

Consultation on the Supporting Disabled Children, Young People and their Families Resource

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Scottish Commission for Learning Disability

Phone number

0141 248 3733

Address

Suite 5.2
Stock Exchange Court
77 Nelson Mandela Place Glasgow

Postcode

G21QY

Email

Oonagh.b@sclد.co.uk

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Consultation on the Supporting Disabled Children, Young People and their Families Resource

SCLD's Response

The Scottish Commission for Learning Disability (SCLD) welcomes the opportunity to respond to this important consultation. SCLD is an independent charitable organisation and strategic partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life* (2013)¹. The strategy defines a learning disability as a significant, lifelong, condition that starts before adulthood, which affects development and means individuals need help to understand information, learn skills, and cope independently. SCLD is committed to finding new and better ways to improve the lives of people with learning disabilities and is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

The aim of this response is to support the Scottish Government in the development and delivery of policy through sharing knowledge and providing practical solutions to policy based challenges in line with SCLD's strategic plan 2017-21.

In forming this response, we have drawn on five key areas of focus at SCLD, employment, housing, parenting, advocacy and scrutiny. SCLD also considered the views of PAMIS and parents who are supported by this organisation. To gain as wide a viewpoint on the handbook as possible, SCLD also conducted a survey with parents. The response to this survey can be viewed in Appendix 1. Due to the low response rate to this survey, this was not used to form the basis of the response but has been included for reference.

¹ [The keys to life, \(2013\)](#)

In SCLD's view, the Disabled Children and Family Resource has the potential to be a valuable tool for parents and children who experience learning disability. To ensure the value to families who experience learning disability, SCLD, welcomes refocus and development being given to a number of areas. These are:

- 1. The strategic objective of the handbook**
- 2. The vision statement**
- 3. The title of the handbook**
- 4. The format of the handbook**
- 5. The accessibility of information in the sub-section 'The Big Picture: Understanding the Wider Impacts of Disability in Scotland'**
- 6. The three central sections of the document: 'Rights and Information', 'Accessibility of Support' and 'Transitions'**
- 7. The case studies**
- 8. The Easy Read document.**

How the above areas can be refocused or developed to support the best outcomes for families experiencing learning disability is outlined throughout this document. Please note that as SCLD would welcome the document becoming a handbook, this response will refer to the document as a handbook throughout.

1. The strategic objective of the handbook

Q3 Do you think the vision for the Resource is appropriate? / Q3a how could the vision statement be improved?

SCLD believes that the strategic objective of this document requires reframing to ensure a social model approach. From conversations with [The Working Together with Parents Network](#), SCLD understands that the handbook aims to take a social model approach to disability. This approach needs to therefore understand impairment as separate from disability and instead view disability as barriers society places on people who have physical, sensory or cognitive impairments.

The social model of disability has had a wide-ranging impact for individuals with physical, sensory or cognitive impairments, through providing a starting point for

collective action and transformational change. However, Chappell et al (2001)² stated that people with learning disabilities have been excluded from this dialogue and, therefore, the wider disability movement. They draw from Simon Apis (In Campbell & Oliver; 1996, p.97)³ and state "...there is a tendency among people with disabilities (without the label learning difficulties) to identify the problems of people with learning difficulties as inherent to their impairments, rather than resulting from issues of access and social barriers" (p.46)⁴. Goodley (2001)⁵ echoes this and states that people with learning disabilities being left out of the social model of disability, can potentially have worrying implications for both policy and practice.

In view of learning disabilities' marginalisation within the social model, it is critical that active focus is given to ensuring this document will be of practical use to families in which one or more member experiences a learning disability. This will firstly require extending the remit of the handbook to include children, young people, and parents with disabilities, with a particular focus on learning disability. SCLD believes extending the remit of this handbook to include all members of a family with a disability would help to improve support for parents with learning disabilities and would strengthen existing legislation and policy including:

- Part 12 of The Children and Young People (Scotland) Act (2014)⁶
- Recommendation 38 of The keys to life (2013)⁷
- A Fairer Scotland for Disabled People - Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities⁸

Refocusing this document towards families experiencing disability would promote an understanding of people with disabilities as full and active social citizens with the right to a private and family life. By including parents with disabilities as well as children, this document would bring itself in line with Marshall's definition which understands social citizenship as, "...the right to share the full social heritage, and to live a life of a civilized being according to the standards prevailing in the society". (Marshall, 1950,

² [Chappell, Lawthom, & Goodley \(2001\)](#)

³ [Campbell & Oliver \(1996\)](#)

⁴ [Chappell, Lawthom, & Goodley \(2001\)](#)

⁵ [Goodley \(2001\)](#)

⁶ [The Children and Young People \(Scotland\) Act \(2014\)](#)

⁷ [The keys to life \(2013\)](#)

⁸ [The Scottish Government \(2016\)](#)

p.30)⁹ as well as The Fairer Scotland for Disabled People Delivery Plan. This sets out that, "Disabled people participate as active citizens in all aspects of daily life in Scotland. Information and communication are accessible and inclusive; barriers experienced by disabled people including negative attitudes, stigma, and discrimination, are understood and addressed and disabled people are involved in shaping their lives and the decisions that impact upon them." (2016, p.36)¹⁰. By bringing the strategic objective in line with Marshall's understanding of citizenship and The Fairer Scotland for Disabled People Delivery Plan, the first important step in improving the practicality of this handbook will be achieved.

2. The vision statement

The refocus of the strategic objective should be followed by a reframing of the vision statement. This reframing should be multi-layered and should consider the following:

- *The need for a wide-ranging policy overview*
- *The relevance of good practice case studies*
- *The value of accessible communication.*

Each of these areas is discussed below:

The need for a wide-ranging policy overview

While understanding the important role national policy has in shaping services for people with learning disabilities, SCLD questions the amount of information about the policy in this document. SCLD also questions the value of this, in a document which aims to drive improvement of experiences of disabled children, young people, and their families.

This is not to say SCLD believes that there should no national level policy information; rather, SCLD welcomes careful consideration about what relevant policy information should be included and how this information can be practically applied by families.

⁹ [Marshall \(1950\)](#)

¹⁰ [The Scottish Government \(2016\)](#)

The relevance of good practice case studies

To ensure that information about national policies as well as entitlements and rights can have real-life practical application for children and families, SCLD welcomes a refocus of the case studies embedded throughout this document. Instead of good practice case studies, SCLD believes more value would be gained from case studies which tell the story of children and families, how they accessed services and the impact these services had on their lives. In particular, SCLD welcomes examples of how the information in the document could be potentially used to help families achieve their desired outcomes (*See response to Question 8, p.16*).

The value of accessible communication

SCLD welcomes the commitment in the value statement that the handbook should be inclusive, and also the production of an Easy Read version. However, SCLD believes that inclusive communication is wider than Easy Read and will involve a number of different methods including, but not limited to, Alternative and Augmentative Communication. SCLD, therefore, believes that a commitment to forms of communication needs to be clearly articulated. In practice this will require two changes to the handbook. Firstly, the definition of inclusive communication should be changed to state that this means providing information to a person in a way that they understand. This changed definition should clearly state that the best way to provide inclusive communication will depend on the individual and may involve any of a number of techniques. Secondly, this document will need to be produced in a range of formats which includes an online version, an easy read document a video version with BSL and subtitles as well as a version using pictures and symbols (*See response to Question 2, p.7*).

3. The Title of the Handbook

Q1 Do you think using the term Resource in the title 'Supporting Disabled Children, Young People, and their Families Resource is appropriate?

SCLD believes a strategic reframing is required to ensure this document has the most value to families who experience disability (*see response to Question 3, p3-5*). As part of this strategic reframing, SCLD welcomes the document reflecting the wider needs

of families who experience disability, either as a parent or a child. To best reflect this SCLD suggests that the document is titled 'The Supporting Families who Experience Disability handbook'.

4. The Format of the Handbook

Q2 Please select your preferred format

As stated, SCLD's preferred format for the document would be a handbook. SCLD welcomes this handbook not only being available as a paper document but also available in a wide range of formats which reflects the diverse communication needs of the population of people with learning disabilities. This can include but is not limited to, an Easy Read document (*in line with the response to Question 8, p. 16*), videos and online resources. This will help to ensure the information has as wide a reach possible. In producing a range of formats SCLD welcomes including people with disabilities in the production of these versions.

5. The accessibility of information in the sub-section: 'The Big Picture: Understanding the Wider Impacts of Disability in Scotland'

Q4a How could information about the wider impacts of disability in Scotland be strengthened?

To support families experiencing disability to understand their rights and entitlements, the handbook would benefit from a simplification of the language and terminology used in this sub-section. While terminology such as multiple discrimination, and protected characteristics, as well as theories such as intersectionality, are commonplace in Equality and Human Rights language, consideration should be given to how this information can be presented in a way which is both accessible and useful to a wide range of families. For example, instead of complex terminology around intersectionality, what may be more helpful is a simple statement which iterates that The Scottish Government understands that individuals may experience disadvantage and discrimination because of a number of different reasons. The statement should go on to say that national policies and service practice should be responsive to this. Following this, a clear definition of what constitutes discrimination may be helpful. This should be supported by information about the Equality and Advisory Support Service. At this point, it may also be helpful to reference hate crime and what individuals should

do if they are experiencing this. To support this, a link to, '[Disability Hate Crime: What to do guide for people with learning disabilities](#)' would be of value.

Similar to the sub-section on Multiple Disadvantage, the two sub-sections on 'Child Poverty' and 'Disability and Trauma: Adverse Childhood Experiences' would benefit from clarity of purpose and simplification. Focusing on the sub-section on 'Child Poverty', the differentiation of child poverty, as opposed to the overall experience of poverty and social inequality, may not be helpful. Instead, SCLD would welcome an overarching explanation of poverty which follows Townsheads (1979)¹¹ definition. This should be accompanied by advice on what measures and services are available to mitigate the experience of poverty across the whole family. With regard to Adverse Childhood Experiences, further simplification of language and explanation of what this means for families in practice would be of benefit.

6. Development of the three central sections of the document: Rights and Information, Accessibility of Support and Transitions

In SCLD's examination of the three central sections of the handbook: 'Rights and Information', 'Accessibility of Support' and 'Transitions', SCLD has chosen to focus on the sub-sections which are most closely aligned to SCLD's key areas of work. These selected sub-sections are:

- Advocacy
- Housing
- Health and Social Care
- Whole Family Support
- Employment and Volunteering.

SCLD's comments regarding each of these areas are discussed under the relevant section headings.

¹¹ [Townshead \(1979\)](#)

Rights and Information Awareness

Q5 Does the content provided the help you make choices about ways to communicate?

Q5a Does the content help you understand more about human rights and advocacy?

Q5b Please suggest any other ways in which content in this section could be enhanced.

SCLD supports the inclusion of information regarding The UN Convention on the Rights of People with Disabilities and The UN Convention on the Rights of The Child. Echoing comments on earlier sections, this information should be provided as clearly as possible with an explanation given on how this impacts families' day to day lived experience. To support this, an explanation of The Human Rights Act (1998)¹² is required. To improve the practical impact of the rights and awareness section, SCLD welcomes the inclusion of a sub-section titled, 'Who protects my family's rights?' This sub-section should present a number of links and contact details for a range of organisations who safeguard the rights of individuals and families, including The Children and Young Peoples Commissioner for Scotland and The Scottish Human Rights Commission.

A critical omission, in the Rights and Information Awareness Section, is practical information regarding advocacy. While the handbook outlines a child's right to having a say in matters impacting them, there are significant gaps in this section with regard to information about parents who experience disability, their potential right to advocacy and how advocacy support can be accessed.

To address these gaps, SCLD welcomes a clear definition of independent advocacy. This should reflect the definition presented in the 'Independent Advocacy Guide for Commissioners' (2013) which states,

"Advocacy has two main themes:

- Speaking up for and with people who are not being heard, helping them to express their views and make their own decisions and contributions

¹² [The Human Rights Act \(1998\)](#)

- Safeguarding individuals who are at risk.”

(Scottish Government; 2013, p.5)¹³

SCLD also welcomes the rights of people with learning disabilities to advocacy being outlined. This should include a clear and accessible explanation of when and why a person can have access to advocacy. This should reflect legislation which makes entitlements for individual’s access to advocacy. This will include, Section 10 of the Social Security (Scotland) Act 2018¹⁴ and Part 17 of the Mental Health (Care & Treatment) (Scotland) Act 2003¹⁵. This should also include a number of other pieces of legislation and policy outlined by The Scottish Independent Advocacy Alliance [here](#).

SCLD also welcomes a clear definition of the role of an advocate in this handbook, alongside information on where advocacy services are available and how these can be accessed. This should include an overview of advocacy provision in each local authority area and contact details for these services. In addition to this, a link to The Scottish Government’s SIAA find an advocate online service and a phone number for the SIAA would be helpful. SCLD also supports the inclusion and explanation of the different types of advocacy available. This should include professional and single-issue advocacy, peer advocacy, citizen's advocacy, group advocacy and self-advocacy. SCLD's (2018) report¹⁶ can provide potential case studies and quotes from people with learning disabilities regarding the experience of accessing advocacy which could support this sub-section of the handbook.

More information about communication methods would also be welcome. This is in line with earlier comments in this response about inclusive communication (p.6) and should include [Communication Passports](#) and [Digital Passports](#).

Accessibility of Support

Q6 Please indicate whether the information within the about each of the following topics is sufficient?

¹³ [Scottish Government \(2013\)](#)

¹⁴ [Social Security \(Scotland\) Act \(2018\)](#)

¹⁵ [Mental Health \(Care & Treatment\) \(Scotland\) Act 2003](#)

¹⁶ [SCLD \(2018\)](#)

Q6a What, if any, additional information should be included that is specifically designed for children and young people?

Q6b What, if any, additional information should be included to help support the families/parents/guardians/carers of disabled children and young people?

Q6c Please suggest any other ways in which the information about support available to could be improved.

In considering Section Two, 'Accessibility of Support', SCLD believes there is a need for a fundamental restructuring of the information and how it is presented. This would involve a reduction in policy focus and an adjustment to ensure that the information provided will enable families to access support.

With regard to the sub-section on housing, again a refocus should include a directory of Housing Associations which can be located online on the Scottish Federation of Housing Associations Website¹⁷. Links and contact information to large-scale housing providers such as the Wheatley Group would also be of benefit. A link to Scottish Housing Regulators Directory of Social Landlords¹⁸ should also be provided. This information should sit alongside clear definitions outlining the differences between social, public and private sector housing, entitlements regarding home adaptations and an explanation of differences in housing options across local areas.

In the sub-section on housing, there is also a significant gap in information regarding homelessness and temporary accommodation which requires attention. SCLD's (2017)¹⁹ report examining the housing landscape for people with learning disabilities in Scotland. This report that stated that "...20% of households who were homeless or threatened with homelessness in 2016-17 were identified as having support needs relating to basic housing management and independent living skills" (SCLD,2017,p.28).

To further support the overall development of the housing sub-section, The '[Housing Options Guide for Disabled People in Scotland](#)' could potentially provide useful

¹⁷ [Scottish Federation of Housing Associations](#)

¹⁸ [Scottish Housing Regulator](#)

¹⁹ [Ormston, Euston, & Mcateer, 2017](#)

information and guidance. Particular attention should be paid to Part 5 of this document, which outlines contact details for a number of relevant agencies.

Akin to earlier parts of the handbook, the sub-section on Health and Social Care requires a move away from policy focus to service level information. This should include Information about Health and Social Care Partnerships and information on what support to expect from services. Moreover, SCLD welcomes the inclusion of information about Local Area Co-ordination and Community Link Workers, given their potential role in providing person-centered and whole family support. In this sub-section, SCLD also supports the inclusion of information regarding NHS complaints procedures ensuring that families who experience disability are empowered through active citizenship. This would be further strengthened by the inclusion of information about making complaints about local authority services including social work services.

In addition to the restructure and rewrite of the aforementioned sections, SCLD would welcome a significant review of the section on Whole Family Support. This should make clear that information in this document is for both children and their parents, and that some parents may need support to care for their child. This is critical for parents with a learning disability due to the specific disadvantage experienced by parents with learning disabilities, as discussed by Tarleton et al (2006)²⁰ and Stewart et al (2016)²¹, it is critical that accessible information is provided about the types of support available to parents. This should include reference to Part 12 of The Children and Young People (Scotland) Act (2014) and examples of parenting support services. Potentially this could include examples such as Aberlour Family Service in South Ayrshire. A social impact assessment of this service can be read [here](#).

Examples of parenting support services such as Aberlour Family Service should be provided in a similar format to the information presented about The Family Fund in the existing document. This section on The Family Fund can be used as a template for providing information on services with the addition of contact details. Located alongside information about parenting support services, information about resources which can support people to parent should be provided. This should include information about the [CHANGE](#) Resources.

²⁰ [Tarleton, Ward & Howarth \(2006\)](#)

²¹ [Stewart, Macintyre & McGregor \(2016\)](#)

As well as ensuring that information is provided which could potentially be helpful to parents with learning disabilities, it is also critical that a wider range of supports for parents is discussed including available supports for parents with physical impairments.

Transitions

Q7 Does the framework provide sufficient information about improving transitions from child to adult services (e.g. education, health and social services)?

Q7a Please suggest any other ways in which the information about transitions could be improved.

Transitions

In considering the section on transitions, SCLD welcomes the inclusion of The Principles of Good Transitions²² and views these as critical in improving the support available to individuals with learning disabilities as they move through different stages of life. These principles are centrally important in helping to form a shared understanding and language around support for transitions. This can be used by a range of professionals who may be involved in an individual's life, for example education and social work.

While supporting the The Principles of Good Transitions, SCLD believes that there is a further need for a reframing of the dialogue surrounding transitions. This should make it clear that a transition does not look the same for every individual. For some individuals transitions may happen over an extended period of time and could involve a process of trial and error while working towards long term goals. This clear understanding, alongside cohesive partnership work across professional bodies, will be required if children and young people are to be effectively supported throughout periods of both long and short term transition. Transition can be a period of anxiety for children, young people and their parents. Anxiety surrounding transitions for families has been demonstrated in a survey their parents whose children were leaving school, conducted by ARC Scotland and The Scottish Transitions Forum²³. This found that

²² [The Scottish Transitions Form](#)

²³ [ARC Scotland \(2017\)](#)

60% of parents being worried about how their child would cope with the social transition and 29% expressing concern about their child being able to move into further education or employment. In understanding parental concerns surrounding transitioning from school into employment, SCLD believes a restructure on the sub-section on Employment and Volunteering is important.

In restructuring this part of the handbook, SCLD suggests a splitting the sub-section Employment and Volunteering in to two distinct sub-sections. SCLD believes this is of importance as there is no direct evidence that volunteering supports people with learning disabilities into employment. Following this, a significant rewriting of the employment sub-section will be required. This section should make clear the Scottish Governments commitment to, "...seek to reduce by at least half, the employment gap between disabled people and the rest of the population" (2016, p.19)²⁴

SCLD believes this ambition can be achieved for people with learning disabilities in the following four ways:

- 1) By overcoming the low expectations held by parents, schools, colleges and employers
- 2) By gathering data more effectively and invest funding where people with learning disabilities in Scotland secure both employment and support to develop in that job
- 3) By use this data to invest in post- school funding of services that can deliver employment outcomes of 50%
- 4) By recruiting and training job coaches who can support people with a learning disability into employment and throughout their careers. As well as, recognising job coaching as a profession, with nationally monitored quality standards.

In addition to stating the commitment of the Scottish Government to seek to reduce the disability employment by at least half, the employment sub-section would also benefit from the inclusion of practical information for families. This should include a map of employability services and contact details for organisations such as Skills

²⁴ [The Scottish Government \(2016\)](#)

Development Scotland. Information regarding the Access to Work Fund should also be made available here. In addition to a focus on moving into employment, SCLD welcomes detailed information regarding individual's transition from school to further and higher education, taking into account the individual's educational aspirations.

As well as restructuring the policy overview and providing practical information, the rewrite of the employment sub-section should consider the appropriateness of the case studies provided. Particular thought should be given the case study on page 54 of the document and whether this is appropriate. While this case study provides an example of a person being supported into employment, no reference is given to young person's aspirations and whether the employment opportunities this individual was offered would support their strengths and longer-term employment goals. Therefore, this case study is not best practice as it does not follow the model of supported employment based on vocational profiling outlined in 'A Working Life for All Disabled People: The Supported Employment Framework for Scotland' (2010)²⁵. In addition to this, consideration should also be given to the suitability of the case study regarding The Single Gateway in this sub-section, due to this projects focus on older people as opposed to children and young people.

With regard to the section on transitions as a whole, SCLD suggests further consideration be given to the following areas:

- Transitions for individuals with complex needs
- Self-Directed Support
- Welfare and financial guardianship
- Transitioning to independent living.

7. The Case Studies

Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics?

Q8a Please suggest any other ways in which the information on rights, policies, and/or access to support could be improved.

²⁵ [The Scottish Government \(2010\)](#)

Q8b Is there any other information that the content does not cover that you think should be included?

Q8c Do you have any other comments?

As previously highlighted, SCLD welcomes the use of case studies which detail families achieving their outcomes. This could take a number of forms. With regard to the sub-section on financial support, practical impact could be better ensured by outlining examples of entitlements based on a families circumstances. An example of what this could look like is provided below.

Family Circumstances	Family's Weekly Social Security Entitlement
<p>A family of two. Single mother and child. The child has a learning disability and a physical impairment.</p> <p>Mother is unemployed, the child is of primary school age. The mother provides care for the child. Mother has savings under £16,000.</p> <p>The family lives in an area within the top 5% of multiple deprivation indexes in Scotland.</p> <p>The family live in social housing in Tax Band C.</p>	<p>Universal Credit: £258.78</p> <p>Council Tax Reduction: £29.46</p> <p>Child Benefit: £20.70</p> <p>Carers Allowance: £64.60</p> <p>This family would also be entitled to Child Disability Living Allowance between £22.65 to 145.35 based on the circumstances of the child.</p> <p>This family would also be entitled to a school clothing grant.</p> <p>If the family were in the process of having their payments set up or having decisions made about entitlements they would be entitled to a Scottish Government Welfare Fund, Crisis Grant.</p>

Examples like the above should be presented with the caveat that entitlements will vary due to personal circumstances and that payments can vary due to making

payments for previous social loans or rent arrears. The handbook should then outline that individuals and families can be supported to access the appropriate payments by contacting their local Citizens Advice Bureaux, Money Advice Centres, or Financial Inclusion project. This information should be accompanied by a comprehensive breakdown of all new and developing social security entitlements. By providing this type of information this document can provide practical guidance on the type of support children and families can expect to get, therefore building the families capacity to navigate a complex system and the family's resilience.

There is also a need for case studies In addition to this there is a need for case studies to share the experiences of a wide range of individuals with learning disabilities, including those with complex needs.

8. Further Development of the Easy Read Document

Q8a Please suggest any other ways in which the information on rights, policies, and/or access to support could be improved

Q8b Is there any other information that the content does not cover that you think should be included?

Q8c Do you have any other comments?

SCLD warmly supports the creation of an Easy Read version of the handbook. However, SCLD sees a need for this document to be further developed. This development can be supported by a number of available Easy Read Guidance documents, including but not limited to, Mencap's Guidelines for Accessible Writing which can be found [here](#). There are a number of organisations who could potentially be able to support with the production of the Easy Read Document. These organisations include, The Scottish Accessible Information Forum, Values into Action Scotland and People First (Scotland).

Summary

The statement that knowledge equals power has at its centre a fundamental truth. For people to fully assert their rights they must have access to information about entitlements. Therefore this handbook must provide clear information which all families can practically apply. To achieve this SCLD believes this document will require

significant restructuring to ensure a truly social model approach. This restructuring will involve

- Refocusing the strategic objective of the handbook
- Renaming the document to 'The Supporting Families who Experience Disability Handbook'
- Ensuring the central document is written in plain English and is accessible
- Ensuring a number of accessible formats are made available including Easy Read
- Considering the practical applicability and accessibility of the policy information provided
- Restructuring across the three key areas of the handbook
- Changing case studies to ensure they are outcomes focused.

SCLD welcomes the opportunity to offer further advice regarding the restructuring of this document.

Thank you for the opportunity to respond to this important consultation.

Appendix 1: Small-scale survey of families

To help to inform SCLD's response to this consultation a survey was sent to those who are signed up to the SCLD e-bulletin and members of The Working Together with Parents Network. The response rate to this survey was small. A total of 13 people responded to the survey. Respondents had the option to skip questions, therefore not all questions received 13 responses.

SCLD targeted this survey towards parents of a child with a learning disability and/ or parents who had a learning disability. However, as the survey was sent out using SCLD's e-focus mailing list and Working Together with Parents Network mailing list, anyone on these lists could have responded.

Respondents were asked which version of the document they had looked at. Respondents were then asked on how useful they found the information on both rights and support. Respondents had the option to give comments on the reasons why they found the information helpful or unhelpful. Due to the small scale of the survey we have chosen to not include the quantitative data collected and instead present the qualitative data collected from the comments. The following outlines these comments.

What information about rights was helpful?

- "Transition for teenage ages to help with work training. The bullying section."

What information about rights was unhelpful?

- "It's all and nothing about older children or adults with a learning disability. I also don't think it's helpful changing the terminology it's called a learning disability for a reason."
- "Too much information that is not easy to understand. Would need somebody to go over it with me."

What information about support was helpful?

- "Same as above"

What information about support was unhelpful?

- “Too much information that is not easy to understand. Would need somebody to go over it with me.”

What additional information should be included?

- "Information for adult children. Are they now forgotten, children?"
- “Phone numbers of people or places where you can get help from people face to face”
- “Rather than tinkering with a flawed to disastrous system, we need a radical new model for learning disability support reform based on the excellent systems available in much of Germany and Norway.”
- "More information about where to go for help in our local area. Also, more help in schools as our local high school doesn't seem to do much about disabled pupils being bullied. Would also like more info about where to get help for young people who have mental health issues as lots of places won't see under 16's".

Any other comments about the full consultation document or the easy read version?

- "For an easy read version, it is not very easy to read. There is a lot of information to read through which many people will find very difficult without help or support from another person."
- “For exhausted parents, these consultation documents are another exercise that looks good (if intimidating) on paper but translates into almost non-existent support for most”
- “Easy to read version still seems to have big words in it, so needs to be easier to understand and in plainer words”
- “Very helpful and easy to read”

Offline Survey Responses

As some individuals do not have access to computers and/ or are unable to navigate the survey, SCLD also accepted comments through informal telephone conversations. One parent who has a learning disability made comments regarding the Easy Read version of the handbook. Their comments are outlined below:

- “Easy Read was good, it was put in language I could understand”
- “Need to put phone numbers in the document so people can get all the information they need, you can always do with extra information”
- “They should have information about organisations like Young Scot.”



Oonagh Brown
Scottish Commission for Learning Disability
Policy and Implementation Officer (Parenting)
Oonagh.b@sclد.co.uk