 'risky' activity”

5.2.2 Children’s and young people’s comments
94% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people, both of which related to a healthy diet being included in the term “health”.

5.2.3 Staff comments
98% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 28 additional comments made by staff respondents.

5.2.3.1 Meaning of term “health”
There was some overlap between the themes included in staff comments and those included in parents’ comments. For example, staff also questioned the scope of the term “health” and questioned whether it included “mental health”; “social well being”; being “physically active”; having a good “nutritional status”.

5.2.3.2 Supporting children to managing their own health
Some staff suggested that the outcome indicator should make reference to older children and young people managing their own health needs and similarly families being supported to manage their child’s health needs.

“Young people and older children should supported to take care of their own health care, in so far as possible, this might include assisting with their medication, views on health intervention”

“Parents need ongoing support at home to achieve this […]”
5.2.3.3 Coordination of services
Some staff respondents noted that coordination within teams and between health and other services should be included in the outcome statement. For example,

“Coordination of education and HSE services is essential”

“There needs to be a better interface between disability and child welfare and protection services as some children with special needs do have child protection issues”

“There need to be clear systems in place to ensure this. When there are multi agency teams, this needs to be agreed before teams are put in place”.

5.2.3.4 Managing risk
One staff member raised the issue of balancing safety and risk taking, which a number of parents also raised.

“Children should be assisted in learning how to keep themselves safe and healthy and to be allowed to manage some risks. Overprotecting children will stunt their development”

5.3 Outcome statement 3: Children and young people have friends and get on well with other people in their lives
This means:

- children and young people feel safe and secure with the main people who are looking after them
- children and young people can make friends with lots of people with whom they want to be friends
- children and young people develop socially and emotionally according to their age. Children and young people understand about sex
- children and young people understand about different relationships and they can choose with whom they want to have a close relationship

5.3.1 Parents’ comments
97.5% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 34 additional comments received from parents.
5.3.1.1 Difficulty for some children and young people to have friendships
Most parents’ comments were supportive of the outcome statement. However, some noted their own child’s difficulty in making friends. Some parents said, it was not possible for their child to have friendships or relationships. For example,

“Not always possible for some groups of children to have friends, same would apply to relationships”

“How does one address the need for relationships (by which I mean friendships) for people whose level of ID [Intellectual Disability] is such that they cannot communicate, and are relatively immobile?”

5.3.1.2 Choosing not to have friends
One parent suggested that an issue for this outcome statement was that some children may choose not to have friends.

“Some people choose to be alone. This may change during the lifespan”

5.3.1.3 Parents’ role in guiding children and young people’s friendships
Some parents expressed the view that the nature of their child’s disability meant that they as parents need to have a role in determining who their child is friends with or has a relationship with. For example,

“If an adult sees that the relationship is not a good one or worse dangerous the adult should retain the right to intervene and stop it”

“Must be supervised though in choosing who they hang out with for their own safety”

“My son needs to feel safe and secure as all children do but he does not have the ability to develop socially and emotionally according to his age, His needs are dependent on intensive therapies to even have the ability to come close to his peers in mainstream. Parental guidance in our case is what determines his close relationships”

“Children and young people with ID [Intellectual Disabilities] do need guidance regarding appropriate friendships. However forming relationships at whatever level is one of the most fundamental parts of living - even for those with communication difficulties. People with ID [Intellectual Disabilities] do not develop socially and emotionally in line”
5.3.1.4 Happiness
Some parents suggested that this outcome statement should make a reference to “happiness” or “a happy life”.

5.3.1.5 Support to make friends and have relationships
Some parents suggested that children and young people with disabilities need supports to make friends and have relationships and some suggested that families need support to help their children make friends.

“Yes, it is particularly important for the Disability Team to support children with a disability in fostering friendships, running groups, etc. Particularly where children with LD [Learning Disabilities] are in mainstream school”

“I believe parents need support from professionally trained personnel with regarding the above [outcome statement]”

5.3.1.6 Appropriate sex education
In relation to children and young people understanding sex, some parents noted that they needed to be involved in decisions on when their child was ready for sex education, while others felt children with certain disabilities needed very specific sex education.

“Parents need to have input into what is not only age appropriate for the child, but also appropriate to how socially aware and mature they believe their individual child is. Not just someone deciding the child is this age therefore can discuss/be told this”

“Those with Aspergers need very different and specific education regarding emotional and sexual intelligence”

5.3.2 Children’s and young people’s comments
88% of children and young people indicated that this outcome statement was important or very important. There were three additional comments raised by children and young people, all of which were affirmations of the importance of friendship to children and young people.

5.3.3 Staff comments
97% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 49 additional comments made by staff respondents.
5.3.3.1 Outcome statement and meaning
A number of staff comments suggested that the meaning of the outcome statement as set out in the bullet points are not well linked to the actual wording of the outcome statements.

5.3.3.2 Support to make friends and have relationships
Similar to the point made by parents, a number of staff respondents suggested that children and young people need support to make friends and have relationships. In addition to this general point, staff also pointed out that:

- some of the support needed to come from the education sector
- non-disabled children needed opportunities to interact with disabled children
- some children needed support “out of hours” to participate in social activities

For example:

“Children with disabilities may need a high level of assistance to be enabled to make friends with lots of people and this involves being in a position to provide some support services out of hours to enable children to participate in community based activities”

“Education and whole school programs are important to facilitate the above for young people with disabilities. Teaching and learning within natural settings, while amongst peers, is key. Consistent collaboration between school, students, parents and professionals is very important”

“Social skills training is needed in schools and a school policy on well being in schools should be developed”

“Health services should not necessarily be accountable for this”

5.3.3.3 Choosing not to have friends
Echoing the point made by one parent, a number of staff members suggested that making lots of friends may not be an appropriate goal for some children. Other staff respondents suggested that a goal around making friends needs to take account of the child’s capacity and preferences.

“Many people on the autism spectrum may feel anxious and distressed by expectations that they need or must have friends, when acquaintances would be sufficient and more suited to their temperaments and desires”
“[…] while friendships may be the important goal of families/parents of children with a specific diagnosis e.g. ASD, this may not be the child’s goal or be motivating/fulfilling for the child themselves”

“The child’s perception here is much more important than the parents. Often parents feel that children should have lots of "friends" where as the child may only be able to cope with a limited number of other people in their lives”

5.3.3.4 Parents’ role in guiding children and young people’s friendships
Echoing the comments made by parents, some staff respondents suggested that the role of parents / guardians in supervising friendships should be acknowledged. For example,

“‘Yes this is important but with the supervision of a guardian or parent’”

“This area needs to be monitored by a trusted adult with the interests of the prime safety of the child at the core. Children with different types of disabilities need the supervision of an adult with their best interests in mind”

5.4 Outcome statement 4: Children and young people learn skills that help them to be independent.
This means that:

• children and young people are interested in and want to learn new things
• children and young people develop day to day skills that help them live their lives as independently as possible
• children and young people take part in and complete education that is recognised as useful
• children and young people are supported when they move between services and supports

5.4.1 Parents’ comments
99% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 29 additional comments received from parents.

5.4.1.1 Role of schools in learning skills and being independent
A number of parents commented that the education system needed to play a greater role in supporting children to achieve the outcomes identified in this statement. In particular, parents suggested that schools had a greater role to play
in fostering independence and in making the school curriculum accessible and relevant to all children.

“Each child needs to be supported properly in school, this is where they spend the majority of their day for 8 years of primary and thereafter, where they’ll meet the local children and where the skills they need to learn can be learned seamlessly. To achieve this, the other services, the child is accessing, should be delivered in the school setting e.g. speech and language so that parents, educators and service providers are all interacting in the best interests of the child”

“Schools also need to be supported in helping the child become more independent. At times there can be an over reliance on SNAs [Special Needs Assistants] in schools which leads to the child with LD [Learning Disability] not being allowed to be independent”

“Every child deserves access to a curriculum. Instead of schools asking the child to manage and cope with the way it feels the child should be educated - shouldn’t schools and adults be asking themselves what they can change so that all children can be successful. Teeny, tiny changes can be the difference between success and failure”

5.4.1.2 Independence for children with significant support needs
Differing views were expressed by parents on the relevance of the emphasis in the outcome statement on independence for children with very significant support needs.

“Independence is not just for the mildly disabled, every level of independence if it improves quality of life, advances self esteem and feelings of self worth, is valuable”

“My child has a severe disability he cannot be independent”

5.4.1.3 Education options beyond the mainstream
The outcome statement explanation refers to education that is useful. Some parents pointed out that for some children with disabilities this may not be a mainstream education qualification. For example,

“When children drop out of school there is so little done to help them return to school or to support other means of education besides mainstream. Parents are not informed of alternatives to the school system as it exists. Children’s area of interest could be used to allow them to function in society regardless of exam results”
5.4.2 Children’s and young people’s comments
88% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people, which expressed the importance of employment, independence and friendship.

“To get a job it is important”

“I want to live in my own place and have friends”

5.4.3 Staff comments
98% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 47 additional comments made by staff respondents.

5.4.3.1 Independence for children with significant support needs
As with comments made by some parents not all staff respondents regarded the reference to independence as unproblematic. An example, of one of these comments, is the following:

“Not all children have the potential to be independent”

5.4.3.2 Role of schools in learning skills and being independent
As with parents there was a view that school and the education system in general was very relevant to this outcome statement. It was suggested by some staff respondents that there would need to be greater coordination between health and education to deliver on this outcome service and that potentially some specialist disabilities services would need to be delivered by schools. It was also suggested by a number of staff respondents that schools needed to do more to teach independent living skills and that teachers needed to be better at differentiating the curriculum.

“Lack of vocational training in schools limits this”

“Life skills should be taught in schools”

“Mainstream education facilities at first level and second level are not equipped to meet the needs of children with special needs e.g. autism. The curriculum, in teacher training colleges, needs to incorporate skills development in this regard and also basic Child Care competencies”

“[…]it would be very positive to see more Initiatives where "health and education look at this in an integrated way to develop the best models and an understanding of the whole child"
“Education that is recognised as useful - role of DES as will depend on school and teacher. They need to be flexible with curriculum to suit children’s individual needs. Also same applies in DES preschools”

“Education for life and the development of the person is the most important element here, but is often confused with doing exams and getting certificates”

5.4.3.3 Role of parents
A number of staff respondents mentioned the role of parents in delivering on the outcome covered in this statement. One respondent suggested that parents, as well as services, need to focus more on teaching skills than on providing support.

“[…] parents should be trained/informed on the best to prepare a child for independent living”

“Parents are best resource and support to children and they will achieve a lot more if their parents are on board […].[Parents need to be shown] their children with disability are capable of independence but only with parents support. To ignore the parent in this is to further disable the child’s chances of success”

“I think it is very important that children and young people are supported to be as independent as possible but I think sometimes families and services disable them further as it is sometimes easier for us to do it ourselves rather than to teach children to do it”

5.4.3.4 Coordination and managing transitions
Several staff respondents noted that coordination is often poor within services and between services and that transitions are often not well managed.

“Based on our experience there are a number of gaps identified when referring to the above statements, i.e., transitioning from one service to another is very challenging for most children and young adults”

“Better communication between service providers will be required to ensure that this is the case and greater awareness of roles and better interface between education and health”

“A Team approach to helping children reach their full potential in all areas is the ultimate goal of a Service for children with strict safety and health promoting guidelines in place. Planning for all of the child’s transitions and placements is therefore very important”
“I think that it is very important to have continuity of services and providers, as many children and parents feel they attend services and there are different staff at each session and this is a lot of the time distressing for the child and annoying for the parents as they have to repeat their story again at each session they attend”

5.5 Outcome statement 5: Children and young people take part in home life, school life and community life in the same way as other children.

This means:

- Children and young people can use community services and facilities that other children are using.
- Children and young people live, learn play and socialise in places with their peers.
- Children take part in the everyday life of their community.

5.5.1 Parents’ comments

96% of parents indicated that this outcome was important or very important to them. Set out below are the main themes identified in 46 additional comments received from parents. Many of the additional comments stressed the importance of this outcome for children and young people with disabilities.

5.5.1.1 Not all children and young people take part in community life in the “same” way

Some parents cautioned against the emphasis on the children with disabilities participating in the “same” way as other children in the outcome statement. These parents suggested that children and young people should participate in ways appropriate to their need and interests.

“There are some children with social disabilities such as Aspergers that may not feel that they need to socialise in the same way or as much as other kids, I think it is important that teachers and healthcare professionals recognise this as a difference rather than a negative thing”

“Within their own abilities as they are different to their peers”

“Not all children can do things the same way as other children. The emphasis on mainstreaming, while essential for some children with special needs can lead to a decrease in appropriate services for children who struggle with mainstream and require a more structured or calm environment. Opportunities to participate must
be based on the individual needs of the child and not polarised by all mainstream or all segregated services”

“I would be careful about equating 'equality' with 'the same'. For me, quality of life; choice; building on skills is more important, than a person with a disability attending a local school where their differences are exaggerated”

5.5.1.2 Support to participate
A number of parents emphasised that children and young people would need support to participate on an equal basis to other children. Many parents mentioned that such supports were not available to their children.

“Very difficult to achieve with limited early supports”

“Children with disabilities will require support to full integrate into their community”

“And they need to be supported to do so. Constant erosion of support during the recession makes this a very difficult outcome to achieve”

5.5.1.3 Barriers to participation
Many parents highlighted the barriers to the fulfilment of good outcome in this area. While some parents mentioned issues relating to physical accessibility most referenced prejudice and attitudinal barriers in mainstream community organisations and society more generally. The issue of negative attitudes is discussed in Section 7.

5.5.2 Children’s and young people’s comments
76.5% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people, which expressed that people with disabilities being seen as individuals and the importance of doing ordinary things that they enjoy in their community.

“I like to go to things in my own community and go to the shops, the cinema, get the bus and do what I like to do”

“See the individual, not the disability”

5.5.3 Staff comments
Almost 97% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 58 additional comments made by staff respondents.
5.5.3.1 Not all children and young people take part in community life in the “same” way

As with parent respondents, some staff respondents highlighted that not all children want or can participate in community life in the “same” way as other children, particularly if “other children” implies children without disabilities.

“Again this depends on the young person and their desire to interact socially”

“Peers sometimes need to be at an appropriate level from a developmental perspective, otherwise it can be extremely difficult for the child to fit in. Some children actually do better in special groups”

“Peers may also mean others with similar difficulties. This should not be overlooked or given lesser weight to peers in the sense of those without disabilities”

“Children compromised by disabilities may not have the same ability or opportunity to engage without significant support, therefore it’s not the ‘same’”

“Not all children can manage in the wider world. There is a need for children to feel safe always and for some children and adults this may be in a special setting”

“Not all children are the same and the extent that they wish to partake in social life needs to be respected and it should not be expected that they have to socialise to a standard but rather to the extent they are comfortable and happy”

“‘In the same way as other children’ is misleading - they may need to adapt things to their own abilities. Should the statement not stop at ‘community life’?”

“Deaf Children and hard of hearing children need to live learn and socialise with peers. Are hearing children their peers?”

The above comments not withstanding a number of staff respondents did emphasis the importance of participation in community life and, in particular, in mainstream community activities.

“Important to have opportunity to learn and play and spend time in ordinary places, ordinary times, - not special swimming times etc, when it’s only children with special needs or at least as much of the
time. Children will generally want to be around other children and can 'up' their game”

“Being involved in everyday places and being part of one's community is an integral part of life, and this should happen at as early an age as possible”

“It is a basic right and inclusion should be the norm rather than the exception. We still have a way to go in this country to change attitudes and break down the barriers to inclusion”

5.5.3.2 Supports to participate and barriers
Similar to the observations made by parents, a number of staff highlighted that children and young people with disabilities may require support to engage in mainstream community activities and that while physical barriers exist the biggest obstacle to participation is attitudes of other people.

“As a general statement this is the ideal. Barriers still exist for children with a disability, e.g. intellectual disability, Autism. Access to preschools - dependant on the individual provider, no legislation to ensure child has access to a place. Environment not suitable in many cases for children with sever/profound disability”

“A range of proactive strategies across communities and nationally to promote a positive image of disability and facilitate an inclusive society while combating prejudice and inequality”

“The need for intensive support for some children to be facilitated to attend a local inclusive service needs to be stressed, and for others even if it's only a small level of support”

5.5.3.3 Consideration for other users of community services
One staff respondent suggested that consideration for other users of mainstream community services needed to be considered in relation to the outcome statement.

Consideration must be given to all others using a facility so that it remains a suitable and comfortable place for all

5.6 Outcome statement 6: Families understand their child/young person's needs, what they are able to do well, and what they find difficult as they are growing up.

This means:
• families have easy to understand information about their child’s needs as they are growing up
• families work together with services so that they can understand what their child is able to do well and what they find difficult
• families work together with their child or young person and services to set goals about what the child or young person is able to do, what they are good at, and what they find difficult

5.6.1 Parents comments
100% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 36 additional comments received from parents. As with responses relating to other outcome statements a number of responses by parents highlighted the gap between the outcome statement and their experience of current service provision. This issue is dealt with in more depth in Section 7 below.

5.6.1.1 Recognition of parents’ expertise
Many of the additional comments made by parents emphasised that they the parents were the experts in their child and neither current practice nor the wording of the outcome statement reflect this. For example,

“I don’t like the second statement "Families work together with services so that they can understand what their child is able to do well" etc. ...... I feel that most parents whether their child has a disability or not understand their child”

“The statements make it sound like external services are telling them what their child is good at and capable of. I don’t think I’ve ever been informed my child was good at something I didn’t already know they were good at”

“Badly worded points as it is information gleaned from the family that will determine what works best for the child. Equally services work with families so that they can understand the child not the other way around”

“How do you work together with a service that actively does not understand your child. My child has semantic pragmatic language difficulties. I told his psychiatrist that he nodded in all the right places but did not understand a word she was saying. I was told that I was only his parent and that I should know my place”
5.6.1.2 Families and services working and making decisions in partnership
A point made by some parents, which perhaps overlaps with the point on parent’s expertise above, is that families want to work and make decisions in partnership with services.

“Services need to consider families and work with families and not just dictate to families what they feel is the most appropriate”

“there must absolutely be much more cooperation between service providers and parents”

5.6.1.3 Families need information, guidance to navigate service system
A number of families highlighted that families need guidance, in relation to their child, and, in particular, around how to navigate the wider services system.

“Information and how to navigate the system are essential […]”

“Getting access to in [information] is vital”

“Support and guidance from services is important […]”

“This is so important in particular for children with special needs. We need the outside support to help guide us as parents and help us to cope better so that the child can cope better and thrive”

5.6.2 Children’s and young people’s comments
85% of children and young people indicated that this outcome statement was important or very important. There were three additional comments raised by children and young people. Two of these comments related to the importance of getting a job and the other related to the need to get information and guidance from relevant professionals.

5.6.3 Staff comments
Almost 99% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 51 additional comments made by staff respondents.

5.6.3.1 Involving families as partners
Many staff comments concurred with the points raised by parents in relation to families being seen as experts on their child’s strength and needs. Examples of these comments are:

“The families are the experts around their child’s abilities”
“Families should be the main players in teams …. it is our role to support them in maximising their child’s potential”

A minority of staff expressed the views that families don’t want the responsibility of being a key player in supporting their child’s development.

“I am not sure if families really want this third statement [i.e. families work together in partnership with services]. Many don’t seem to appreciate the amount of work they are expected to do and that therapists are there more for guidance, and some are not able to cope with this, especially if their child has a significant disability”

“Unfortunately some families are unable/ unwilling to work together and some do not seem to be able/ come to terms with their child’s needs”

There was also a lack of consensus among staff respondents regarding whether or not families were realistic in relation to setting goals for their child.

“Families need to have a realistic understanding of what the young person is capable of - some goals set by families may not be realistic or what the young person needs from the professional’s point of view”

An example of a point made in contrast to this view:

“Often professionals underestimate the abilities interests and skills of both the individuals with disabilities and their family constellation”

“[Families are] well able to identify priority areas which need to be listened to”

5.6.3.2 Less focus on deficit / medical approaches

A number of staff respondents suggested that there needs to be a greater move away from the medical model or deficit based model. However, views differed as to whether services or families are responsible for the continuing focus on children’s deficits.

“A concerted effort needs to made by health professionals to move away from the medical model and notion that you bring your child to services to ‘make them better’. Services need to revolve more around education and developing the skills of the parents/family to meet the needs of their child”
“Families work together with services so that they can understand evidence based models which can best support their child's needs. (Many parents understand a deficit based model and I think a lot more work needs to be done to demonstrate and build confidence in appropriate approaches, e.g. empowering parents, whole school approaches rather than 1:1 appointments to work on problems being the preferred option)"

“The absence of medical jargon supports identifying goals from everyday life and being person centred again takes the goal away from the disability or body part and focuses back on what the person wants to be able to achieve/do and how services can support that e.g. need for 10 hours physio[therapy] to mobilise leg is better identified as, "Paul wants to play football with his friends" - this is more inclusive, meaningful to the child/family and draws on all the resources of a talented multi-d [multidisciplinary] team rather than therapy based medical needs only"

A staff respondent suggested that the wording of the draft outcome statement should be changed to focus more on strengths and abilities as opposed to needs.

“Can it begin with "abilities" or "strengths" rather than 'needs'?"

5.6.3.3 Supporting and empowering parents
Staff respondents suggested that there is a need to support and empower parents and that some parents or families will need more help at particular periods in their child’s life.

“It is important to note that there are times and families when basic survival or crises prevent this from being the most relevant goal for the family. It is necessary for a true family centred service to have a way of identifying these families, and assisting the family unit, as an extension of the child, in the most relevant way”

“Parents need support while they are on this journey -from early intervention / diagnosis to and through all the transitions the students needs to make”

“The concept of working with parents in partnership is critical. Resources do not allow for 1:1 intervention for all children. Vital parents' skills are developed so they have capacity to promote their child’s development within their day to day routines.

“Parents and families would benefit from access to counselling services and peer support from other parents”
“Very important that families are facilitated with information and support to achieve this important that parents are given information which is understandable to them, as many parent have social/educational difficulties”

“A range of measures aimed at empowering parents of children with a disability, in their role as carers and as advocates. Greater respect and value to be given to parents in their role as carers and as experts on their own child”

5.6.3.4 Key workers
A point that a number of staff respondents raised which is related to the point above on support for parents was the need for key workers or for existing staff being facilitated to use some of their hours for key working functions to improve service delivery to children / families.

“Key working relationships will be invaluable in this regard, some families need a lot of assistance initially in setting goals but, over time, [they] become more confident and adept in this”

“Support and information needed by families-a key family support worker perhaps?”

“What about outreach worker posts or, as distinct parts of worker roles, to allow this to happen in a cost neutral way?”

5.7 Outcome statement 7: Families look after, take care of, and support their child or young person.
This means:
• parents are confident in their parenting skills
• families make sure they have a safe and caring home for their child or young person to grow up in and learn new things
• families support their child/young person in learning new life skills and how to become more independent

5.7.1 Parents comments
99.5% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 36 additional comments received from parents.
5.7.1.1 Supports for parents / families
The vast majority of additional comments acknowledge the importance on this draft outcome statement but emphasise that parents / families need support. Examples of such comments include the following:

“Parents and siblings of a young person with a disability need a great deal of support and information in rearing a child with a disability”

“Again, families of children with substantial needs need support and respite to be able to do this - I cannot emphasize this enough”

“But families need support from schools and the Government to assist in the relevant need of each individual child depending on the child’s ability or disability”

“Families will need support to achieve this as they are often isolated and overwhelmed with the day to day task of living-again this needs to be resourced but should help to ward off crises”

“Obviously parents do their best but are being seriously hindered by the lack of support available to them in many ways”

“I want to care for my son for the rest of my life or as long as I am able, I do not expect anyone else to do it for me. I want him to be able to live independently but I need the skills and support of the therapeutic services team to ensure that the work I put in to helping him achieve his full potential is correct”

Variations on the above themes that run consistently throughout the comments on this draft outcome statement are that:

• there are significant financial costs to families of caring for a child with a disability
• that parents and other siblings can become cut off from participating in the community if they are not supported to care for their child
• it is important to facilitate family-to-family support structures
• some parents of children with disabilities need access to parenting classes
• parents of teenagers with disabilities who engaged in anti-social behaviour need specific parenting skills

Examples of these comments include:
“Families need support to carry out this function both emotional and financially”

“People with special needs often require more caring; safety support; health & social support and other support to meet needs than others do. This causes other family activities to stop and mean that opportunities for community living of both the special needs person and their family are reduced and sometimes entirely curtailed”

“Facilitating family to family (where both have children with disabilities) is very important. You get most inspiration, hope and practical information from other families who have 'walked in your shoes'. Therapists should be open to the fact that parents have a wealth of knowledge and experience”

“One word (well 2 really) parenting classes. The only ones available are in the Dublin area and I am a single mom in limerick so not an option really”

“It can be sometimes very difficult for parents to seek appropriate supports for troublesome teens. If this is not addressed, it can lead to a life of crime in extreme cases. A different set of parenting skills is called for [in these circumstances]”

There were two additional comments on the wording of the draft outcome statement. The first related to the use of the “parent” and suggested that it be changed to “parent or guardian”. The second point suggested that parents, in general, are probably not “confident in their parenting skills” and therefore that the wording of the outcome statement should perhaps focus on the parents making progress in their parenting skills.

5.7.2 Children’s and young people’s comments
82% of children and young people indicated that this outcome statement was important or very important. There were three additional comments raised by children and young people. Two of these comments related to the importance of support from families and the other stressed the importance of families being supported.

“Important how my mom can help me in years to come”

“Every first lesson is learned in the home”

“Parents need help too”
5.7.3 Staff comments
Almost 98% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 47 additional comments made by staff respondents.

5.7.3.1 Supports for parents / families
Similarly to the comments made parents and children / young people, many of the comments by staff respondents relate to the fact while the principle of the outcome statement is welcome families need support to deliver on this outcome. To quote some of these comments:

“The capacity of the whole family should be built, rather than the professionals being the only 'experts' instead family confidence and skills should be prioritised”

“I think you could have a 4th statement here about families being supported to do all of the above”

“.......with sufficient supports to enable them to do this”

“Wording isn't the best – [it should read] Families are provided with support, skills and information so they can support their children”

“Some families need support to develop the ability, confidence and skill to ensure this outcome is achieved for their child”

“Parents can only achieve this with consistent backup support”

Variations on the above themes, which run consistently throughout the comments on this draft outcome statement, are that:

- some families are better equipped to deliver on this outcome than others
- some families are so burdened that delivering on this outcome is a very significant challenge
- capacity building, group work and parent-to-parent support is required
- other agencies will need to cooperate with disability services and families to deliver this outcome
- in some cases the parents will have disabilities themselves

Examples of these comments include:

“In our experience parents are not as confident as they would like to be themselves in all areas of parenting. Parents become over
burdened, stressed, and burnt out, due to ongoing care and management of their child in their home”

“Parents should also be treated as individuals and their abilities, aptitudes and circumstances may be such that they are not well suited to supporting their children”

“In many cases this is an aspiration. Where a family are under severe stress (sleep deprivation, high medical needs of child, parental psychiatric issues etc) it is often difficult for them to focus on supporting their child to learn new skills”

“Capacity building for parents is very important. The new FSA [Family Support Agency] will have to forge strong links with disability services to work together on these issues”

“Group work with parents is a very cost effective, [so too can] peer based support when facilitated by social work”

“What training is available to staff in this area and are teams working with local agencies and schools who provide parent training etc”

“Also need to provide systems of supports for parents who have disability themselves”

5.8 Outcome statement 8: Families try to make sure that their rights and the rights of their child or young person are respected.

This means:

- families know how to get the information and supports that they need.
- families know their own rights and the rights of their child
- families know about the different kinds of services and supports available and how to access those services and supports of their choosing
- parents are able to tell staff in services what their child’s needs are and give their ideas on how to make the service better
- families know how to tell if a service is good or bad
- families are comfortable telling staff if they have a problem with the service and also what worked/is working well
5.8.1 Parents comments

100% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 41 additional comments received from parents.

A number of themes in the comments made by parents in relation to this outcome statement are discussed in Section 7 as they were comments which were also made in relation to a number of other outcome statements and address more general issues of service delivery. These comments relate to:

- consistency of services
- access to services
- resources for children and young people’s disability services

5.8.1.1 Complaints, feedback, quality improvement systems

A number of parent respondents identified fear of consequences for their child or their allocation of services if they were to challenge service providers.

“Families are often fearful to challenge or demand certain things for fear of a service being cut or withdrawn”

“It’s very difficult to address an issue where you may be concerned that the young person may be victimised as a result”

“I think parents find it hard to complain about services and there is an overriding sense that you should be grateful for what you are getting”

“Parents are fearful to give feedback, we need to create a culture of trust and openness”

“I have had very poor reaction from service providers, overall, when I have attempted to address unsatisfactory issues”

“Huge issues here with parents being apprehensive to criticize service provider standards for fear their child will suffer. Think this is mostly misplaced, but exists nevertheless. Think this is partly cultural and because historically, disability services provided by charities and religious orders with huge power”

5.8.1.2 Access to information

Quite a number of parents highlighted that it is hard to access information on available services for their children. The following are sample of parents’ responses in relation to access to information:
“Families are not given relevant information as a matter of course - you find out what you need to know either from other parents or often by accident”

“Would be helpful if there was a standard booklet with the above information given to each family”

“Again, it is very important to be aware of supports and how to access information as in my experience we have not always been informed of entitlements, best approach etc, for our situation by the services”

“Again very hard to get info outside of Dublin”

5.8.2 Children’s and young people’s comments
80% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people. The first related to the importance of rights for young people with disabilities and the second related to staff understanding young people’s needs.

“We all have rights and we need our rights so that we can be happy with life”

“It’s been my experience that not all staff are understanding of issues that arise not all are text book cases”

5.8.3 Staff comments
Almost 99% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 47 additional comments made by staff respondents.

5.8.3.1 Complaints, feedback, quality improvement systems
Like the parent respondent a number of staff highlighted the issue of difficulties around families providing services with feedback. However, while one staff respondent noted a culture of reprisals against complainants other staff respondents highlighted a number of other factors which create a difficulty in parents engaging with service providers in relation to service quality, such as:

- lack of resources / funding for services
- lack of legal underpinning for service provision
- structure / organisation of disability teams
- capacity of some parents to engage / advocate
“Many families may be afraid to express dissatisfaction with services for fear of repercussions/losing the service”

“[It is] very difficult for parents to tell a service if they are unhappy if it is the only service they can access - parents don’t have a choice of service - staff have a choice to work elsewhere - big power difference”

“Families may not be able to raise an issue with direct support staff who they see regularly - others staff/team leader needs to be accessible as a point of contact. Service co-ordination is extremely important in this. Often there is no Team Co-ordinator”

“This is often dependent on the family’s perspective - what they feel is a bad service may just be the service being realistic about what the young person can achieve or what can be provided within restricted resources”

“Families and children do not feel respected if they are on long waiting lists for supports”

“Families need to understand that where there are rights there may not be services to support these rights”

“The current Disability legislation does not really support this as assessment of need is the only definite”

“Some parents/families may not have the skills themselves”

Staff respondents suggested some mechanisms for dealing with the challenge of dealing with service-parent dialogue on service provision in the context of constrained resources.

“Parents should be part of governance structures of all services. Where feasible the voice of the child should be included in Governance policy etc.”

“In cases where there is a conflict between families and services, an independent binding third party should be brought in with a final say”

“Need for more parent participation/consultations within organisations”
“Parents also need to be educated in order to understand and accept different types of interventions/support that might be (more) helpful than those they have learnt to expect”

5.9 Outcome statement 9: Families take part in community services and supports.

This means:

- families understand why it is best to have their child or young person included in the home, at school and in their community
- families use good childcare and services that will look after their child or young person for a while as they choose
- families use community services and facilities that other families are using
- families use community health services that they need
- families take part in community activities such as church, school and play as they choose
- families take part in parent support groups as they choose

5.9.1 Parents comments

Over 97% of parents indicated that this outcome was important or very important to them. Set out below are the main themes identified in 28 additional comments received from parents.

Some of the themes that emerged from parent respondents to this outcome statement are dealt with in Section 7. These themes include:

- isolation of people with disabilities and their families
- capacity and willingness of community services to include people with disabilities
- attitudes towards people with disabilities

5.9.1.1 Choice of specialised services

A number of parent respondents indicated that they didn’t see using community services as an alternative service model but rather that parents should be able to choose between community and specialist services depending on their needs. For example:

“A right to access community facilities, does not obviate the need for specialist facilities and services, possibly separate, (by times of access or location) which can meet the needs of children who cannot cope with the demands or limitations of community facilities”
“While also recognising the need for specialist services for some and at various stages”

“Depends on needs and ability of the child e.g. my child unable for mainstream school and needs a special school environment. I am concerned that push to mainstream does not recognise diversity of needs that children with disability experience”

5.9.1.2 Support to access community services
A point similar to points raised previously under other outcome statements is that some children and young people with disabilities require support to access mainstream / community services.

[...] community services can’t operate if they themselves are not provided with the help they need to include the disabled person [...] 

“We take part in community services - supports are horrific and getting worse”

5.9.2 Children’s and young people’s comments
82% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people, which expressed a positive experience of inclusion in community activities. For example:

“It’s been my experience that children with special needs are very much included in community and people are more accepting and understanding, that is, clubs are facilitating”

5.9.3 Staff comments
Almost 96% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 39 additional comments made by staff respondents. A number of staff expressed support for this outcome statement. Staff comments on this outcome statement addressed similar themes to those made by parents. Staff respondents highlighted public attitudes and the accessibility of mainstream / community services to children and young people with disabilities. These points are discussed in Section 7.

5.9.3.1 Support to access community services
Staff highlighted the need for supports to be in place for (some) children and young people with disabilities to access community activities.

“Parents of children with a disability may require extra supports in this”
“A family’s ability to use community services that other families are using is dependent on the availability of appropriate supports being place”

“It’s very difficult to promote community inclusion when we don’t have the adequate resources to support families”

Other staff respondents noted the particular difficulties for deaf children and children with autism in accessing mainstream community activities.

5.9.3.2 Choice of specialised services
As with some parents’ respondents, some staff highlighted that accessing mainstream / community services should be a choice for parents but not the only option. Examples of comments which addressed this view include the following:

“Obviously - as the family chooses all of above. They are not all generic outcomes for families”

“If it is in the best interests of the individual”

“Families sometimes understand that their child requires specialist services/educational placement - however, professionals sometimes overlook this in favour of ‘inclusion’”

5.10 Outcome statement 10: Families feel supported by family, friends, and neighbours in their local community.

This means:

• families have contact with all their family members as and when they choose.
• families have friends and neighbours who can provide practical support as well as using paid support if they need it
• families feel supported and secure and know that their family and friends can continue to support them if they need it.
• families meet and get to know other families with children of all ages

5.10.1 Parents comments
Almost 94% of parents indicted that this outcome was important or very important to them. Set out below are the main themes identified in 28 additional comments received from parents.

5.11.1 Difficulties accessing natural supports
Many parents expressed the view that support from family, friends and neighbours is important but for a variety of reasons this can be very difficult to
The reasons identified by parents as limiting opportunities to avail of supports from families, friends and neighbours include:

- lack of understanding of disability
- isolation of family as a result of caring duties
- distance from friends and families

Examples of these views include the following:

“Family support is not always available although desired”

“Family generally don’t understand a disability unless they can see it”

“It’s a lot to ask people to mind your child unless they are willing to accept all that goes with that”

“But for many people, these opportunities are diminished long ago from all the time they spend in the home with the person with a disability. The entire family has less social support than the average family”

“That all sounds great but in the real world where family members do not live locally, this can be very difficult. It is very difficult to get the same support from neighbours”

“Families need to be supported but family and friends with no experience with the issues at hand are not always the ones to be very helpful”

“Families are often "abandoned" by family and community because they do not understand the child’s disability and needs or misinterpret the child’s disability as "bad parenting"! Some are genuinely scared off because they don’t understand the child's disability and many are unable to physically help out”

5.10.2 Children's and young people’s comments

Almost 94% of children and young people indicated that this outcome statement was important or very important. There were two additional comments raised by children and young people, which noted the importance of family / community supports but also that in reality such support may not be available.

“We all need friends and help sometimes from neighbours and other families”
“Families and neighbours do not help. We are left to ourselves. The above would be living in an ideal world”

5.10.3 Staff comments
Over 94% of staff indicated that this outcome was important or very important. Set out below are the main themes identified in the 35 additional comments made by staff respondents.

5.10.3.1 Difficulties accessing natural supports
Like the parent respondents, staff respondents emphasised the importance of support from families, friends and neighbours and also pointed that for many families of children and young people with disabilities find gaining such support a challenge. Many staff noted that wider changes in the economy and society made accessing such supports more difficult than had been the case previously. Staff had some suggestions for generating links between families but some also felt that building families’ social networks was beyond the responsibility of disability service providers.

Examples of processes which providers could use are as follows:

“Supports for extended family and other informal supports to learn about supporting child, e.g. include in training or therapy sessions, if parents want this. Often they are excluded”

“If services could support peer mentoring of parents by parents this would be an invaluable support”

“Need to also recognise the supportive role of meeting other parents of children with special needs”

“The group process can be very supportive to parents/carers of all children right throughout the different phases of a child's life”

Examples of the changed context identified by staff respondents include:

“With modern times, families are more nuclear and may experience a lack of support. Also many people do not know people in their community and may not be able to seek or avail of support”

“The sense of family involvement /friends /neighbours has changed dramatically. Economic climate has impacted. Many families living away from family members”

Staff identified some family units for whom availing of such support is particularly difficult:
“This can be an area of need for single mothers and/or people who come to live in Ireland from abroad”

“With families from different cultures / English not being their first language this can be hard to ensure”

A number of staff respondents noted that developing social support networks was beyond the scope of what Health Service Executive funded disability services could deliver.

“Friends and neighbours may be busy with their own lives! We cannot insist on this aspiration”

“This is not something the HSE can enforce....”
6 Outcomes not covered in 10 draft outcome standards

In addition to asking for comments on the ten draft outcome statements, respondents were asked if there were outcomes which were not included but should have been. 68 parent respondents and 81 staff respondent made observations in answer to this question. However, 3 of the parents and 12 of the staff responses indicated only that they did not have any suggested additional outcome statements.

The majority of comments ostensibly about the need for additional outcome statements were in fact further comments on the need for improved service inputs. It would not add to this report to set out those comments in detail but in summary they related to:

- Staffing of early intervention / children’s teams (specifically, filling vacated posts and including dieticians and social workers on teams)
- Need for increased resources
- Better access to information on services for families

6.1.1 Additional outcomes statements mentioned by parent respondents

Themes identified in the comments by parents on the need for additional outcome statements, which were directly relevant to outcomes are summarised below.

6.1.1.1 Supports for families to cope

It was suggested by one parent respondent that supports to ensure that carers are adequately supported to ensure that they have some stress free time, thus enabling them to better support their child with a disability, is not covered by any of the 10 draft outcome statements.

“Families that are seen to be struggling need respite care on a very regular basis. The entire family suffers and respite offers the family a chance for some stress free quality time with the other children who have to often cope with so much at home. It is also important to give caregivers a chance to relax and have a break”

6.1.1.2 Profoundly disabled children

One parent suggested that the draft outcome statement appear not to have been written with profoundly disabled children in mind and that perhaps this need to be considered.
“I feel that the outcomes (all appropriate) fail to address the social/support needs of profoundly disabled children and their families. Many of the outcomes seem, to me, to relate very well to children with a variety of disabilities including only the mild/moderate range of intellectual disability”

6.1.1.3 Evidence based services
A number of parents suggested that there should be outcome statement which conveys that service delivery will be in line with best practice, evidence base or research base.

“[Parents should have] rights to advocate for their child’s right to evidence based interventions”

“In 2010 the centre of disease control in the US funded a publication of a new standard of care for children with Duchenne, The Diagnosis and Management of Duchenne Muscular Dystrophy. Surely if services are to keep up with ongoing research this publication should be immediately adopted in all Irish centres of excellence”

6.1.1.4 Continuity of provision
One parent suggested that services seeking to ensure more continuity of personnel in service delivery should be an outcome standard or an element of an outcome standard.

“Continued intervention with familiar MDT [Multi-Disciplinary Team] members”

6.1.1.5 Coordination
Some parents suggested that coordination with other services, particularly education services, should be more explicitly included in an outcome statement

“That our children can fully participate in school, and that divisions of responsibilities between the health service and the education providers are invisible to our children and families, and do not restrict support”

“Each child needs to be supported properly in school, this is where they spend the majority of their day for 8 years of primary and thereafter, where they'll meet the local children and where the skills they need to learn can be learned seamlessly. To achieve this, the other services the child is accessing should be delivered in the school setting e.g. speech and language so that parents, educators and service providers are all interacting in the best interests of the
child. This is in accordance with best practice as determined by research”

6.1.1.6 Choices
Some parents noted that the draft outcome statements don’t make explicit references to supporting children and young people to make choices for themselves. Comments, for example, included the following:

“Could we also see Rebel Advocates for teenagers? Our teenagers don’t know the choices available to them. How many people with ID have piercings, tattoos, mohicans, etc. Just a thought […]”

“Freedom to make choices. Many people will need support to know how to make a choice”

6.1.1.7 Planning for post-school aged services
A number of parents mentioned post-school aged or after care services such as:

“Employment services / work experience”

“Vocational / after school training / services”

To large extent these services are located in adult services as services are currently configured. Perhaps the point being made is that families need information on pathways to available adult services for their teenage children.

6.1.1.8 Clarity from services on allocation rationale
One parent suggested that in addition to information on available services, families needed information on or a rationale for how resources within services are deployed.

“Families need clearer information as to how services work and are allocated. Currently it seems that those who shout loudest get the most resources. It also seems that those who can cope to a certain extent get very limited support regardless of their needs”

6.1.1.9 Sports / physical activity
Some parents noted that sports and physical activities are not explicitly mentioned in the draft outcome statements. Outcome statement 9 mentions inclusion in “community activities” so perhaps sports and physical activities are implicitly included in this outcome statement.

“We would like after school sports/activities as a social outlet for our son”
6.1.2 Additional outcomes statements mentioned by staff respondents
Themes identified in the comments by staff respondents on the need for additional outcome statements, which were directly relevant to outcomes are summarised below.

6.1.2.1 Coordination
One staff respondent cited families and children and young people experiencing coordinated rather than disjointed services as a possible outcome statement

“Services are delivered in a coordinated and coherent manner […]”

“[…] there needs to be a focus on services working together in the interest of children and families”

6.1.2.2 Timeliness
A staff respondent mentioned timeliness of interventions as a possible outcome statement.

“Children have timely access to services required”

6.1.2.3 Training
A number of staff suggested that families and children and young people being supported by professionals with an appropriate training as a possible outcome.

“Staff training and development”

“Teachers receive appropriate training with respect to teaching children with disabilities”

“Training of staff involved with disability”

“We currently do a lot of work to support the children in education. Providing programmes and support to teachers to enrich the child’s experience of the education system and help them access the curriculum. This should be captured somehow”

6.1.2.4 Clinical / functional outcomes
Some staff suggested that functional and / or clinical outcomes needed to be included in the draft outcome statements. For example:

“Functional Outcomes (e.g. related to participation in daily life such as - physical participation)”

“Feel there is a lack of clinical goals reflected in the above - perhaps these could be related to areas such as communication, mobility, ADLs [Activity of Daily Living], etc.”
6.1.2.5 Transitions
Staff respondents suggested that successful transitions in and out of services should perhaps be reflected in one of the outcome statements.

“Transition / access to services is a difficult time for children and families and this needs to be looked at”

“Children and young people go through a huge amount of transitions in their lives. They and their families often need extra support during these times. I wonder if this extra need for support during times of transitions should be acknowledged somewhere in the outcomes as it impacts on both clients and service providers”
7 Other relevant issues raised in relation to draft outcome statements

Included in comments under each of the ten draft outcome statements were themes which were more suitable to discussion in a general way. Themes have been included in the section because they:

- Address children and young people’s disability services more generally - as opposed to addressing an issue which is specific to a discussion on outcome statements
- Raise a general query about the outcome statements overall rather than relating one specific outcome statement
- Address an important, substantial point more indirectly than directly related to any one draft outcome statement

7.1 Gap between outcome statements and current service delivery

A theme running through both staff and parents comments was that the outcome statements were an ideal which was quite unrelated to the reality of current service delivery. This suggests, perhaps, that there is considerable work to be done in explaining the nature and purpose of outcome statements.

Staff for example commented that:

“Aspirational statement - reality very different”

“It difficult enough managing with the realisation that you have a child with a disability than having to also deal with the gap between these sort of high-minded aspirations for a service and the reality on the ground”

7.2 Measurement of outcome statements

Under a number of outcome statements respondents raised queries about how the outcome statements would relate to measurable outcome indicators. Comments along the lines of “how will this be measured?” were made by staff respondents under each of the ten outcome statements.

7.3 Resources

A theme cutting across comments from both parents and staff respondents was that the outcome statements and the vision of the overall Progressing Disability Services for Children and Young People programme were undermined by lack of resources.
Parents for example commented:

“Having read the 2009 report I believe that the theory is good but it will only work if there is a huge increase in the resources and funding for children with a disability”

“Yes, this will require resources so please don’t propose it as an outcome unless you are willing to resource it”

A comment, which was typical of several others made by a staff respondent was:

“We should and do strive to assist children/young people and their families to attain these outcomes however increasing caseload numbers and reduced resources makes this increasingly difficult”

7.4 Supports in mainstream education inadequate

A theme running through comments by staff and parents under a number of outcome statements was the inadequacy of supports for children in mainstream education. The lack of emphasis within the school on developing children’s independence was also noted.

“Each child needs to be supported properly in school, this is where they spend the majority of their day for 8 years of primary and thereafter, where they'll meet the local children and where the skills they need to learn can be learned seamlessly”

“Need the ESPEN Act implemented. All this is mainstream education is totally aspirational and will not happen unless underpinned by legislation”

“Supports are not enough right now, so children do not get to participate fully in mainstream education”

“Schools also need to be supported in helping the child become more independent”

7.5 Access to services

The theme of access to information was highlighted by parents and some staff respondents. Respondents also highlighted that services are disjointed, that the level service provision is not always well matched to level of need and that there is no clear pathway through disability services.

Example of parents’ comment include the following:

“All families should be given equal access to the services”
“Accessing services / supports can be constrained by reduced capacity”

“Families need clearer information as to how services work and are allocated. Currently it seems that those who shout loudest get the most resources. It also seems that those who can cope to a certain extent get very limited support regardless of their needs”

“There is no clear path to services if you do not come under one of the registered charities”

A staff respondent made the following comment:

“Services are piecemeal, uncoordinated and not transparent”

7.6 Access to information

Comments under the theme of access to information were discussed under outcome statement 8 as some comments were made which directly related to that outcome statement. However, both staff and parent respondents highlighted that information on services for children and young people with disabilities is not easy to access in their comments on related to other outcome statements.

Examples of parents’ comments include the following:

“Information is not easily accessible. In the main if organisations or service providers are budget holders, families are seldom given complete or informative information”

“A parent is rarely told their rights or the child’s or any information or supports available. This should always be independently supplied […]”

“Families need to be well informed on the rights and services available to them and their child. A family may have the best needs of their child at heart but without the correct information they may not be able to help their child as best as they can”

“[There is a] lack of information and lack of central listings of service providers”

Staff respondents made the following comments:

“Many families do not know where to access information...especially those who themselves have literacy/disability/mental health issues themselves”
“Information is the key to parents. The services need to co-ordinate their approaches to give a holistic service. The professionals need to take off their white coats and listen to parents and be where the parents are at”

7.7 Variable quality of services
Some parents commented that service quality of services varied from provider to provider and parents were ill equipped to assess this as they were typically referred to one provider for all their specialist services. This view is most comprehensively set out in the following comment:

“Parents also have no idea how good or bad the service is, because service is so inconsistent between service providers and there seems to be no national standards. For most parents coming into a service provider initially it’s their first experience of disability services, so they have no idea what to expect. As children are referred to a single service provider who provides all the clinical services, parents would little to no choice about the services they do or do not get, apart from to choose not to attend. No quality standards measurement in place in service providers. They do not measure the outcomes of their services. So no one has any idea how good or bad the service is. It’s a total adhoc-racy”

7.8 Choice
Supporting and encouraging children and young people to make choices was mentioned by some parents something which should be included as an outcome. A view, although very much a minority view, was expressed by some parents, that they as parents should be able to choose between services providers. An example of this is the following comment:

It would be great if the services money was paid to the parent and they could get their own Speech, OT [Occupational Therapy] and Physio[therapy] - as that way they can pick and choose whom they want to work with

7.9 Public attitudes toward children and young people with disabilities
A theme which the comments of many parents and staff touched on was the issue of public attitudes to people with disability. This theme is mentioned in relation to comments on outcome statement 5 but comments on the impact of negative attitudes in the community towards people with disabilities were raised in relation to many of the outcome statements.
“Before this can happen satisfactorily the general population would need to be educated about disability- there is a lot of prejudice out there just beneath the surface and it can come out in all sorts of ways. Bullying of the families of persons with disabilities can go unrecognised- the law apparently only protects the person with the disability and siblings and parents can find themselves being systematically isolated an/or actively intimidated in their own neighbourhood”

“Son was bullied so much going to local youth club and GAA that he eventually would not go!! Both youth services and GAA have a lot to answer for”

“We need to raise awareness and provide training for the community in a deliberate and planned way. There is a lot of fear and stigma in our culture. We need to support children and families to be active members of their community”

An example of staff comment is the following:

“All sounds lovely in theory but disjointed in practise, stigma still attached to disabilities in communities”

7.10 Community service ill-equipped / supports to participate

A theme which ran through parent and staff comments in relation to a number of those outcome statements which emphasised participation in the community was that there is work needed to make community services and activities accessible and accepting of children and young people with disabilities.

For example the comments below are typical of comments made by a number of parents.

“In order to do this the physical structures have to be in existence for the disabled person, and in some cases how about designing for the disabled person first!”

“Community also needs to be encouraged, educated and supported that this is a right that children with disabilities should have, not the ‘icing on the cake’”

“This will require resources so please don’t propose it as an outcome unless you are willing to resource it. That does not necessarily mean expert intervention but using and educating existing resources within communities but it will take time and commitment and need monitoring”
Staff similarly highlighted the need to educate and upskill the community to ensure that community services and activities can include all children:

“This is so important but the community may need to be aware of how they communicate with the child/young person, this may require a plan to raise awareness and educate the community”

“All buildings to be made accessible and training to be offered to the Leaders of Community activities in order to promote full participation of children with disabilities”

“The important aspect is that the community / society should also be educated to receive and accommodate and respond appropriately to students with disabilities. Disability awareness / raising awareness should be a key aspect of our work!!”
8 Consistency of draft outcome statements with current service delivery

Staff respondents were asked whether or not the ten draft outcome statements were consistent with the current work of their team. Table 8 below set out the responses of staff members.

Table 8 – Consistency of outcome statements with work teams are current doing

<table>
<thead>
<tr>
<th></th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistent</td>
<td>125</td>
<td>45.6</td>
</tr>
<tr>
<td>Not consistent</td>
<td>15</td>
<td>5.5</td>
</tr>
<tr>
<td>Partially consistent</td>
<td>133</td>
<td>48.5</td>
</tr>
<tr>
<td>Not consistent at all</td>
<td>1</td>
<td>0.4</td>
</tr>
</tbody>
</table>

\[ n = 274 \]

Staff respondents were also asked for additional comments in relation to the consistency of their team's current practice and the draft outcome statements. 79 respondents provide additional comments. Of those 79 staff respondents who answered this question and expressed a viewed directly related to the consistency of the outcome statements with their team’s practice, the vast majority stated that the draft outcome statements did reflect ideal outcomes but one which their service struggle / would struggle to deliver. Reasons cited for teams not having the capacity to deliver these outcomes were:

- Lack of resources
- Lack of staff numbers
- Uncoordinated teams

Typical comments included the following:

“The above statements of outcomes are extremely important however at present they are not consistently measured in a methodical way. At present, we do not have a measurement tool available to complete this- in addition due to pressures on the service, the organisation of same has not been possible”

---

3 Many respondents to this question simply responded that they were not members of teams or that due to the nature of their profession not all the outcomes were relevant to their work.
"Yes these outcomes reflect the ethos of the Early Intervention Teams I am working on. However staff shortages and administration difficulties render some of these important points, as simply ideals on paper. This undermines greatly work of team members on the ground and the quality of services available for family"

"The ethos of all the above statements are consistent with how we want to work as teams. However, we are not able to support the service users and their families to achieve these outcomes due to resource issues. Some of these statements were supported more in the past but with the ongoing cuts to budgets, the services considered less essential but no less important, have had to be cut"

"While all of the above may be desirable or proclaimed as intended outcomes for service provision from our service, it usually depends on the abilities, motivation and engagement of individual staff and service users whether or not the outcomes are pursued or achieved"

"Our service strives to meet these outcomes but it is not always possible because of the large number of children and families we support. This number is increasing month on month but there has not been a corresponding increase in clinicians working in the service"

"I started filling out the above and feel it’s a bit like asking me if I believe in ‘World Peace and an end to hunger’. Let’s be real folks, aspirational and delusional planning helps no-one. With cuts in staffing, mileage and funding for equipment, more and more pressure is being placed on staff who are providing skeleton services. It would be better to look at what we all can provide and then work up from there. Without a link to resources the above is not very useful"

"These outcomes are very aspirational - it would be lovely if we could say services were meeting all of these needs"

"We work hard on all of the above but we fall short of what is actually required due to lack of appropriate supports and resources"
“These are aspirations we would all like to achieve. Due to resource issues families are no longer receiving consistent support and a lot of the support provided is crises driven”

“Depending on staffing levels and multidisciplinary coordination hopefully yes but not all the time unfortunately”

“While we are not necessarily reaching all of these outcomes with complete success at the moment, they are certainly outcomes targeted by the team, in a conscious way, and reviewed regularly, in order to continue to improve the service we provide”
9 Processes of gathering and reporting on data on outcomes currently in operation

Staff respondents were asked whether or not their team currently had processes in place to gather and report on outcomes for the children and young people and families using their services. Table 9 below presents the responses to this question.

**Table 9 – Teams with processes in place to gather and report data on outcomes**

<table>
<thead>
<tr>
<th>Processes in place</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processes in place</td>
<td>119</td>
<td>46</td>
</tr>
<tr>
<td>No processes in place</td>
<td>139</td>
<td>54</td>
</tr>
</tbody>
</table>

n = 258

Respondents were asked to name “some measurement tools”. 105 respondents provide additional information but as can be seen in Table 10 below responses elicited information on processes deployed to gather data on outcomes rather than information on specific outcomes measurement tools per se.

**Table 10 – Outcomes measurement process currently in operation**

<table>
<thead>
<tr>
<th>Outcome measurement process</th>
<th>Nos.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No system</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Informal system*</td>
<td>54</td>
<td>52</td>
</tr>
<tr>
<td>Formal outcomes measurement tool**</td>
<td>44</td>
<td>43</td>
</tr>
</tbody>
</table>

n = 103 (105 less 2 “N/A” Responses)

* “Informal system” denotes a variety of responses which described systems, such as, “focus groups”, “family meetings”, “needs and satisfaction questionnaires for parents”, “parent evaluation forms”, etc, etc.

** “Formal outcomes measurement tool” denotes a variety of responses which inter alia made reference a standardised tool. It is beyond the scope of this study to verify if the tools mentioned are appropriate for measuring some or all of the outcomes linked to the ten draft outcome statements.

Of the 44 respondents who cited a formal tool in responses to whether their team had processes for gathering and reporting outcomes data 29 mentioned Personal Outcome Measures (Council on Quality and Leadership). Other tools which were mentioned were:

- HELP - Hawaii Early Learning Profile - VORT Corporation
- Goal Attainment Scaling (GAS)
- Canadian Occupational Performance Measure (COPM) - Law, M., Baptiste, S., Carswell, A., McColl, M.A., Polatajko, H., and Pollock, N.
• Measure of Processes of Care (MPOC) - CanChild
• Therapy Outcome Measures (TOM) - Enderby P, John A, Petherham B.
• WHO DAS II [“positive goal setting achievements”]
• European Foundation of Quality Management (EFQM)
• The Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) - King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N
Appendix 1

Tables 11, 12 and 13 below contain some more detail than was included in the summary table (Table 7) on page 14.
<table>
<thead>
<tr>
<th>Outcome statement</th>
<th>Not very important</th>
<th>Somewhat important</th>
<th>Don’t Know</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity.</td>
<td>1.4</td>
<td>1.8</td>
<td>0.7</td>
<td>22.3</td>
<td>73.7</td>
</tr>
<tr>
<td>Children and young people are safe and enjoy the best possible health.</td>
<td>1.1</td>
<td>0.4</td>
<td>0.7</td>
<td>2.5</td>
<td>95.4</td>
</tr>
<tr>
<td>Children and young people have friends and get on well with other people in their lives.</td>
<td>0.7</td>
<td>0.4</td>
<td>1.8</td>
<td>16.8</td>
<td>80.3</td>
</tr>
<tr>
<td>Children and young people learn skills that help them to be independent.</td>
<td>0.7</td>
<td>0.4</td>
<td>0.7</td>
<td>9.3</td>
<td>88.9</td>
</tr>
<tr>
<td>Children and young people take part in home life, school life and community life in the same way as other children.</td>
<td>0.7</td>
<td>0.7</td>
<td>1.8</td>
<td>17.6</td>
<td>79.2</td>
</tr>
<tr>
<td>Families understand their child/young person’s needs, what they are able to do well, and what they find difficult, as they are growing up.</td>
<td>0.7</td>
<td>0</td>
<td>0.7</td>
<td>12.5</td>
<td>86.1</td>
</tr>
<tr>
<td>Families look after, take care of, and support their child or young person.</td>
<td>0.4</td>
<td>1.1</td>
<td>0.7</td>
<td>11.1</td>
<td>86.7</td>
</tr>
<tr>
<td>Families try to make sure that their rights and the rights of their child/young person are respected.</td>
<td>0.7</td>
<td>0</td>
<td>0.4</td>
<td>16.1</td>
<td>82.8</td>
</tr>
<tr>
<td>Families take part in community services and supports.</td>
<td>1.1</td>
<td>1.4</td>
<td>1.8</td>
<td>25.2</td>
<td>70.5</td>
</tr>
<tr>
<td>Families feel supported by family, friends, and neighbours in their local community.</td>
<td>0.7</td>
<td>3.6</td>
<td>1.4</td>
<td>27.3</td>
<td>66.9</td>
</tr>
<tr>
<td>Outcome statement</td>
<td>Not very important</td>
<td>Somewhat important</td>
<td>Don’t Know</td>
<td>Important</td>
<td>Very Important</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>------------</td>
<td>-----------</td>
<td>----------------</td>
</tr>
<tr>
<td>Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>22.7</td>
<td>74.2</td>
</tr>
<tr>
<td>Children and young people are safe and enjoy the best possible health</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Children and young people have friends and get on well with other people in their lives</td>
<td>0</td>
<td>1.0</td>
<td>1.5</td>
<td>10.7</td>
<td>86.8</td>
</tr>
<tr>
<td>Children and young people learn skills that help them to be independent</td>
<td>0</td>
<td>0.5</td>
<td>0.5</td>
<td>4.6</td>
<td>94.4</td>
</tr>
<tr>
<td>Children and young people take part in home life, school life and community life in the same way as other children</td>
<td>0</td>
<td>1.5</td>
<td>2.0</td>
<td>9.2</td>
<td>87.2</td>
</tr>
<tr>
<td>Families understand their child/young person’s needs, what they are able to do well, and what they find difficult, as they are growing up</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7.1</td>
<td>92.9</td>
</tr>
<tr>
<td>Families look after, take care of, and support their child or young person</td>
<td>0</td>
<td>0</td>
<td>0.5</td>
<td>6.6</td>
<td>92.9</td>
</tr>
<tr>
<td>Families try to make sure that their rights and the rights of their child/young person are respected</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5.1</td>
<td>94.9</td>
</tr>
<tr>
<td>Families take part in community services and supports</td>
<td>0.5</td>
<td>1.5</td>
<td>0.5</td>
<td>23.6</td>
<td>73.8</td>
</tr>
<tr>
<td>Families feel supported by family, friends, and neighbours in their local community</td>
<td>0</td>
<td>3.1</td>
<td>3.1</td>
<td>24.1</td>
<td>69.7</td>
</tr>
<tr>
<td>Outcome statement</td>
<td>Not very important</td>
<td>Somewhat important</td>
<td>Don’t Know</td>
<td>Important</td>
<td>Very Important</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>--------------------</td>
<td>------------</td>
<td>-----------</td>
<td>----------------</td>
</tr>
<tr>
<td>Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity</td>
<td>0</td>
<td>5.6</td>
<td>5.6</td>
<td>5.6</td>
<td>83.3</td>
</tr>
<tr>
<td>Children and young people are safe and enjoy the best possible health</td>
<td>0</td>
<td>0</td>
<td>5.9</td>
<td>17.6</td>
<td>76.5</td>
</tr>
<tr>
<td>Children and young people have friends and get on well with other people in their lives</td>
<td>0</td>
<td>5.9</td>
<td>5.9</td>
<td>29.4</td>
<td>58.8</td>
</tr>
<tr>
<td>Children and young people learn skills that help them to be independent</td>
<td>11.8</td>
<td>0</td>
<td>0</td>
<td>5.9</td>
<td>82.4</td>
</tr>
<tr>
<td>Children and young people take part in home life, school life and community life in the same way as other children</td>
<td>0</td>
<td>11.8</td>
<td>11.8</td>
<td>5.9</td>
<td>70.6</td>
</tr>
<tr>
<td>Families understand their child/young person’s needs, what they are able to do well, and what they find difficult, as they are growing up</td>
<td>6.3</td>
<td>0</td>
<td>6.3</td>
<td>0</td>
<td>87.5</td>
</tr>
<tr>
<td>Families look after, take care of, and support their child or young person</td>
<td>0</td>
<td>5.9</td>
<td>11.8</td>
<td>11.8</td>
<td>70.6</td>
</tr>
<tr>
<td>Families try to make sure that their rights and the rights of their child/young person are respected</td>
<td>0</td>
<td>13.3</td>
<td>6.7</td>
<td>26.7</td>
<td>53.3</td>
</tr>
<tr>
<td>Families take part in community services and supports</td>
<td>5.9</td>
<td>0</td>
<td>11.8</td>
<td>17.6</td>
<td>64.7</td>
</tr>
<tr>
<td>Families feel supported by family, friends, and neighbours in their local community</td>
<td>0</td>
<td>0</td>
<td>6.3</td>
<td>6.3</td>
<td>87.5</td>
</tr>
</tbody>
</table>